Active EHE Patients

Patient ID	Date of update	Story
*B0814	1-Jun-2015	EHE in liver 17 Jan 2008 - intensive pain thought to be biliary colic. Disappeared after a few days. 21 Jan 2008 - U/S shows multiple liver lesions, confirmed by second U/S a week later. 25 Jan 2008 - CT of pelvis confirms 9 lesions, the largest 5.4 cm (segment 5/6), 3.1 (segment 4b), 2.5 cm (segment 4a), and 2.3 cm (segment 2). The lung bases clear. 2 Feb 2008 - Needle biopsy inconclusive due to insufficient cell block material 7 Feb 2008 - Laparoscopic biopsy – diagnosis of HEHE. Referred to Liver Clinic in RPAH, Sydney to be assessed for liver transplant. 15 Feb 2008 - CT of pelvis and lungs shows the largest lesion measuring 5.6 cm, the second largest 3.3cm. Conclusion: no appreciable change in size or appearance of lesions. Scans through chest show normal lungs. Comprehensive liver transplant tests including total blood work, CT of brain, bones finds all OK. On waiting list for LT. 13 May 2008 - CT chest / abdomen / pelvis. Three subcentimeter a few little nodules in right lung. Conclusion: no significant changes in reference to previous CT scan. _____ continues to be fit, active, enjoys sporting activities and is asymptomatic. But is extremely stressed. 27 May 2008 - PET scan report describes metabolism consistent with high grade tumour and abnormal metabolism in bone marrow in vertebral column suggestive of metastatic disease. MRI recommended as these finding are inconsistent with results of previous tests and hot glucose intake maybe related to low haemoglobin. 13 June 2008 - MRI of spinal column reports no evidence of metastasis. Also CT scan radiologist suggests that lung nodules do not look cancerous. This is a great relief but we feel very confused by constant inconsistencies in reports. In April 08 _______ moved herself from active to pending LT list because she is scared of side effects of LT, concerned about differences in reports, but primarily because she feels healthy and fit. She plays soccer and plans to go for a week skiing before her 3 monthly tests in August. Her hepatologist thinks she should return to the active list asap. 6 August 2008 - CT scan shows no changes from the time of diagnosis. This is confirmed by MRI. The conclusion is that, most likely EHE is in liver only. Lung nodules do not look cancerous and have slightly shrunk. ______ cannot decide whether to continue "wait and see" approach or go back on LT list. Nov 2008 - ________ keeps being physically well. A new interpretation of her August scan through volumetric analysis shows an 18% increase of the tumour volume. The error margin for this new analysis is not established so we do not know how to take it. The November scans show a definite further growth of liver lesions. Possible shrinkage of lung nodules. Mar 2009 - Ready for IRE the first of which will happen on 24 March. We keep having lots of confusions about images. These discrepancies may be partially caused by the type of measurement - the latter from the coronal scans. Maybe there is an inflammatory/cellular infiltration that varies....a dynamic response, like a swollen gland going up and down, or possibly blood flow varying in a dynamic fashion. We are also testing VEGF in the blood to serve as an indicator. If tumour burden is debulked through IRE, VEGF levels should drop June 2010 – no change. The Bartonella infection has so far failed to respond to antibiotics. _______ will have been on antibiotics for a year in August. This will be the time for her scans and the next step will be decided then. Most probably a move to different set of antibiotics. ______ has been well, with no liver pains at all. Aug 2012 - ________ was found Bartonella positive in tests performed at Prof Breitschwerdt's Tick Borne Disease lab in Raleigh. It was not possible to detect this bacteria in Australia. Prof Breitschwerdt is the only one in the world who is able to produce a specially enriched culture to detect this bug which is extremely fastidious and difficult to find, and even more difficult to eradicate. 2013 - Bartonella test, After a year of negative DNA results we stopped antibiotics (after over two years on Doxy/Azithromycin and Rafimpicin) a year ago with DNA in spite of substantial antibodies still present. She initially had 9 tumors in the liver, then they reported 13. All were exposed to IRE. 2014 - MRI showed that most of the tumors are gone, the rest (3-4?) shrunk about 50%. Shrunk to the point where we are doing nothing until June 2015 hoping _______'s immune system acts to at least shrink them further. June 2015 - hoping _______'s immune system acts to at least shrink them further.
*C0711	1-Feb-2011	EHE in left lung and pleura of lung Oct 2007 – July 2008 – intense and constant pain in chest, suspected to be muscular (Nurofen masked it). Physiotherapy and exercise prescribed. Cancer initially not suspected due to age. Aug 2008 – EHE Diagnosed by lung biopsy. Pleural effusion. Effusion worse after biopsy and emergency surgery required. Chemotherapy (Taxol) prescribed along with Thalidamide. October 2008 - Gefitinib (Iressa) commenced (in combination with Thalidamide). Initially worked then felt worse and taken off all meds after 4 months. Told there was nothing more that could be done and to look at quality of life – not quantity. March 2009 - New chemotherapy – Alimta (used mainly for mesothelioma patients). 21 day cycle and feel unwell for about 7 days per cycle. March 2010 – Continuing to improve all the time with hydrotherapy and physiotherapy and have recently started back at work part time. High doses of pain medication (morphine based plus Gabapentin for nerve pain). Pain gets worse when can't exercise, after chemo, when stressed, etc. Suspect some pain from surgery but nerve endings in pleura (where cancer is) are very sensitive so cause ongoing pain. Scans for last 12 months show cancer STABLE slight REDUCTION. Scans every 3 months now. Just started a Chemo holiday because immune system is a little run down and feeling mostly fantastic (with a few ups and downs). Have even reduced pain medication slightly. June 2010- The oncologist, Professor Phil Clingan, has just returned from an international conference and is also quite excited about recent results reported for the Alk1 receptor which can apparently inhibit endothelial cell proliferation. If Alimta stops working, plan B is to test for this new Alk1 receptor through Melbourne hosipital (although apparently it works better in non-smokers) and my husband smoked for 20 years. July 2010 - scan shows no significant change. 3 monthly scans and no more chemo unless things deteriorate. Thanks to advice from other members he has adopted the 'watch and wait approach' for now. February 2011 – Scan in November 2010 showed 'no cancer in the scan'. Still has massive pain and is finding it hard to get through each day. ___'s lung is a mass of scar tissue and it is having terrible effects on his posture and his general health. We are wondering is some type of surgery – even a lung removal – may be an option. Next appt. is in a few weeks.

*L0814	1-Jan-2016	EHE in liver and lungs. Nov 2008 – Detected one month after childbirth - temperature, back pain and shoulder pain, and the blood tests showed an infection. Diagnosed with pet scan and biopsies. The origin is in the liver with lungs nodules. I also have a nodule in the thyroid but for the moment we do not know if it has a link with the disease. It seems certain that I had this pathology for a long time but it is the hormonal treatments over two years that accelerated everything. Doctors are considering either a liver transplant, or double transplantation (liver and lungs). Have to stop taking thyroxine in anticipation. May 2009 - transplant. Jan 2010 – doing fine, at present I am under immunosuppressants only - Everolimus. I have scans approximately every five months because I also have nodules in lungs. I am very anguished in the idea that the disease does it again. August 2014 - everythig stable, no recurrence. January 2016 - no recurrence of EHE but was diagnosed with breast cancer. Bilateral mastectomy & chemo.
0C0015	1-Feb-2016	EHE in liver and lungs June 2015: diagnosed. After many controls, at last a liver biopsy analyzed by doctor Dei Tos confirmed EHE. She has multifocal tumors in liver (right side) and lung (left one). June 29 2015: Many tumors in the liver between 1 cm and 4 cm, some subcentimeter tumors in the lungs. September 3 2015: The biggest two in the liver grew, and are about 4,5 cm and 3 cm. The lungs are stable. December 11 2015: The biggest two in the liver grew again, and are about 5,3 cm and 3,8 cm. The lungs again are quite stable, with one nodule about 1,8 cm and the others subcentimeters. January 12th 2016: As both Stacchiotti and Grignani suggested to start a therapy with Sirolimus she started on 5mg per day. She will go on till January 27th, then we'll go back to Stacchiotti in Milan to make blood analysis, so we can see how his body is reacting and if we need to change the dose of Sirolimus. February 2016: Scan showed stability in liver.
0L0015	1-Dec-2015	EHE in liver. September 2015 - after a simple abdomen u/s we found these liver nodules. November 2015 - she was isthologically diagnosed. She was asymptomatic this summer - she felt weak and had abdomen pain in the right side. She had a PET scan and it was hot at the liver and in the right pelvic area (they didn't succeed to locate it exactly, so they wrote roughtly "some ileum loops"). She had a total body CT with and without contrast agent which was negative for lung, but we made it before the isthological diagnosis so maybe if these nodules are tipically are very little "maybe" they didn't see it. She often has cough but not every day from September.
AA0614	1-Jun-2015	EHE in Lungs. February 2014: High fever and vomiting. Diagnosed with Epitheliod Hemangioendothelioma at CHOP. Treatment with Sorafenib, 200 mg twice a day. She was on this drug for ten days before the stomach pain got worse and the fever, vomiting and diarrhea began. March, 2014: ______'s chemotherapy was changed to Sirolimus. She was originally given 1mg once a day. With that, she was given Bactrim, one tablet twice a day on Mondays and Tuesdays. One of the attending doctors at CHOP suggested _______ start taking Celebrex. She was given 500 mg of Celebrex: 200mg in the morning and 300 mg at night. Adverse side effects experienced. She was then given 100 mg of Celebrex in the morning and another 100mg at night: more night sweats but not as bad as the previous night. We decided to discontinue the Celebrex. ________ was released from CHOP after spending five weeks there. When we left the hospital she was on so much medicine. In the first couple of weeks after release, she had periodic vomiting and nausea. I treated that with Marinol and or Morphine, if the pain was really bad. May of 2014: We took her to Boston Children's Hospital to see Dr. Cameron Trenor, in the Vascular Anomalies Center. He reviewed her scan, charts, and hospital reports. He recommended splitting her dose of Sirolimus to .05mg in the am and another .05 mg in the evening, twelve hours apart. He also recommended cutting ________'s CT scans back from every two months to every three months. ________'s doctors at CHOP followed that advice. The plan at that time was to keep her on Sirolimus for two years and repeat a PET Scan in a year. _______'s scans after taking the Sirolimus have indicated tumor shrinkage in the liver and stable conditions in her lungs. Over the past year, we have eliminated all pain medications, leaving _______ on the Sirolimus twice a day and Bactrim twice a day, twice weekly. May 2015: Scan shows stability, still on 1 mg of Sirolimus
AA1415	1-Mar-2016	EHE in liver and lungs. March 2014: Diagnosed with EHE to the liver, so I was one step away from the liver transplant and a resonance later they realized that I also lung nodules, so no transplant. September of 2014: After a visit to 'IRCSS Milan with Dr. Stacchiotti we started with a course of Avastin every two weeks and IFN 9 MIU three times a week at a time, I went on like this until March 2015, then not I could no longer be the Interferon for pain, treated with targin depalgos + + lyrica and saw a slight decrease in nodules, we interrupted the' interferon and continued with Avastin. June 2015: Taking the 'interferon dose more' light (mui 3) at a time three times a week, up to 17/09/2015, view the 'futility of care we decided to start a treatment with everolimus dose of 10 mg per day. November 2015: Tumors shrinking, enverolimus working. March 2016: Liver stable but new nodule in the lungs.

AB7210	1-Jan-2016	EHE in liver and lungs. September 2010 – 38 year old wife was diagnosed with EHE throughout the liver. It was multifocal, nonresectable and throughout the liver, nodules also found on her lungs, none of which was larger than 5 mm. Initially Dr. Kristen Ganjoo prescribed Avastin and Tremodar. After two courses of this medication, further imaging showed the tumors had grown. _____ encountered significant pain, as the liver capsule was pressed by growth of the tumors. There was no change in the lung nodules. December 2010: The Avastin & Tremodar was discontinued and ________ was evaluated at UCSF Liver Transplant Clinic and accepted. Gemzar/Taxotere was prescribed by Dr. Ganjoo as a bridge measure before transplant. This medication was effective on reducing the size of the tumour and pressure on the liver. Mobility, appetite and overall health improved significantly. January 2011 – Scans showed tumour size reduction in liver, but no change in the lungs. February 10, 2011- She underwent living donor liver transplant. April 2011 - Repeat scans were done which showed stable nodules in the lungs. Anti-rejection meds are being reduced, and UCSF plans to start her on sirolimus at 90 days post –implant. She has regained her strength and looks amazing. Aug 2012 - ________ is still doing well. Scans at regular intervals show lesions in lungs are stable. No sign of recurrence in abdomen. She's on sirolimus, and has tapered down on the prednizone post-transplant. Nov 2014: Regular scans with no recurrence so far - everolimus for transplant - no adjuvant chemo. Jan 2015: everything clear. Jan 2016: No changes, everything stable, on Sirolimus.
AC0016	1-Apr-2016	EHE in liver Dealing with really bad gastritis. Had been seeing a GI for years and had several ultrasounds and scans. Last scan was done in 2013 and showed no lesions in her abdomen. January 2016 - Taken to ER, ultrasound shows liver lesions. Needle biopsy, diagnosis of EHE from UM but Moffit suggestd angiosarcoma. Saw Dr Wilky st Sylvester, she confirmed EHE. March 2016 - Based on the second CT the tumors are growing and increasing in size from one month ago. The tumor's size varies from 0.7cm to 6.3 cm. There are 4 in the right side and one in the left. They grew from a couple mm to 10mm. A surgeon in Sylvester suggested to do emabolization of tumors on the right side of the liver. April 2016 - succesful embolization of the right side of the liver.
AC4607	1-Aug-2015	EHE in the artery 2002 - pain with any accidental slight pressure or bump to the inner left thigh..but not enough to visit the doctor... 2006 - painful to walk up the steps February 2007 - went to GP who sent him for ultra sound....and the radiologist called the Dr to look at the mass he could see ....and it was dismissed as blood is flowing ok typical of a smoker (________ is a non smoker)...Cat Scan and MRI, thought it was a blood clot! July 2007 Exploratory surgery over 4 hours later he had a resection with a replacement of the artery with not good margins ...4 days later Dr Terrence Frost a hematolisgist for rare diseases came in and said we might have to send it to Boston to find out what it is ....then they got a result 5x8x3 cm Epithloid Hemangioendothelioma!!.....Pet Scan and MRI were done before ______ left hospital with no spread. 30 Lots of Radiation and did not do Chemo… From the first 3 month check up MRI showed a 4cm Encapsulated Hematoma they have wait and watch. No biopsy, Dr Schlect said leave it alone...________ did develop Lymphodema in his left leg had treatment for a while with a massage and a stocking..but it is much better now. Aug 2015 - He has a painful side around his liver which is a worry to him but Dr Schlect doesn't seem concerned over it... ultra sound showed a fatty liver...________ is a Type 2 Diabetic and B/P ......when he was 17 he had a high fevers with the Asian Flu...and Glandular Fever in his 30s.
ADUS1011	1-Apr-2016	EHE in Ankle Cancer was discovered when I had an ankle pain during a marathon(Virginia Mason Medical Clinic); initially thought to be a non-acqueous lesion, biopsy revealed EHE; confirmed at Johns Hopkins; 1/29/2010: Surgery 1/28/2011: Follow-up surgery Treatment: No radiation; no chemotherapy; MRI and X-rays every three months 2012: Slight increase in size of lung nodules. Moved to semiannual scans. 2016: Everything has been stable till this year there was a 3 times increase in size of two nodules in the lung. They were removed by VATS in April 2016. Surgery went well.
ADUS1015	1-Dec-2015	EHE with tumors in my spine, liver, and lungs. I was born in 1942. I was diagnosed with EHE at Yale New Haven Hospital November 2009: Extreme Back Pain December 2009: X-rays showed compression fracture in thoracic vertebra and radiologist report "could not rule out the possibility of neoplasm". My physician treated it conservatively but with little improvement. April 2010: MRI on April 8th and was hospitalized on April 9, 2010 with plum size tumor anterior to T8 and T9 and severe damage to those vertebra and smaller tumors in liver and lesions in lungs. Spinal tumor and liver biopsies showed EHE in both. Had multiple surgeries to fuse spine, embolize and debulk spinal tumor, remove the affected vertebra and encase the exposed spinal cord with a titanium cage and bone graft. This was followed by 28 days of max radiation tx to the spine in June and July 2010. My oncologist at Yale was Dr. Farber and I consulted with Dr. George at Dana Farber Hospital in Boston. I was offered the possibility of drug/chemo but chose to wait and watch. Most recent blood tests and scans show no growth of tumors and my blood is normal. I continue to wait and watch and use holistic methods to reduce inflammatory response and produce anti-angiogenesis. I am a Vietnam veteran who was exposed to Agent Orange (dioxin) in 1967-68 and the VA has determined my disease to be service-related. I know of other Vietnam vets who have had similar sarcomas (not necessarily EHE). Dr. George indicated that in her opinion I have had EHE for decades. I realize that I probably began to notice its symptoms perhaps five years ago but thought it was muscle cramping or aging. January 2015: Evevrything stable December 2015. Stable

AE1415	1-Jul-2015	EHE in Lung 11/13/2014 - diagnosed with Tumor. Found in the right lung (2 lesions was found, one was -3,5 cm and another 1,5 cm). After lung surgery the patient was diagnosed with EHE. The number of mitosis in the tumor was 7/10. National Cancer Institute Hospital has done right lower lobectomy with mediastinal lymphaddenectomy. 01/ PET/Study foci in sacrum and right iliac lesions. In order to prove examination MRI was performed. Study found: The foci in 7,5*8 cm area of right iliac throughout body in around bone thickness(~3cm), of mixed osteoblast clastic type, destructive foci of clastic type in the central part of the body ~2,2 x 2,2 x1,3 Uneven area of destruction ~ 3,2 x 2 x 2 cm in S2 body right and lateral mass, reaching the right sacral joint. To confirm the right diagnosis the biopsy was ordered. BIOPSY RESULTS: Tumors cells positive for CD34, CD31 immunomarkers. Tumor cells in mitosis found 14/50 DPRL(5 mm^2) Diagnosis: Epithelioid hemangioendothelioma (high degree of risk). 03..2015 The patient had It radiotherapy to the right iliac. Dose of radiation 25 times at 2 grey. 06..2015 After the radiation the tumor was reduced by 60%. New foci were found in the spine :Th2, th10 and th11. After a new diagnosis patient went to Germany to consult with Essen town's professor Sebastian Bauer. He advised to use bisphosphonaten (denosumab), radiation therapy to the new foci. In case it will not work, he advised to work with chemothrapy (Doxorubicin(Caelyx), and if this would not work, then use Paclitaxel. Lithuanian oncologist prescribe XGEVA 120 mg (denosumab) and radiation therapy to the spine's focis.
AEAU0512	1-Aug-2012	EHE in lungs and liver Sept 2005: Chest pains, CT scans detected nodules in lung and liver, thought to be remnants of past illness. PET scan for cancer came back positive, while the biopsy came back inconclusive. Had operation to have one of the nodules removed (the biggest one in my right lower lung lobe) which was about the size of a golf ball. Oct 2005: Surgeon said I had this EHE, a form of angiosarcoma. May 2006: last 2 scans ok, though slight growth in number of tumours in lungs. Still no pains, the occasional dry coughing and short of breath. Monitoring 3 monthly. Not on any medication. June 2008: It's close to 3yrs since my EHE diagnosis in lungs and liver. I have had no treatment during this time; just quarterly ct scans - all is ok. March 2009: all is fine. Aug 2012: I am now on 9 to 12 monthly ct scans (previously 6monthly a couple of years ago), with my next one in December. I have not had any change to size and numbers of the tumours in both lungs and liver. I am still not on any treatment or medication, nor do I experience any pain. ***Jane Gutkovich contacted ________ in November 2014 for update and received no response.
AJUS1115	1-Dec-2011	EHE in Lung, Lymph Nodes and Liver 12/2011: Diagnosed with EHE, multiple small nodules in lungs, possible same nodules were also in the jugular lymph glands and liver. I am a woman of age, non-smoker and usually in good health. Following a routine CT check-up in which 15 small discontiguous nodules in the lungs were witnessed, I was directed to conduct a biopsy of these which turned out the diagnosis of EHE. The biopsy slides and report were confirmed by Prof. Fletcher of Harvard Medical School. Further a PET-CT examination was conducted in the Rambam Medical Center in Haifa, Israel and the findings were that the same nodules were found also in the jugular lymph glands and in the liver. Awaiting to begin treatment with experimental biology medicine called Pazopanib or Votrient. I am awaiting approval of this medicine. ****Jane Gutkovich contacted in January 2015 for update and received no response.
AS9005	1-Jan-2016	EHE in liver, lymph nodes and possibly lungs I was diagnosed at age 15 by Mayo Clinic in Jacksonville, FL but have scans showing the disease in my liver from the age of 13 on and it was apparent that it was there long before then. I had being going to Nemours / Wolfson's Children's Hospital for those years but a gastroenterologist and oncologist were very insistent that they were benign hemangiomas or fatty deposits, even though they could see them multiplying and growing. 2005: Dr. Mellana Bridges, radiologist at Mayo looked at my scans and diagnosed the EHE but Nemours and Wolfsons still insisted that this wasn't the case. Eventually after many other misdiagnoses the Armed Forces Institute of Pathology and a Pathologist in Houston, TX (I'm not sure what institution) confirmed the EHE diagnoses. I was sent to Mayo for a Liver Transplant evaluation because the disease had progressed far enough that that was the only treatment option available. Jan 2006: Liver transplant. There were 10 major lesions and many other small ones in my liver at the time of transplant, the largest being 10 x 5 x 12.5 cm in the right lobe and they were all throughout both lobes of my liver. After I had the transplant they said that my entire liver was basically all tumors. It also had spread to my lymph nodes and I have 3 tumors in my lungs that they believe are EHE because they have always been stable. They have never confirmed that because they would have to crack open my rib cage in order to biopsy. 2009: EHE was back in my liver and confirmed with biopsy in 2010. January 2016: My hepatologist at Mayo is Dr. Raj Satyanarayana but I am overseen by the Transplant "Team". They don't assign any specific doctor post-transplant, just a transplant coordinator. There are 3 tumors that are over 1 cm and they are relatively stable. I have an MRI every 6 months to check the growth and there is one tumor that has been growing aggressively. This tumor was 17 x 21 x 22 mm and was previously measured as 15 x 18 x 11 mm 6 months prior (January to July). I had Microwave Ablation in August 2015. It seems to have been successful but won't be confirmed for certain until my next scan. This scan typically would have been in January with my regular yearly transplant follow ups but I am currently pregnant so they are going to wait until after the baby is born (probably in July) to do the yearly evaluation. The only other treatment that I am undergoing is just immunosuppressants for the liver transplant.

AT7307	1-Feb-2016	HEHE Sep 2007 –acute pain in upper right quadrant of the abdomen. Seemed like a gastric pain but it persisted. Ultra sound, CT & MRI. Blood work was clean except for elevated Alkaline Phosphate. Scans revealed a several lesions on the liver. Saw a liver specialist at Yale – Dr. James Boyer. Oct 2007 – Dr. Boyer. diagnosed HEHE from tissue samples taken. I was transferred to liver transplant group at Yale for follow up. Thankfully it had not metastasized (or so we thought) anywhere else. December 14 2007 - I was put on the UNOS list with a score of 22 and was expecting to get a liver in about 3 – 6 months time Dec 22, 2007 - A week later, I got the call. Liver transplant was done by Dr. Sukru Emre (head of Yale organ transplant surgery). I underwent 6 months of chemo (Doxyrubicin), due to potentially infected lymph nodes that were uncovered during transplant. July 2008 - Chemo ended and I have been fit since then. Regular follow ups and scans are performed every 6 months. I am on 2 mg of Rapamune. Feel completely healthy. Leading a completely normal life with wife & two lovely kids – almost 6 & 4.5. Early 2012 - they saw some new lesions in my transplanted liver. Since I had relocated to NJ and my Yale oncologist had moved to Columbia, I switched to Columbia. The biopsy and confirmation that it was a recurrence of EHE was done there. This time also there were several lesions but still very small in size. They decided to perform Trans Arterial Chemo Embolization (TACE) to kill the tumors and then put me on Thalomid. Before Undergoing TACE, I decid to get a second opinion at Dana Farber in Boston. I met with Dr. Jeffrey Morgan at DFCI. He recommended to flip the treatment and try Thalomid first to see if it worked in controlling the growth of tumors. We could always do TACE at a later time. I decided to go with his recommendation. I was on 400 mg of Thalomid for almost 9 months. It worked very well in stabilizing the tumors...no more growth in number or size. Unfortunately one of its side effects is periphe neuropathy, which I suffered significantly from. Hence Dr. Morgan decided to take a break. April 2013 - I stopped taking Thalomid. I have had 3 follow ups since then and there has been no change. Since April of 2013, besides my regular transplant related meds, the only meds I have been on are for neuropathy...after a point it is irreversible, which seems to be the case with me. No major change in diet or life style except no alcohol since the initial diagnosis. January 2015 - everything stable, tumors don't grow. February 2016 - No change in condition, taking Sirolimus (2mg/day) as anti-rejection for liver transplant in 2007.
AVEN1015	1-Jan-2015	EHE in lungs and liver Feb 2010 - The disease was spotted on a chest x-ray, where it appeared I have multiple nodules on my lungs. Otherwise, I am in good health. June 2010 - Started on chemo drug - Liposomal Doxorubicin. Sept 2010 - Treatment failed - will explore other treatments. Nov 2010 – I was on liposomal doxorubicin. not many side effect apart from fatigue and more infection. but it didn't work so we stopped after 3 months. According to the scan the disease is progressing slowly in my liver and lungs, and they found the disease was also in a bone in my foot. I am now on a clinical trial called axitinib targeting people with soft tissue sarcoma. I started 2 weeks ago. Nov 2010 - April 2012: on a clinical trial for axitinib. Treatment slowed down the growth of tumours but did not entirely stop the progression. April 2012: new tumours and further progression in the liver. Treatment stopped. Awaiting for doctors advice on a new treatment. January 2015 - From 2012 on interferon, it stopped progression, everything stable.
AYJA0915	1-Feb-2016	EHE in liver, lung and heart Feb 2009 - Diagnosed by liver biopsy a year ago. Only taking any supplements (e.g. Shark Lipid and AHCC, etc). But I don't know if these supplements have effect. No symptoms. January 2015 -everything stable. February 2016 - No change in condition.
AZUS0414	1-Nov-2014	EHE in neck 2004-2006 - Increasing pain in the right arm starting at the shoulder and radiating to arm, fingers and head. Diagnosed as a sprain and no treatment or scans done. Dec 2006 - Increasing weakness and difficulty writing. Noticeable lump at the base of neck over right collarbone. MRI revealed a Neuro sheath tumor and directed me for consultation with Dr. Khan at St. Mary Hospital. Jan 2007 - It was decided that that a surgery and biopsy occur on the same day. Feb 2007 - Biopsy performed. Most of the tumor remained and extended to mediastinum. Biopsy results from Mayo Clinic revealed Epitheliod type Hemangioendotheleoma. Moved to specialists at UIC hospital. March 2007 - Consultation with Dr. Massad at UIC hospital who confirmed the diagnosis and recommended resecting the tumor with the help of Dr. Yao. April 2007 - Successful sternotomy. All visible parts of the tumor removed. May 2007 - Consultation with Oncologist and Radiation Oncologists who decided to use radiation treatment to ensure that the maximum amount of the removal of the tumor is achieved. Commenced treatment and going ok. July 2007 - Radiation treatment ended, several burns on my skin took about a month to clear entirely. I lost my voice but it came back slowly over a months time. August 2007 - Follow-up with Oncologist, the cancer looks good, and follow-up with Radiation Oncologist, recommended physical therapy for lymphedema as a result of surgery and radiation Oct 2007 - Blood tests showed thyroid function completely impaired (due to radiation treatments), now on sinthyroid. Nov 2007 - I had a couple follow-up appointments and a CT scan. CT revealed little swelling in the area of the surgery. Dec 2007 - Measured for a compression sleeve for right arm lymphedema (due to radiation treatments). Sept 2008 - was on Synthroid. This has caused some stomach discomfort which is being followed by Dr. Ng (my new primary care physician at Northwestern University), so I am on Previcid to keep that under control. I had all my follow-ups with Dr. Ho (oncologist), Dr. Minn (radiation oncologist) and Dr. Masad (CT surgeon) in June of 08 as well as a CT scan (all at UIC hospital) and everything looked good. Healing from the surgery (in Feb 07) is still in process; little weakness and swelling in the RT arm remains, but doesn't interfere with daily activities. Next appointments and scans will take place in Dec 08. Aug 2009 - Several scans and follow-up appointments with my surgeon and oncologist reveal no signs of a tumor. My general health has been mostly good. My hypothyroidism medication still hasn't been resolved to a single unchanging dose and other hormonal side effects are present as a result, but nothing that interferes too much with my everyday life. The lymphedema in my right arm keeps it slightly swollen, but wearing the sleeve while travelling helps it stay under control. Nov 2012 - I am celebrating my 5th year in remission this year from EHE over my lungs, no signs of remission. There is hope. Nov 2014 - No recurrence, all good.

B*5615	2-Jan-2016	EHE in liver & lungs November 2014: patient had constant pain in upper abdomen with flatulence and constipation. December 2014: a mass in the right liver found in abdominal sonography. January 16th 2015: MRT on mass reported haemangiomia. April 2015: The patient's pain in upper abdomen was still getting worse. Had a laparoscopy. Result - a moderate grade EHE cancer in the liver peritoneum. Age 59. A CT of the lung showed three tiny spots. With the EHE diagnosis, the family physician sent the patient to Prof. Dr. Bauer (hospital Essen, Germany) and Prof. Dr. Stippel (hospital Köln) to get opinion for therapy. June 1st 2015: Because of the severe pain in the abdomen: surgery by Prof. Dr. Stippel, Universitätsklinik Köln with extended hemihepatectomy right, lymphadenectory peritonectomy at right upper quadrant, omentectomy and partial resection of diaphragm with plastic closure. The surgery went well, but wound healing was delayed. The patient had to remain in the hospital for two months. September 2015: the patient had recovered enough to start chemotherapy. The plan for therapy was suggested by the oncologists of the hospital in Köln. The therapy is administered by Dr. Dübbers. the oncologist at the hospital in Ahaus, where the patient lives. September 15th 2015: The first chemo was given with liposomal doxorubicin. Because of the patients' severe weight loss after the surgery, therapy was reduced, divided into 8 infusions. November 2015: After the 5th chemo there was a little growth of the tumors in lung and liver, compared to the last CT from August 2015 (around 6 weeks before starting chemo). Taking into account a newly appeared rash, which was considered adverse effect, the chemo was changed from Caelyx to Myocet. After the 6th chemo (= 1st with new medication) CT was repeated, this time no tumor growth. The next CT is planned to be done after two more chemos. Secondary diagnosis: art. hypertonia, recurrent paranasal polypsis nasi, asthma bronchiale. s/p abdominal hysterectomy uterus myomatosus, s/p appendectomy, shoulder arm syndrome right, heparin-induced thrombocytopenia, s/p temporary bleeding disorder. Because of the polyposis nasi, the patient has been treated with corticosteroids for 20 years.
BC7911	1-Oct-2015	EHE in Liver and lungs 2009 - Diagnosed at age 30. Pain in upper right quadrant, doctors felt it might be bone injury from working out. Ultrasound of the liver showed multiple tumors (2 to 6 cm) and sclerosis. Blood work normal. Biopsy of the liver came back no diagnostic, It was sent to other 2 places and finally was diagnosed with EHE in 2011. By then there were a few nodules detected in the lungs. 2011 - Dr Gross from Baylor suggested transplant and meanwhile put on Thalidomide, very bad side effects but some of the tumors shrank. February 2014 - transplant, on 3 mg of Rapa as anti-rejection drug July 2015 - No recurrence, lung nodules are stable and seems to be calcifying. October 2015 - LIver is clean
BCUS0210	1-Jun-2010	EHE in liver and lungs. March 2002 – diagnosed with EHE, multiple tumors in liver and both lungs and "suspicious" lymph nodes in the aortic region. It was discovered when I had a chest x-ray taken when the doctors were looking for pneumonia. August 2006 - bad headaches and joint pain, causing anxiety. I have another check up coming up in a few months. 7 March 2007 - at MD Anderson. Still have tumors in the right lobe of my liver with no significant change. I have subcentimeter lymph nodes in my gastrohepatic ligament that measure 8 mm. I also have 8 mm lymph nodes at the proximal aspect of the ascending colon. I was suspicious for lymphadenopathy/metastasis. I still have multiple bilateral subcentimeter tumors in my lungs with no change. June 2008 - I was diagnosed in March 2002 with EHE. I have 14-16 tumors throughout my liver and 22-26 tumors bi-laterally in my lungs. I am going on 6 years without treatment. I started having CT scans every 4 months, backed down to every 6 months, and for the last 3 years it has been on an annual basis. The tumors in my lungs appear to be stable. The tumors in my liver are growing but at a slow rate. I am asymptomatic and my doctor (Dr. Benjamin -- MD Anderson Cancer Center) has told be that any treatment will not start until the disease makes me sicker that the side effects of any medicine. Apr 2010 - going for check ups on a yearly basis. The doctor said that most of the tumors had not changed significantly in size since his previous appointments, but that some of them have actually improved in size which may indicate some healing. June 2010 - most of the tumors are still stable, a few of them actually appear to be SMALLER than they were before. He also said that instead of coming back for a yearly check up, we could push his check ups back to every year and half. *Editor's note - patient notes that prior to starting treatment with Dr. Benjamin at MD Anderson there were consultations with Dana Farber and Sloan Kettering. Trtmt with Dr. Benjamin began in 2002.
BDUS0910	1-Sep-2010	EHE in the mouth and lungs March 2009 - This has been going on for about 2 years. Biopsy result showed Anterior Maxilla, Epithelioid Hemangioendothelioma. First surgery my son had they removed his front 3 teeth because it was in the bone tissue and soft tissue around the teeth. My son said he felt like the lesions were back. We went back and had another biopsy, it had recurred. So they removed some more tissue and found it was running up in to the palette of his mouth into the bo again. Mar 2010 – possibly spread to the lungs. Awaiting a Thoracoscopic lung biopsy at Emory Hospital. Apr 2010 - biopsy came back positive for EH in the pleura, left parietal biopsy. Sept 2010 - We had to stop treatment in mouth and started treatment on lungs. The VATS showed he had EHE in plural lining in both lungs. ______ is having Chemo treatment at Winship Cancer Institute at Emory in Midtown Atlan GA US. His Chemo consist of doxorubicin and paclitaxel. He has to do 6 cycles. The two chemo's the first week and the pacilitaxel for the next two weeks. The fourth week he either has off or every two cycles he has MRI and pet scan that week. So far the chemo shows a little decrease in fluid in pleural lining. We have one more cycle to go. Dr.Owonikoko wants to sit and wait after the last treatment. ______n has multiple tiny bilateral pulmonary nodules, all less then 6mm in size, are stable in size by CT, but remain too small to characterize by PET.

BDUS1011	1-Jun-2011	EHE in Liver – metastasized to spine 24 Sept 2010 - diagnosed with EHE. Sept – Oct 2010 – underwent radiation therapy on spine. October 2010 I had major back surgery on the spinal tumor at the end of October due to the fact that the tumor had gotten larger after radiation therapy did not work. Nov. 2010 I went for 6 cycles of chemotherapy. Jan 2011 - currently on my 4th cycle of chemotherapy, in which we are working on the spots on my liver and the tumor that is attached to my spine. June 2011- I have a scheduled scan.
BE8914	1-Jan-2016	EHE in liver & lungs Also suffering from Crohn desease. Summer 2014: I discovered my EHE disease when I was pregnant when I was 25. March 3 2015: I had a CT that confirmed the multiple tumors in my liver, with the biggest one measuring 6,5 cm; I had also many in my lungs, but all are subcentimeter nodules. After that I had 3 months of antiblastic therapy weekly with antracicline schedule weekly. July 17 2015: I had another CT and the situation was stable. I kept on taking epirubicin weekly for another month and a half till September 21th 2015 when I reached the 810 mg dose of epirubicin. November 2015: I had another CT and everything was stable.
BE9107	1-Nov-2014	EHE in lungs, abdomen, brain and extremities July 2007 - Tight muscle in right arm. Doctor's checkup for school and blood work was normal. Aug 2007 - Started spitting up blood.. X-ray, then CT-Scan of her lungs and sent us to a pulmonary specialist. Both lungs were filled with nodules, most of them small but about 5 or 6 fairly large ones. Again complained about a spot on her back that felt like a tight muscle that had grown into a good size lump by the time we saw the specialist. Hospitalised for various scans and tests, as well as a needle biopsy of her lungs. The biopsies came back negative for malignancy. We were told at first it was some kind of parasitic pneumonia and that the two were unrelated but they sent the samples to Mayo Clinic for help with a diagnosis. Sept 2007 - Open lung biopsy - preliminary report of hemangioma in the lung. The lump on her back at this point, although it was not removed, receded but she started with another on the underside of her right arm. Oct 2007 - Finally got a diagnosis of EHE without malignancy from Mayo Clinic. Lump on her arm continued to grow until it became the size of a small baseball. Also complained of pain in her leg. Dr. prescribed Tylenol 3 for the pain. Had MRI of the arm and the leg as well as the abdomen where they found several nodules but none on any organs. Two weeks ago she all of a sudden began trouble reading. She could not recognize words and had to sound them out like a first grader. Then she began having terrible headaches and vomiting. Had an MRI of the brain and they found 3 nodules one of which is about 2 inches which is slowly bleeding and causing swelling in the left temporal lobe. The lump on her arm began to recede about the time she began having headaches. Nov 2007 - Began treatment with steroids (Decadron) to reduce swelling in the brain. Anti-Convulsant (Kepra) as a precaution, and Interferon-A. No further growth in lungs prior to medication. Growth in brain stabilized - no further bleeding. Lump on her arm is almost completely gone (about the size of a penny) and the one in her leg is not causing her any pain. She is seeing a neurologist to monitor her progress, a learning specialist to help with reading and an ophthalmologist as she has had some reduced vision. Dec 2007 - She has just come off of 28 days of steroids. Swelling on the brain is reducing and the blood pool is also decreased. She still suffers from headaches that are a result of the lesion in her brain. Good news from the latest MRI the oedema surrounding the lesion is gone and the lesion itself has shrunk just a little. The other areas are not bothering her too much right now. ______ was able to keep up with school until she had trouble reading as a result of the lesion in her brain. Since she has improved some, she is starting to catch up. Jan 2008 – Boston Hosp said that the diagnosis could be high grade EHE or a low grade angiosarcoma. They agreed with the Alpha Interferon treatment, but reduced her daily dosage and suggested we go off of the steroids if the swelling in her brain has reduced. The last MRI showed most of the swelling gone and she is scheduled for another MRI in mid Feb. so maybe one more 5 day round of the steroids and she will be done with that. So far, since being on the Interferon, she has not had any other outbreaks anywhere so we are hoping that she has stabilized. Mar 2008 - A couple of weeks ago we had a CT scan of her chest taken – some of the lesions in her lungs had disappeared and some of the larger ones have begun to shrink. We also had an MRI of her brain last week and so we were hoping that the results would be as good. Instead it was mixed. The one large lesion that was a bleeder is shrinking albeit very slowly. However there is another one that has grown over the last month or so and is now bleeding. This in spite of the Interferon and steroid treatment. She is also continuing to fight infection from a pilonidal cyst that developed a couple of months ago. We are going to be consulting a surgeon to see what can be done about removing the cyst. Overall she continues to have good days and bad days. Lately most of the bad days have come from the medication prescribed to try and get rid of the infection. We are considering taking Avastin for treatment. Aug 2008 - She was doing really great. The Dr. had just told us that we did not have to come back for another 2 months. She cleared us to go on a family vacation to Hawaii (provided by Children's Dream Fund). While she was in PA she had a focal seizure (inspite of being on anti-seizure medication) which was caused by a new bleeder in her brain and she had to be med flighted to Philadelphia for treatment and observation. To date she has had at least 3 bleeders (maybe some others in the past) and several other smaller ones. None of the neurosurgeons here want to run the risk of the surgeries, which I don't even know if I would agree to that since there are so many of them. She has become intolerant to milk products so does not eat many of those now anyway as they cause her digestive issues. She has lost quite a bit of weight. Nov 2008 - In September we started her on Taxol and Sutent as recommended by Dr. Klement. In late September she had another spell with seizure clusters and they found 5 lesions bleeding in her brain. The weekly chemo treatments have really taken their toll on her system and in spite of trying to keep a normal routine the last few weeks have been miserable. She just spent a week in the hospital with extreme abdominal pains and it was discovered that she has a hemangioma in her colon along with ulcerative colitis. We are now nearing the end of 12 weeks of treatment and are debating whether we should take a break from medication and let her body heal some before we continue with any other form of treatment. We are not sure how effective the treatments have been. We have also consulted with Dr. Denise Adams of the Vascular Anomaly Center at the Children's Hospital in Cincinnati Ohio. She has agreed with the course that Dr. Klement has laid out for us. One good piece of news is that the lesions in her lungs are continuing to shrink and disappear. Jan 2009 - The combination of the Taxol and the Sutent were taking it's toll on _________ and she was one very weak kid. She was unable to eat without pain as the Sutent had caused ulcerations in her stomach and colon. She was so weak that she could not shower on her own and could barely walk. In early December, MRI of her brain showed one lesion had actually grown 1.5cm and the others had not even been touched by the chemo. At this point our Dr. here decided to take her off of the drugs and we asked for a reprieve for the holidays before putting her on anything else. Responded very well to not being on the medication. Within a week she was eating (more than normal due to the steroids) and only 10 days after stopping the meds we walked around an amusement park for 4 hours without a whole lot of stops. She missed a lot of school before the holidays, but since school started last week she has been able to go every day. Right now she is not in a lot of pain, an occasional stabbing headache, and daily nausea from the anti-seizure meds. This week we are flying up to the Vascular Anomalies Center attached to the University of Cincinnati Children's Hospital. to see Dr. Denise Adams . July 2009 - Since January, when we consulted with Dr. Denise Adams at Cincinnati Children's Hospital, she has been taking Rapamycin (Rapamune) with fairly positive results. She has shown some shrinkage, but mostly stabilizati
BE9415	1-Jun-2015	EHE in Liver October 2012 - _______ was diagnosed at the age of just 18. Multiple tumors in the liver. September 2013 - She had a liver transplant at Kings College Hospital, London. June 2015 - The only medication she is currently taking is 4mg daily of tacrolimus

BFUS8810	1-Jun-2015	Hepatic EHE 1988 – diagnosed with hemangeomas of the liver when he slipped and banged his liver on a metal ladder at work, infarcting one of them. Because we were told these hemangeomas were benign, we have ignored them for all these years. Jan 08 - developed a DVT with PE — we refused biopsy because we “knew “ they were benign from 20 years before. They put him on Warfarin. February 2009 - Increasing pain in the back between shoulder blades and general body pain Full GI workup over the next 2 months—endoscopy, colonoscopy, abdominal CTScans, liver tumour flow study on one large tumour. May 09 - gallbladder removed with a liver biopsy taken at the same time — diagnosed as hemangeoma. Pain, at times in waves of the 8-9/10 level, continued to occur daily after gallbladder removal, and does to this day. Does not tolerate narcotics because of IBS/severe constipation when he takes them, so he is on lyrica and tramadol for pain. He has been through the gamut of pain meds, anticonvulsants, sleep meds etc, but is sleeping only a couple hours nightly and is fatigued all day long. So we can’t just ignore/”wait and see” about “silent tumors” because the symptoms are so debilitating. OCT 28, 2009 - abdominal CT and MRI in September 2009 showed a new low-density lesion, so another biopsy was ordered and after 2 weeks of radiologist tests on both biopsy specimens (including May 09’s), came back as HEHE. November 2009 - The new lesion is 5-6 CM and is near the portohepatis region of his liver. He has one tumour about 4 CM pressing against his liver capsule — the oncological surgeon wants to chemoembolize it — the one next to the porto hepatis he wants to demolish with radiowaves, and he wants to leave the two 2 cm lesions alone — suggesting surgery the NEXT day because of pain. PETscan showed tumors not highly reactive, so are not acting like cancer. No tiny EHE tumors found throughout the body. Dr felt that PETSCAN was not a good way to view the characteristics of his tumors. Oncologist Recommended Resection, although he said it would be touchy due to the sensitive nature of the tumors in the porto hepatis region of the liver. Dec 2009 Second opinion, Dr. Volpe, Head of Surgery at UF Shands, JAX. He said because ______ has 4 tumors in different parts of the liver, he does not think a resection is a good idea--recommends we consider only transplant. Referred to Mayo Clinic,JAX. 28 Dec 2009 CTscan shows new large tumour (4.5cm) in porto hepatis region, pressing other newer-older tumour (4+cm) against the vena cava. Oncologist freaked - tried to get _______ put to the front of the line at the Mayo Clinic Transplant evaluations. Told no openings till JAN 15. Told this is very aggressive growth for HEHE. Apr 2010 - ______ is being listed at Mayo, Jacksonville for a liver transplant. They have dealt with about a dozen EHE patients in JAX. _______ is on 75 MG/hr fentanyl patch for pain, plus 15 mg oxycodone for break through pain. Also, Loratadine 10 mg, one per day. And sublingual melatonin plus a sleep aid. Doctors at Mayo did not recommend any further treatment pre-transplant. He is on many supplements plus an organic diet, and an oil-protein regimen. Don't know how effective it will be. June 2015 - Had a first CT for 5 years. Everything is stable!
BJ0007	1-Jan-2016	EHE in liver 2007: I had breast cancer, treated with bilateral mastectomies, chemo and radiation. The cancer was estrogen-receptor positive, HER-2 negative. It was present in both breasts and developed in between annual mammograms. 2012: I also developed a low grade B cell lymphoma (first symptoms in late 2011). My optic nerve was swollen and inflammed, which is why I sought treatment. That was treated with 2 weeks of Predisone and subsided thereafter. The lymphoma was treated with Rituxan and Temodar initially and followed with PET scans. It did not subside until a second round of chemo consisting of Rituxan and Treanda. This occured in 2013. Spring of 2014: I had a PET scan to follow up on the lymphoma status and two areas of increased metabolism in my liver showed up. This turned out to be EHE. I had been receiving treatment at Bryn Mawr hospital by my oncologist Dr. Sandra Schnall. She recommended I go to Jefferson for further evaluation and treatment of the EHE. Fall 2014: I had Ytrium-90 beads injected into my hepatic arteries. The tumors in my liver had progressed to "innumerable " and were growing. August 2015: I had chemo injected into the right side of my liver but it was felt to be ineffective and so was not performed on the left side. Winter of 2015: serial MRIs showed tumor shrinkage. My liver function so far has been unaffected. January 2016: At present we are watching and doing serial MRIs. I see Dr. Ashwin Sama at Jefferson presently. I feel good and am able to function normally.
BJ0315	1-Oct-2015	EHE in Leg January of 2003 - I was diagnosed with EHE in my right leg when I was 21 and serving in the US Air Force. I had two marble sized lumps on the back of my leg that hurt to the touch, so I decided to get them checked out. After first being told they were just cysts I got a second opinion and decided to do a biopsy on the tissue after removing it from my leg. They had to send the samples off to be analyzed before the diagnosis was made. This diagnosis led me to the cancer center at the University of North Carolina where further tests uncovered lesions all throughout the bone and soft tissue starting in my toes and going all the way up into my femur. The highest node was about 2 inches abo my knee. Amputation was recommended before my family and I ultimately decided to try my luck with radiation therapy on my leg. April 15 2015 - I started radiation and had daily treatments through the end of May. No further treatments have taken place or been necessary since then. All of my follow up care has been through the VA in Durham, NC by Duke University doctors.
BJ1015	1-Jun-2015	EHE (?) in Liver June 16, 2010 - I was diagnosed at 25 by a GI named Dr. Leonard Fischer. I was then seen by a hepatologist at Georgetown University Hospital who is part of the transplant. All the tumors were on my liver ranging up to 7cm. Oct 13, 2010 - I received a liver transplant at Georgetown University Hospital. Jun 2015 - I have had clear pet scans since transplant.

BJAU1015	1-Feb-2016	EHE in lungs, pelvic area and lymph nodes 29th December 2014 - DIAGNOSED. I may have had EHE for up to 4 years (or more) prior to diagnosis at age 35.5 years. HOSPITAL: Diagnosed at Peter MacCallum Cancer Centre Melbourne via biopsy through the Cervix wall. Overseen by Alan Walker Cancer Centre Darwin. August 2014 - I noticed a pain very similar to sciatic on my right side. My movement became restricted and simple things like sitting down and driving became very painful. After a few visits to a physiotherapist thinking it was a muscular issue involving the adductor muscle I was sent for a scan late September when the lesion was found. November 2014: Partial destruction of ishius ramus (pubic ramus) bone in pelvic region and tissue involvement Approx 5cm, Approx 15 lung nodules sizing from 4mm to 1.1cm. January 2015: Increased size of tumour in pelvic region (approx 1.5 cm growth) Lymph node increased in size in groin region. Lung nodules increased in size, two almost doubling plus new nodules identified in lower lobes COMMENCED CHEMO JANUARY 2015 after SCAN IN JANUARY COMMENCED RADIATION APRIL 2015 (6 days only) March 2015: Main tumour appears Larger (approx 1cm increase). Further bony destruction and involvement of muscles surrounding tumour. Lymph nodes reduced by 3mm. Lung nodules appear smaller. The bigger nodules reduc by half a centimetre. June 2015: Main tumour appears to have stabilised. Is it a result of the chemo or the radiation? Lymph nodes reduced in size, Lung nodules have either remained the same or slightly reduced in size. TREATMENT: January 20th - June 20th 2015 Weekly Paclitaxol Regime 185mg This regime is easy to live with, no side effects, except hair loss, moderate tiredness, and some neuropathy towards the end. Major side effect was from swelling, which still hasn't resolved some two months after finishing treatment. I was booked in for 24 sessions, only completed 22 sessions. There was a reduction in lung and lymph nodules as a result of this treatment. April - Had a 6 day course of radiation on pelvic legion - 6 minutes at 6 grey. The Radiation specialist was not really experienced with EHE and it was more an "attempt" to halt any further progression, as this tumour didn't seem to respond to chemo. As expected, side effects were as predicted and lasted approx 4-5 weeks before fully resolving. My next scan after Radiation showed that it had remained stable. FOLLOW UP I will have scans every three months via CONTRAST ENHANCED CT SCAN CHEST, ABDOMEN, PELVIS FAMILY HISTORY OF CANCER Paternal Grandmother - Passed away in 1952 aged approx 50 from Breast Cancer Father - Hodgkin's Lymphoma in 1996 successful remission after radiation. Passed in 2012 from undiagnosed cancer that had spread to his bones. Sadly he didn't tell us until it was too late, so I don't know any more than that and mum doesn't remember anything and has lost paperwork that could give a clue to what he had. He decided again Chemo due to his age and failing kidney and liver function. ANY OTHER INFO Not sure what the original site of EHE is. I must say that looking back I did notice shortness of breath in 2011-12 and an odd feeling in my pelvic area around the same time. I was very active in my year of diagnoses and believe that excessive inflammation, and some dmage to the pelvic bone from excessive activity may have triggered it to become somewhat aggressive. January 2014 - When power walking 7km a day, noticed a stitch in my side. I would also feel like I was out of breath, especially when walking up hill January 14-August 14 - Riding to work I would notice it hurt in my groin area if I went over a bump heavily January - August 14 - Perfecting the handstand. I would kick off and land on my right side, same side as tumour. Sometime I would practice again a tree and knock my pelvic region hard on the tree if I missed 2006 - 2014 When lifting weight on the bench I would sometimes rest in on my pelvic area and every now and then the bar would land heavily, again on the site of the tumour November 12 - August 15 - Dancing, modern and pole, lots of hard drops onto the floor, kicking of legs etc. Aggravating the region of the tumour. Also noticed shortness of breath and put it down to not being as fit as I used to 2006- Letz procedure to remove pre-cancerous tumours from the cervix. Could this have inflamed the region causing spread? 1997 - Pain in back, spreading and intense, got really bad before I went to the Dr's who sent me in for an emergency Appendix removal. Same side as my pelvic lesion. Could this have been symptom of EHE misdiagnosed. 1994 - At Boarding School has bad pain in groin area, suspected Netball injury. Could not stand after sitting easily. Saw a chiropractor, issue did resolve by itself after some time. Often wonder if this was the start of EHE or just a coincidence. It fits with prepubescent presentations. If I was at home maybe I would of had a scan. At this stage no one with any experience with EHE is looking after me or my progress, hoping to meet with Jayesh Desai September. Overseen by general Oncologist in Darwin. FURTHER UPDATES December 2015: The main site on my tumour has continued to shrink from is maximum 9cm by 8cm to now being 7cm * 3.4 with rim calcification. My lungs (on paclitaxel) all shrunk, but two have come back to original size and one that disappeared has reappeared. One is located in the upper right lobe apical segment (1.2 * 1.2), and the other is in the upper left lobe 1.9 AP * 1.9 transverse. The one that disappeared then reappeared in my lower right lobe a
BK6212	1-Nov-2015	EHE in liver and possibly lungs. Diagnosed July 2012 at age 50. Number, location and size of tumors – There are innumerable small nodules throughout both lungs measuring up to 7mm in maximum diameter. She also has three lesions in the right lobe of her liver although there may be more as the Doctors have refused to count them saying only that they are numerous. A liver biopsy confirmed EHE and it is assumed that the lungs are also EHE however this has not been biopsied. EHE treatment and results – _________ has CT scans every 6 months at the Royal Marsden Hospital and she has been taking Celecoxib 200mg twice a day since diagnosis – In terms of results these are unknown but the EHE has been stable so it might be working we just don't know – no serious side-affects to date from taking it Additional information: a. _________ also has MGUS (Monoclonal Gammography of Unknown Significance) which means she has a Paraprotein of 16 g/L in her blood which is a Pre-Myeloma marker but which she is now only on 2 year check up's having been on 3 month watch for 2 years b. ___________ also has Hashimoto's Autoimmune disease and is on Liothyroine T3 (20 microgram half a table alternate days) & Levothyroxine T4 (1x25 microgram daily) In the UK they will not usually prescribe Liothyroine T3 but as we could show __________ has a defective D102 gene which means she cannot convert T4 into T3 they have given it to her. c. _________ was extremely ill for 6-8 months prior to diagnosis – sometimes she would only be awake for 2 hours before needing to go back to bed. These symptoms have gone now but she now suffers from dreadful migraines for which she take Sumatriptan 50mg upon onset and which manages it well.

BKBE1010	1-Dec-2010	FB Member EHE in liver and lungs Sept 2010 – Highly pregnant with my first child, and taken to the hospital with severe pain in the upper right side of the abdomen. One week later my baby was born. It took another 10 days for the diagnosis of epithelioid hemangioendothelioma. I took painkillers for the pain for about 2 weeks but the pain disappeared and now I only have occasional pain shots in my liver. The CT-scan showed 8 tumors in my liver and about a dozen tiny ones in my lungs. Dec 2010 - The follow-up scan showed the tumors to be stable. 7 out of the 8 tumors have even slightly decreased in size and 1 has slightly increased. All the doctors (except the head of surgery of Gent and the homeopathic doctor) advised the following treatment: - first wait and see to determine the speed of evolution of the tumors - chemotherapy - angiogenesis inhibitors The head of surgery in Gent was of the opinion that surgery was possible and he had already performed a liver and lung transplantation on another patient with the same tumor in 2001 and 2004. Unfortunately a recent examination showed that a new tumor has grown in the 'new' liver. Of course, the patient gained almost 10 years of her life in the meantime! The other doctors say that transplantation is not an option for me because new livers are not given to sick patients ("lost causes") like myself.
BKGE0510	1-Mar-2010	EHE Lungs, Esophagus May 2005 – diagnosted two EHE`s by sheer coincidence while x-raying my lungs, because I collapsed in a store. Jun 2005 – first operation: amputated my lower right lobe of the lung, where the bigger of the two tumours resided (tumour-size: 3.5cm). Nov 2005 – second operation: second EHE (size : 0,7 cm) was removed from the left side of my lung. Neither medication, nor radiation, nor chemo therapy, because my attending doctors did not have enough experience concerning EHE to rely on - but x-ray + CT lungs every 6 months. Jan 2009 – pain in my chest, increasing in quantity and intensitivity. Feb 2009 – meanwhile everyday intensive pain, at night even more intensive. First problems with swallowing (solid food got stuck in my oesophagus more and more often). Apr 2009 – gastroscopy: clear results. (neither stomach, nor oesophagus); by now I was losing weight, because I was only able to eat soup and other liquid food. Often sleepless nights because of pain. Losing concentration at work. Even losing my voice (like permanent hoarseness). Jun 2009 – CT (lungs+abdomen): found 4-5 small metastases in my lungs and a tumour in my oesophagus. Aug 2009 - Operation in the “Surgical Clinic” in Heidelberg, abdomino-thoracal oesophagusresection, lifting the stomach after that and an atypical resection of a part of the right lung. Latest CT scan shows one metastasis progressing in the left part of the lung. Nov 2009 - restaging with CT thorax/abdomen – no new results compared to 22.10.09: intrapulmonal metastasis; splenomegaly; diaphragmatic elevation on the left side with colonmeteorism (?) (german: colonmeteorismus); no sign of malignancy. Dec 2009 - implantation portacath(port); chemo therapy with „Paclitaxel“ analog to the treatment of advanced angiosarcoma (compare: Schlemmer et al., Eur J Cancer 2008) Paclitaxel 90 mg/m^2, day 1,8,25, repeated on day 29; Optimisation of the pain therapyL-Polamidon, Katadolon s long and Novalgin instead of Matrifen 175 (plaster, 3 days) and Lyrica, but pain remained just as strong as before. Feb 2010 - thorax/abdomen; intrapulmonal metastasis unvaried new: multiple, ostelytic (?) (german: osteolytisch) lesion of the spine which is progressing in size; application for new chemo therapy using „Revlimid“ accepted by health insurance. Mar 2010 - Optimisation of the pain therapy; implantation second portacath(port) in order to intrathecally test ziconotids (?) (german: Ziconotide ...extracted from the poison of bevel worms (german: Kegelschnecke))
BM9015	1-Oct-2015	EHE of soft tissue, bones, liver and lungs Feb 2015 - diagnosed at age 25. Tumor locations: Left leg: distal tibia, proximal tibia, patella, distal femur, patellar tendon, liver, left lower lobe of lung, soft tissue nodules in my left leg and inguinal area. 3 soft tissue nodules remain, 2 were resected, multiple lesions in my bones, at least two in liver and two in lung all less than or equal to 1 cm. I had lesions removed from my patella which was three cm I believe, and smaller lesions removed from my distal femur. Surgical resection of two soft tissue nodules on left leg, resection of patellar and femoral lesions. Otherwise medical history: pcos, osteopenia Since the initial scans in Feb a new nodule was detected in my lung and another in my femur however we are not sure whether they are new or just newly found due to differing slices on different MRI and CT scans. The subcutane tumors in my leg crop up and grow at a rate of about 1-2cm/year, whereas the tumors in my bones, liver and lung have not grown since they were discovered in February.
BP0715	1-Jun-2015	EHE in Liver and lungs 2007 - worsening wheezing and a dry cough for approximately 10 months. A CT scan of the chest, abdomen and pelvis found multiple bilateral subcentimeter pulmonary nodules and multiple rim enhancing liver masses with liver capsular retraction. A core biopsy of a liver lesion suspected lungs or breast cancer. (PET) scan reported no abnormal uptake in the liver lesions. carboplatin and gemcitabine two cycles, stable CT, a treatment break which lasted 14 weeks. Restaging imaging revealed enlarged liver lesions. Initial core liver biopsy was re-reviewed at another institution and the consensus was that the liver findings were the result of a bile duct carcinoma. This information prompted a change in regimen to single-agent oral capecitabine. Remained on capecitabine for 1 year with stable disease demonstrated with repeat serial imaging. After a 4-month treatment break, subsequent restaging imaging revealed enlarging liver lesions. Another biopsy of a liver lesion was performed. Results of molecular profiling of the liver lesion biopsy suggested hepatocholangioma. Treated with sorafenib for 6 months at which point, elected to stop given adverse side effects and stable disease demonstrated on imaging. After 1.5 years of observation, capecitabine was reinitiated after of right upper quadrant pain and imaging revealed enlarging liver lesions. Another liver lesion biopsy was performed, which confirmed HEHE. IHC was positive for CD and CD34. Bevacizumab was added to capecitabine. June 2015 - Only Bevasizumab infusions, scans stable.

BR6097	1-Dec-2015	EHE My tumor was in the chest, specifically on the thymus and in the innominate (brachiocephalic) vein. 1997 - The thymus was removed surgically, and a Teflon graft placed in the innominate vein. The surgery was performed in Montreal Quebec, at the Royal Victoria Hospital by Dr. Morin. I was thirty seven. The pathologist was very excited to find EHE. At the time (perhaps still now) there was little knowledge of benefit of adjuvant therapy. No one in Montreal had any familiarity with treatment modalities. We made inquiries at Sloan Kettering, and were told that there was a lack of treatment familiarity at that facility as well. It was recommended we visit the Dana Farber Hospital in Boston. The suggestion at DF was to follow up with radiation therapy. I recall the panel saying that while there was no specific data supporting that choice, inasmuch as I was healthy, and the consequences of recurrence would be life threatening, their recommendation was to undergo radiation therapy in the hope that it might serve to ward off tumor recurrence. I had the radiation therapy in Vancouver BC, and then followed up with CT scans a couple of times a year for a number of years.
BS1215	1-Oct-2015	EHE in Lungs and liver May 2012 diagnosed with one liver ehe tumor, 3 cm. June 2012 - had a lung resection and confirmed ehe in both lungs. About 32 nodules. Oct 2015 - Have been untreated and on a wait and see approach since with ct scans.
BSOO1010	1-Sep-2010	EHE in liver and lymph nodes 01/2010 2 weeks Pruritis then Jaundice. 02/2010 Bile duct constriction, CT & MRI no cause found, ERCP - stent placement, jaundice & pruritis resolved. 05/2010 ERCP & EUS, stent missing, pancreatic duct and bile duct accidentally perforated during procedure, misdiagnosis chronic pancreatitis. 05/2010 MRCP shows narrowing of bile duct, but blood work normal. 06/2010 liver profile slightly elevated. 07/2010 liver profile significantly elevated, pruritis and jaundice return - ERCP stent placement. 08/2010 evening only fever for several days, reaches 101 F going to ER admitted to CMC - cholangitis - treated with IV antibiotics. Since we have been struggling with this for several months we decide to get the bile duct surgically reconstructed. Surgeon found enlarged lymph nodes pressing on bile duct. No immediate findings in pathology. 09/2010 pathology finding EHE in one of the removed lymph nodes. CT & MRI shows 2 or more lesions in extended right lobe of liver. All less than 2cm. 10/2010 FNA biopsy of 2 lesions confirms HEHE diagnosis official. Medical team recommends resection of affected part of the liver after explaining that nobody knows what to do.
BZCA0811	1-Jan-2011	Diagnosed with EHE which is in the lining of my right lung and possibily in my liver (the liver has not been biopsied as yet). September 2008 - mastectomy of right breast. May 2009 - 7 chemotherapy treatments and 25 radiation treatments completed. August 2010 - bone scan indicated abnormalities in right lung - excess fluid and thickening of lining around the lung. January 2011 - diagnosed with EHE after open biopsy of right lung. Cancer found in the lining of lung. A nodule behind the liver has not yet been biopsied and MRI was inconclusive. Oncologist has arranged for consultation on February 14, 2011 with specialist at the Mt. Sinai Hospital Sarcoma Unit in Toronto Ontario. Experiencing pain in right shoulder, chest, arm and back and presently taking prescribed pain medication. Also experiencing fatigue.
CA0014	1-Feb-2016	EHE in liver 2014: diagnosed by accident. Several tumors in the liver, largest about 3 cm. Had 4 tumors ablated with microwave. Had serious side effects (kidney falure). 2015: doing abdominal MRI and Chest Xray annually. On wait and watch approach. Several more tumors in the stomach and in the liver.
CA1315	1-Oct-2015	EHE in Liver 2013 - I was diagnosed at 43 years old. The location is in the liver and here there are in S/4 multiples nodules, the largest of 5mm, S/5 subcaps 51×29 mm, S/7 multiples of 1 cm. The emisistem biliary sx is ectasic. I haven't had any treatments, I intend a liver transplant.

CA8609	1-Sep-2015	EHE in skull and liver and lungs December 2005 - discovered a first 'bump' on my head. It was a little bit painful and red so I went to a dermatologist. Jan 2006 – surgery to remove the bump - diagnosed as Epitheloid Dermatofibroom. Feb 2008 - there was another bump on another location. Surgical removal, rediagnosed as Epitheloid Hemangioendothelioma. Told it was a benign tumour and that it was totally removed so there was no problem anymore. July 2009 - another bump. Finally I made an appointment in the University Hospital of Ghent. Additional scans showed tumors on my liver and in my lungs. Now I am treated by Dr H. Denys and she decided not to start any treatment yet. Mar 2010 - Feel well. Received the news from my doctor that my tumors in my liver are slowly growing. Liver transplant in discussion. I had a consult with a liver specialist and he advised me that a transplant is my best chance for a long and healthy life. July 2010 - My scans are still stable. I have scans every 3 months but so far they are showing no growth. I still feel very well. But because my first scans (in January) were showing some small growth in my liver, doctors have decided to put me on a liver-transplantation list. For the moment I am on the list, but as long as my scans stay stable I will not get any points on the list October 2011- Presently I am on the liver transplant list awaiting a new liver. I'm still feeling good, no medical complaints. Tumours on my liver as very slow growing. As an experiment I am also taking Rapamune for the past six months. I will continue taking this medication after the liver transplant as an immune inhibitor, but it also has an anti-cancer influence. I am taking Rapamune to see if it indeed stops the growth. My scan in September was again stable, but still hard to say if it was the Rapamune March 26 2012 - please be advised that I have had a liver transplantation. Before my transplantation I have been taking Rapamune for a while to stabalize the growth of tumors in my liver. Aug 2012 - Now I'm also taking Rapamune (4mg) together with cellcept (2x 500mg). At the moment I'm doing great. Nov 2014: Only treated for liver transplant at the moment. Before also taking Rapamune but treatment stopped since January 2013. 1 new skin lession after stopping Rapamune (June 2013) Now my doctors really believe Rapamune is suppressing the EHE. January 2015 - Pregnancy, stopped Rapamune (Sirolimus). May 2015 - MRI Scan: Everything stable Aug 2015 - Switched medication from Prograf to Rapamune Sep 2015 - CT and MRI: Everything stable.
CBUS0514	1-Feb-2015	EHE in Liver 13 tumors in right lobe of liver, none larger than 3cm. 2000 - Confirmation of disease by Univ of Pitt, Dana Farber (George Demetri), MD Amderson (Dr. Burgess), Univ of Miami, Sloan Kettering (Bob Maki), Folkman's group, & others. Possibility of a liver transplant, but decided not to go ahead, is active and enjoying good quality of life now, not worth the risk. Not on any treatment. Jan 2005 - Still stable and hoping to stay that way. Although I feel like there is a bomb ticking away-that will one day explode-but I feel well. Aug 2006 - I have been diagnosed for 6 years and have remained stable with no treatment. I have numerous tumors in my liver, but aside from mild abdominal pain, maintain a very active life. I have considered liver transplant but am reluctant due to fairly symptom free life. Sept 2007 - I haven't seen anyone except my regular oncologist in years, I still get MRI's every 6 months, and luckily no changes have been seen. I still don't know a good treatment route, and am still scared to get a liver transplant June 2008 - I am fine, a few of my tumors are a tiny bit larger, but we are not doing anything about it. March 2009 – stable and feeling fine June 2011 – Liver tumours are stable, no treatment and feeling fine. Aug 2012 - am doing well, I've been diagnosed for 12 years with EHE of the liver with no treatment the tumors have been stable. Nov 2014 - Stable. Feb 2015 - CT Scan, no changes. Feb 2016 - Stable. Feels healthy.
CC1011	1-Nov-2014	Infantile EHE, leg Son was born with EHE. The tumour was removed from his right leg when he was 5 months old, after months of misdiagnosis. Margins were left, and very little information given. He will be monitored over the next 5 years April 13 2013 - Reconstruction showed latent EHE August 7 2014 - MRI - Stable November 2014: Resection at time of biopsy. Further resction not suggested. Watch and wait aproach

CD0715	1-Jul-2015	EHE in Lungs February of 2007 - I was admitted into the hospital in which a mass was found in my upper left lung. They did a biopsy and determined it was a fungi and at the same time they did a CT scan on both of my lungs and also found these tiny nodules. The doctors had no idea exactly what they were. The mass in my upper left lung was treated with antibiotics for a week and devolved it. After that I was taking CT scans every six months to watch the tiny nodes up until 2009 and my pathology doctor saw no changes and told me to stop taking CT Scans. This all took place at William Beaumont hospital in Troy Michigan. April 2013 - I went to my family doctor for my once a year physical and for part of my physical he had a X-ray of my chest and found a mass in the lower left lobe of on my lung. He decided to have me see the pathology doctor at William Beaumont hospital in Troy Michigan. They did a PET scan and found the mass was a hot spot. The decided to do a biopsy of the mass and had a hard time getting one because of the location, it was behind a rib bone. So my pathology doctor decided I would have to have surgery to remove the tumor to determine if it's cancer or not. They give me a choice to go in and remove just the tumor and if showed up as cancer they have go back in and remove r left lower lobe of my lung and have it tested. I told them to do it all at the same time. July 24 2013 - I had the surgery and they removed the tumor, left lower lobe of my lung and some lymph nodules. They sent everything out for testing and everything came back good except the tumor and lung tissue that's when I w diagnosed with EHE. My oncologist at William Beaumont told me they didn't know enough about EHE to treat it and I would have to go some where else. So I researched local hospitals and doctors and found a doctor at the University of Michigan, Dr. Scott Schuetze, Associate Professor of Medicine Sarcoma Cancer Research. He put me on a wait and watch program July 2015 - I've been on CT scans every six months and so far everything seems to be stable and some of the nodules are smaller. Doctor is thinking about putting me on every nine months for my CT Scans. So far everything seems to be good.
CD1115	1-Oct-2015	EHE of Spine 2011 - I was experiencing severe back pain with symptoms that seemed indicative of a pinched nerve between my shoulder blades. An MRI revealed a compression fracture of Thoracic-3, with moderate stenosis. I began to see neurosurgeon Dr. Charles Striebinger. A needle biopsy was ordered to sample the cause of the pathological fracture. This was performed at Olathe Medical Center in June or July 2011, and staff determined the tissue was consistent with a benign hemangioma of the bone. Aug. 5, 2011 - surgery. Post surgery I saw immediate improvement in the neurological and pain symptoms. But soon I began to notice in the morning at work that there was something wrong with my balance. MRI revealed that T3 had collapsed. Another surgery in November. Post-op I was on Decadron for a few days, was diagnosed with diabetes and had to receive a 20units per hour insulin IV drip to lower my blood sugar. I began inpatient physical rehab at KU, which lasted for about six weeks. During this time I began to stand and walk with a walker again, suffered multiple pulmonary embolisms. On New Year's weekend, my legs began to weaken. CT showed that a mass is putting pressure on my spinal cord. Another surgery. Dr. Lovick removed tumors coming out of T3 that had wrapped around and were pressing on my spinal cord from two sides, pinching it between them, couldn't get everything because th were vascular and bled profusely. I had awoken from surgery unable to bend my legs or move my feet or toes. EHE of the spine was confirmed. After surgery, I received 28 days of guided radiation with entry points through the throat in the front, and through the shoulders in the back. April 2012 - After intensive therapy I took my first steps. October 2015 - I can stand for up to ten minutes at a time, walk up or down up to one flight of stairs, and walk on flat ground for a couple hundred feet at a time. I have annual imaging to check for involvement of soft tissues such as liver and lungs that has always come back clean so far. I have type two diabetes, gene mutations that cause blood clotting requiring lifelong warfarin therapy.
CD5601	1-Jan-2009	PEH (now called EHE?) 2009 - I have been living with PEH for nine years now, and was referred to this site. I was in the Journal of Thoracic medicine for the then IVBAT tumors obliterating my optic nerves. They believe it was from saran gas exposure in the 1st Gulf War. I believe there are others out there who have this, but docs are having a hard time diagnosing it. It was originally listed as Gulf War Syndrome, but the civilian doctors identified the PEH.
CHOO1111	3-Jul-2011	Diagnosed with EHE I received chemotherapy for 4 months. Surgery was not successful as the tumour could not be removed, but the tumour size has decreased.

CJUS0410	1-Feb-2010	EHE in lungs, bones, ovary End 2004: - Kept getting sick with many colds, and bronchitis, and chest pains. My primary care physician would prescribe antibiotics, but the bronchitis came back a few weeks later, and I continued to have the chest pains. Jan 2005: - severe chest pains, and unusual upper back pains - taken to the emergency room in hospital. Chest x-ray and a cat scan showed multiple nodules inside both lungs. Doctors thought it was sarcoidosis. In a month's time, they grew some. March 2005: - Inconclusive bronchoscopy. Had an open lung biopsy. Pathology slides sent to the Mayo Clinic in Minnesota for a 2nd opinion. April 2005: - diagnosed April 11, originally saying it was angiosarcoma, low-grade. Dr. Patel at M D Anderson told us not to refer to it as angiosarcoma, refer to it as EHE and that it was low grade. It had not spread anywhere else when I was there in May. June 2005: - Currently not on any medications, or treatments. Because the tumors had no significant growth since my surgery, we decided I would not go on any treatment at this time. There are numerous tumors present in the lungs, about 1 cm. They have told me that the back pain that I experience is not related, and upon doing an MRI of the spine and a bone scan both showed negative. Doctors think that the frequent colds and bronchitis was more than likely not related. There is no history of any cancer in my family. Aug 2005 – Had scans at MD Anderson in July. The tumors had not spread anyplace else. There were no significant changes with the tumors in my lungs. I also have regular visits with my Primary Care Physician and Oncologist here in Michigan. I just recently returned back to work. Oct 2005:- Thorough scans, MRI etc. - Stable, no growth, no increase in the number or tumors. Were going to go on Avastin, but for several reasons, the Dr.'s have postponed this. Still as bad pain in back and leg. December 2005: chest x-ray, lab work all fine. Tumors still stable. Cat scan - pleural lining of right lung irritated, which causes pain when I take a breath. 10 day course on celebrex – slightly better. Feb 2006 - Still having pain from hip down through both legs. On 300mg Gabapentin for pain in back and legs. Tumors stable. April 2006 – Had scans at MD Anderson in February. Whole body bone scan showed a new area. The left 6th rib which is consistent with a new osseous metastasis. Also a lesion at my left mid tibia is stable. Chest X-ray and CT of Chest show bilateral pulmonary nodules are unchanged/stable. Had MRI of the Brain, due to headaches, but it was clear. Aug 2006 – Full scans - No change, no new tumors. Was told at a stage 4 - because of location and multiple tumors. Also was told, no chemo because a little to odrastic, not necessarily the right option; plus there is nothing so effective that would be the right treatment and not sure if it would make a difference at this time. I continue to have the hip/thigh/leg pain. Was told to see a Rhumatologist (which I'm currently seeing) or a Pain Specialist, because they are unsure if the pain is related to the cancer. Jan 2007 - My visit to MD Anderson was very good. Everything is stable. May 2007 – all is fine, other than leg pain. Aug 2007 - My leg pain is somewhat better over the last few weeks, but still no resolution. I am still seeing the neurologist. I had a chest x-ray, and that was fine, tumors in lung are stable On the other hand, at times, I get a lot of pain right underneath my left lung that takes my breath away, but nothing, has ever been found. Oct 2007 - Latest cat scan showed that there have been some enlargement in a few of the tumors in the right lung and there is some progression, but not aggressively June 2008 - Full scans 2 weeks ago - Bilateral multiple lung nodules are stable. But, there is a small lesion in the tail of my pancreas. Sept 2008 - I'm going for further testing on my pancreas in October Dec 2008 - I had another visit to MD Anderson earlier in November. Everything seems to be going fine. Had CT Scan of chest, abdomen, pelvis, Bone scan, Chest x-ray, labs. Just have some enlarged lymph nodes that they are watching. Just began IV infusion of iron today for 5 days straight, then once a month. Feb 2010 - I have been doing well. I had another surgery for a tumor on my ovary last September, but everything was fine with it. Otherwise, all OK.

CL6014	1-Jun-2015	EHE on the Liver and soft tissue of the gut. Two calcified lymph nodes removed and resection of a portion of the small intestine. Dr. Maria Zarzour, Sarcoma Medical Oncology, MD Anderson, Houston, TX Dr. Benjamin Powers, Oncology with University of Kansas Cancer Center, Overland Park, KS (provides pain medicine) November 2002 – 1st back Surgery. September 2003 – 2nd back Surgery. November 2003 – Neuro-Stimulator surgically implanted. ???? ???? – Fusion of the S-1 through L-3. Although I had these back surgeries and the neuro-stimulator was implanted I was still in constant pain. 2010 – Replace battery in neuro-stimulator. 2012 – Rash on the upper back. November 2012 - Hospitalized with jaundice, high liver enzymes (“through the roof”), unable to drive or walk, incoherent. November 2012 – February 2013 – Lost 45 pounds. Unknown as to why. February 2013 – April 2014 - Liver enzymes fluctuated between normal and high. October 2013 – Started seeing a Neurologist for MS symptoms. October 2013 – Rash now showing up on the legs. Rash is still apparent on the back. November 2013 – Tested for mental problems. Oral and written tests. April 2014 – Requested that the neuro-stimulator be removed so scans could be performed on the brain and spine to test for MS. April 2014 – Neuro-stimulator removed. April 2014 – Spinal tap completed to test for MS. July 8, 2014 – Brain and spinal scans for MS. Negative. July 2014 – Since everything was Negative for MS, my wife requested a scan on my liver. July 2014 – Liver showed shadows on the liver and a tumor in the gut. Initial thought was that the tumor that showed up in the gut was a Carcinoid tumor. August 12, 2014 – Surgery to remove the ‘carcinoid’ tumor. Surgeon had difficulty finding the tumor via laparoscopy. He ended up making a large incision in order to find the tumor. The tumor was two calcified lymph nodes next to t small intestine and had shrunk the diameter of the intestine to the size of a pencil. Therefore once the calcified lymph nodes were removed the surgeon continued on and re-sectioned a 4 inch portion of the small intestine. August 14, 2014 – The pathology report was provided and the diagnoses was that the cancer was EHE. Patient is 54 years of age. October 2014 – MD Anderson appointment. While gathering the information for MDA it was determined that one of the hospitals had a scan of the liver from back in 2012 showing the tumors on the liver but no one had relayed that information to me. When the 2012 scan was compared to the June 2014 there was some growth. MDA – Appointment showed no growth of the tumors on the liver from the June 2014 scan (prior to diagnoses). Wait and watch. MDA offered cream for the rashes. January 2015 – MDA appointment – no growth of tumors. Wait and watch. Rashes are now covering the arms and legs. Considerable itching “to the bone”. Scratching is to the point where it is raw! MDA seems not concerned with the rash. May 2015 – MDA appointment – no growth of tumors. Wait and watch. Pain meds, nausea meds, turmeric with black pepper, ginger root
CO4514	1-Oct-2015	EHE in Foot and lungs Breast Cancer 2005 & 2006. Growth between toes 3 & 4, left foot. Thought it was possibly a wart as I had one in the same location when I was in my teens. Foolishly, I applied a wart remover. Needlessto say, it didn't work. Over the courseof a year and a half, I tried to find an answer as to what it was. A dermatologist took a scraping which came back benign. Primary Care Physician suggested I see an Podiatrist. March 2014 - At age 68. Finally diagnosed as EHE by my dermatologist's associate after she did a biopsy. Dr. George from Dana Farber ordered a complete body scans, head to toe. This revealed the original growth between my toes, lesions in the ball of my foot and tibia along with too many to count very small nodules in my lungs. Dr. Bueno, thoracic surgeon, performed a surgical biopsy which confirmed they were EHE. (Believe it or not, that was good news as it was not metastasized breast cancer.) Treatment: 4 chemo infusions (Doxil) with little success. July 2015 - Due to one new lung nodule and growth in the tibia lesion, I am monitored every three months with PET Scan & MRI. FYI: to remove the lesions my foot would have to be amputated. Since the EHE as metastasized to my lungs, I chose to keep my foot for as long as possible.

CTUS0810	1-Aug-2010	EHE ? in chest and bones Jan 2008 - having congestion - treated as sinuses but would not clear up. May 2008 - bronchoscopy. June 2008 - several pathologists describe tumour in chest as epitheliod vascular neoplasm and/or hemangioendolthelioma. July 2008 - emergency surgery to remove benign tumour in stomach, part of small intestines removed. (Unrelated to chest tumour) July 2008 - chest tumour enlarging and changing shape, lymph nodes enlarging. Sept 2008 - thoracic surgeon tried to remove chest tumour - too involved with lung and bronchial tubes - pathology indicates angiosarcoma. Nov/Dec 2008 - chemotherapy (adriamycin and ifosimide). Nov 2008 - second opinion with Dr Paul Savage Wake Forest Baptist Hosp - their pathologist and pathologist at Mayo Clinic and Emory University indicate lipoma and epitheliod hemangioma. Jan/Feb 2009 - continue with chemo. April 2009 - pet scan shows T11 vertebrae with suv of 6.2, and left iliac bone with an suv of 3.8. April 2009 - radiation on chest tumour 33 treatments. July 2009 - Pet scan post radiation shows chest tumour almost gone but 6 spots on bones. August 2009 - thyroid removed - Papillary cancer Dec 2009 - I131 ablation of thyroid Jan 2010 - Pet scan - chest tumour gone, neck clear, all bone spots gone with exception of T11, right femoral neck and inferior to the lesser trochanter. July 2010 - Pet scan indicates all clear except bone spots. A new spot in the left acetabulum (hip joint) has an suv of 11. July 2010 - Biopsy done on hip joint. MCV Pathology shows that it is metastasis from the chest tumour (angiosarcoma). Sent pathology to Wake Forest for second opinion. They feel that since it metastasized that it could be an EHE. The pathology of these tumors has been unclear from the start. August 2010 - Planning to begin radiation on the hip joint tumour in September.
CTUS0911	1-Oct-2011	2009 - Diagnosed with EHE in liver. September 2009 - I had a “partial resection of the liver” done at UCSF in, in which they removed the tumors and some of my liver. I then had CT scans every 3 to 6 months which always turned up completely clear October 2011 - my scan showed another small tumor and a “shadow.” The “tumor panel” had me wait six months before pursuing any treatment for them in order to watch how quickly they grew over that time. Dr. Edwards had left that practice, so I now see Dr. Corverra. I am driving down there tomorrow for a P.E.T. Scan and discussion with Dr. Corverra about treatment.
DA0014	1-Jan-2016	Hepatic EHE Dec 2000 – diagnosed. Jan 2001 - MD Anderson – offered no help! Treated locally (Kansas City) by Dr. S. Ethirajan at KC Cancer Center, he recommended looking into a Liver Transplant. May 2003 - Went to Kansas University Medical Center for Transplant Evaluation. Sept 2003 - Liver Transplant, returned home 13 days later. All checkups since are good. Nov 2008 - Have celebrated my five year transplant anniversary and have a clean bill of health. Transplant was a GO because there were no tumors outside of liver. Have since become a father and am active in promoting Organ Donation and transplantation. You are welcome to email or call for more information. Feb 2010 - I am a former EHE patient who was lucky enough to get a liver transplant in the fall of 2003. The transplant has removed all of the cancer from me and I am now very healthy and have been since the transplant. My wife and I became parents three years ago to a little boy - the thrill of my life. I am happy to communicate with anyone who would like to discuss treating EHE via transplant. I now work at a not for profit organization called Gift of Life in Kansas City and I manage a Mentor program for transplant patients. We provide support and encouragement to people waiting for a transplant to show them that a transplant is the best option for them - especially when there are no other options. Nov 2014 - all good, no reccurence. Jan 2016 - Everything stable, no signs of cancer.
DAUS0014	1-Nov-2014	EHE in liver and spread to her neck. My wife’s cancer was discovered only after it had spread to the C-1 vertebrae. She underwent two death-defying surgeries under Dr. Edward Benzel of the Cleveland Clinic where they removed the entire tumour, along with the left-rear vertebral artery and part of the bone. They repaired the C-1 with bone from her hip and fused the skull, C-1 and C-2. The surgery was a complete success, with no recurrence at that site. A tumour was also found around that time inside the C-5. That was treated with radiation at Cleveland Clinic, and nothing has appeared there since. She then underwent a live liver transplant, with her sister being the live donor, at North-western in Chicago. Unfortunately, when they began _______'s surgery they saw that the cancer had spread to the lymph nodes. The transplant procedure was aborted, and instead the surgeons performed Radio Frequency Ablation to burn out 30+ tumors. A year later, a lymph node was removed that also had cancer. At that point, it was determined that only a systemic approach would help. She is in a clinical trial at the University of Chicago right now, and they recently presented her case at the AACR conference in Denver. The link is below. Her base tumour is now 49% smaller than when she began this clinical trial a year and a half ago. I thought you might like to know more about it.http://www.eurekalert.org/pub_releases/2009-04/uocm-gjb041909.php. November 2014 __________ is stable on Rapamune.

DB1315	1-Mar-2016	EHE in brain, lungs, skin and liver December 2005 - birth of child. Approx.July 2011 - Guessing it was around July 2011 developed an open hole type sore on right cheek. Never bled and was never oozy, but did keep scabbing over and gradually, slowly became larger. Characteristics were very distinctive. Lesion was very circular with a slightly raised lip or "doughnut" around the perimeter. Did some online research and thought it might be a keratoacanthoma based on photos I found on the web. Approx. Sept 2011 - In September I saw my GP and she froze the lesion. It recurred and she wanted to biopsy it, but got busy with other things and let it slide. Approx Nov 2012 - I left my job and was without insurance until February 2013. Dec 2012 - In December, during that insurance gap I developed a second lesion, this one on my left check. At the end of February, when I once again had insurance coverage I made an appointment with a dermatologist. March 2013 - I saw Dr. Rene Bermudez in March and he took a punch biopsy of each cheek. About a month and a half passed before he had results for me. I came to find out that the original pathology had come back as something that did not make sense to based on my age and the condition of my skin, so he sent the pathology back out to another lab. The second pathology test was a Dx of EHE. Because my best friend is married to an oncologist and she, herself, is an NP in Pediatric Oncology, I sought their advice first. I decided to seek treatment at Levine Cancer Institute in Charlotte, NC with Dr. Michael Livingston. April 2013 - I had a full body derm checkover but saw no other places on my body. On my face there was another tiny little place just starting to come up, but already with that distinctive shape. Dr. Bermudez punched it and path confirmed that it was another EHE lesion. May 2013 - First appointment with Dr. Livingston and we decided to We scheduled a full body PET scan, a Chest/Abdomen/Pelvis or CAP CT scan, and an MRI of the brain. It was found that I had two large lesions in my liver with some smaller lesions, two small lesions in my lungs, and multiple tiny lesions in my brain in addition to the three we had already seen on my face. Largest liver lesion had SUV of over 8. June 2013 - Stereotactic radiation to treat 3 tiny brain lesions done at Levine Cancer Institute by Dr. Anthony Crimaldi. July 2013 - August 2013 - Began intravenous chemotherapy with Doxirubicin and Avastin. Doxil was given 1 infusion per cycle and the Avastin was given 2 infusions per cycle. First reaction to Doxil was anaphylactic. Stopped infusion and rec'd intravenous Benadryl. Tried 1 week later with Dexamethasone on board and tolerated infusion. Had already been on Pepcid prior to treatment with Doxil. After Doxil stomach problems went crazy. Tried many different things until finally several months later ending up on double dose daily of Nexium. This FINALLY controlled my stomach acid. Prior to that I was so miserable that I would sleep sitting up on the bench at the foot of our bed would barely eat except for a bit of toast, broth, and white rice. Lost about 20 lbs over the course of the two cycles of the Doxil and Avastin. September 2013 - CAP CT shows slight growth in liver. Lungs stable. Switch is made to Gemzar and Abraxane (albumin-bound Paclitaxel). Rec'd treatment every other week for 7 cycles ending late March 2014. December 2013 - brain MRI showed another tiny lesion - rec'd stereotactic radiation. March 2014 - Last infusion end of March. April 2014 - MRI, CT, and PET. PET showed SUV of 0. June 2014 - Started on Pazopanib (Votrient). Experienced immediate high blood pressure even at low dose. Began taking Lisinopril to reduce BP and gradually ramped up to 800mg daily of Pazo. Sept 2014 - PET showed SUV score back above 8, but stability in tumors. December 2014 - MRI shows small brain lesion. February 2015 - small brain lesion persists. May 2015 - Pazopanib therapy continues. Small brain lesion will require radiation, PET scan shows SUV down below 5 with liver tumor measurements slightly decreased. Current medications include 800mg Pazopanib. It causes the need for blood pressure medicine (lisinopril), Gabapentin for neuropathy, and Immodium and a probiotic. Have now gone on thyroid medicine as last physical showed low thyroid levels. To date have had no symptoms from the cancer except the visible skin lesions. All physical problems have come as a result of the various treatments I have received. October 2015 - Radiation on a lesion in a brain. January 2016 - Radiation on a new lesion in a brain. March 2016 - MRI showed that the lesion radiated in October increased in size.

DCUS0714	1-Oct-2014	EHE in liver April 2007 - Stomach pains off and on for over a year - doctor thought it was possibly an ulcer. When medication didn't work, I was sent to the emergency room for a CT scan. The CT scan detected tumors in my liver believed to be malignant. Extensive testing ensured the cancer was no where else. A liver biopsy was performed and results provided by UVA confirmed EHE. I was referred immediately by my oncologist, Dr. Hauck III to Dr. Ettinger at John's Hopkins. May 2007 - Dr. Ettinger, he thought my stomach pain was unrelated and put me on Reglan. After 2 weeks on medication, I have not experienced any stomach pain. A couple options were mentioned, such as chemoembolization and liver transplantation. I'm considered higher risk for a transplant due to the radiation I had for my Hodgkin's Disease 17 years prior. I was also ordered off birth control, which I had been taking for over 20 years. Sept 2007 - Accepted into a clinical trial out of Blumenthal Cancer Center in Charlotte and begin on the chemotherapy drug, Sorafenib, in a little over two weeks. I'll be traveling to Charlotte every 2 weeks for at least 4+ months. From last scan in July, tumors are stable. Oct 2007 - I've started the sorafenib and unfortunately, had to go off of them for 2 weeks after only being on them for 2 weeks. My side effects were so extreme, including a pain in my side/liver area, that took me to the ER. I've been back on the meds for 5 days now and the side effects are slowly creeping back. Fortunately, they're tolerable right now. Nov 2007 - I had two starts and stops on the drug due to extreme side effects, the most concerning to doctors was my blood pressure. I've started the trial for the 3rd time on the lowest possible dose and after 6 days, so far so good. I've made a lot of changes to my diet, buy juicing and eating more raw foods. Due to digestion and IBS issues, I felt this was the best thing I could do for myself. I also cut out all meat, except for an occasional piece of fish, most all dairy and other healthy changes. I also started exercising again, something I used to be a fanatic about but fell off the wagon a couple years ago. Aug 2008 – taken off Sorafenib trial due to many side effects. The determining factor for the doctors was my blood pressure that kept creeping up to Stage III hypertension, even after reducing the Sorafenib to the lowest dose and putting me on Benecar, a blood pressure medication. Since November, the doctors had gone back to a wait and see approach. I had CT scans in December and again in March. Both CT scans indicated that the tumors in my liver were stable and possible even a little smaller. My next CT scan was scheduled July 17th. This scan revealed that the tumors have increase in size and number. There is also one lymph node that it has spread to which has caused my doctor to kick into aggressive mode. I was referred to another Clinical Research doctor, Dr. Sausville, out of University of Maryland Medical Center. During our consultation Aug 5th, he informed us that he doesn't believe chemo is the best route and it was his opinion that the best form of treatment was a liver transplant. A CT of my chest was ordered to ensure that the cancer had not spread any further and fortunately the results concluded that it had not spread to my chest. Johns Hopkins accepted me for the transplant. I am moving forward with the evaluation process. March 2009 - I started the New Year (Jan 3rd) with a new liver. The doctors at Johns Hopkins did a fabulous job and I'm recovering well. I only had one little scare (scared me anyway) the end of January. So far, my blood counts ha been perfect except for a little tweaking of my program. I returned back to work 8 weeks after my transplant. I have good days and not so good days and many side effects to the many medications, but all in all, I can't complain. By the time I was transplanted, I had a minimum of 25+ tumors, yet the cancer had not spread outside my liver. October 2014 all good, no recurrence.

DD5110	1-Jan-2016	EHE in liver, lungs November 2007 - Triple (-) IDC L breast. Routine follow up CT scan indicated R lung lesions & 2 hepatic masses suspicious for malignancy. 10/21/09-10/27/09 - Additional diagnostic tests. PET scan, brain & abdominal MRIs, CT of abdomen & pelvis; Lesions in R lung & liver confirmed; No abnormal metabolic activity on PET. Underwent u/s guided fine needle aspiration biopsy of largest hepatic lesion; results inconclusive but characteristic of metastatic breast cancer. Core needle liver biopsy results showed Stage 4 metastatic breast cancer but not Triple Negative (PR receptor is positive) - unusuChemotherapy begins. Bi-weekly combination of Gemzar & Carboplatin with Avastin; plan to receive 4 treatments then repeat scans; regular meds include Norvasc 10mg, Atenolol 25mg, HCTZ 25mg, KlorCon & Vit D. 12/18/09-2/12/10 - Chemo rounds 2-6 Minor side effects: mouth sores & blisters, flushing, hot flashes; elevated BPs so added Lisinopril & Clonidine prn & discontinued Avastin; platlets low. 2/25/10 - Abdominal MRI. No change in tumors; discontinue Gemzar/Carbo. 3/5/10-4/19/10 - New Chemo Regimen. Begin 3 week rotation of Ixempra by infusion; pre-meds include Benadryl, Pepcid, Decadron, & Zofran; side effects included flushing, hot flashes, chills, aches & pains from head to toes, strange feeling in head & elevated BPs 170/115. 3/27/10-4/9/10 - Added Oral Xeloda. Daily dose 500mg x 4 in am & x 3 in pm; side effects continued & worsened by 4/5/10 including diarrhea, stomach cramps & shortness of breath. 5/4/10-5/5/10 - Hospital Admission & MRI. Felt much worse; treated at AGH for dehydration; admitted overnight for IV fluids including 8 bags of KCL & 1 bag of magnesium. 5/14/10 - All Chemotherapy Discontinued. No change in lung & liver lesions; chemo ineffective so discontinued; consideration of radiation. 5/21/10 - Consult with Radiation Oncologist. Dr. Kirichenko @ AGH; resection of liver is preferred option but because of size & locations of lesions resection not advisable; recommends Stereotactic Radiosurgery but will present to tumor board. 5/28/10 - SBRT Simulation. Stereotactic Body Radiation Therapy set up. 6/15/10 - SBRT Begins. 5 treatments @ AGH on T & Th of week 1 & M/W/F of week 2; able to radiate only 2 larger lesions; unable to radiate 3rd lesion. 6/25/10 - SBRT Ends. 3rd lesion sits against chest wall where SBRT is too risky as may cause permanent damage to chest wall; tolerated SBRT well; Dr. Kirichenko pleased with ability to specifically target 2 lesions. July-August 2010 - Consult with AGH Transplant Team. Referred to Drs. Thai & Tom of Liver Transplant Team to consider liver resection of 3rd lesion. September 17, 2010 - Liver Resection. Performed by Drs. Thai & Tom @ AGH; tolerated well; no complications. September 27, 2010 - Biopsy Results – EHE, which usually occurs in lungs & liver. That's why chemo didn't work. December 17, 2010 - Follow ups - Chest CT & Abdominal MRI. In December began having severe pain behind R shoulder blade; CT scan showed pleural effusion; thoracentesis performed by Dr. Kim; removed 580cc from chest wall; CT scan also revealed atelectasis; recommends bronchoscopy. January 2011 - Bronchoscopy. Dr. Zikos performed bronchoscopy during which he observed vascular mass; did not attempt to biopsy as too risky for bleeding; removed fluid from bronchi which will be biopsied; biopsy came back negative for cancer cells. February 7, 2011 - Chest CT Scan. Follow up for continued pain & to monitor lesions; report indicates fractured 9th rib & increase in one lesion from 1.9cm to 3.0cm. March 2011 - Thoracic Surgery. Referred to Thoracic Surgeon Dr. Keenan @ AGH for consultation; recommends lung resection chest CT showed 8th rib fx. 5/4/11 - Lung Resection. VATS procedure removed mass; didn't have to remove rib as healing now; biopsy confirmed EHE. 5/27/11 - Mammogram & ultrasound for L Breast changes. Biopsy of L breast positive for Triple Negative IDC 6/3/11 - PET scan & breast MRI. Modified Radical Mastectomy. Radiation Treatments. 10/18/11 - Chest & Abdominal CTs. Good report - Liver & lung both stable. 2/13/12 - Chest CT scan. New lesion lung .8cm. 2/20/12 - Follow up appointment. Enlarged lymph node in R axilla; performed ultrasound & biopsy of R axilla. 2/24/12 - Biopsy Results. Positive for Triple Negative Breast Cancer. 2/28/12 - Bone/PET/CT scans & Breast MRI. Bone & CT scans OK; PET showed uptake in lung & lymph node areas. 3/20/12 - Thoracic Surgery. Referred back to Dr. Keenan for best option to determine if new lung lesion is benign, MBC or EHE. 3/23/12 - Thoracentesis. Scheduled for thoracentesis to check fluid for cancer cells but ultrasound revealed insufficient fluid to perform procedue. 4/4/12 - VATS Procedure R Lung. 3 nodules removed & 2 positive for EHE. 5/4/12 - R Axilla Resection. Performed R Axilla resection; removed 4 nodes & 3 tested positive for Metastatic BC-Triple (-) IDC. 7/20/12 - WVU Rad Oncology. Appointment with Dr. Jueng but questioned why surgery is not being considered; consulted with Dr Wolmark at AGH who recommended another biopsy of R axilla & suggested it could be done
DG8813	1-Mar-2016	EHE Mediastinum,liver,lungs Doctor William Tap, Chief Sarcoma in Sloan Kettering , NY January 2013 - Pesrsistent cough that would not go away with treatment, chest Xray showed 10x9 cm mediastinal tumor, CT was read as teratoma, several liver lesions on CT were thought to be hemangiomas. Surgeon in Sloan Kettering, NY requested abdominal MRI which showed that liver lesions are actually cancer. Needle biopsy of mediastinal tumor inconclusive. Core biopsy of the liver suggested EHE. Surgical biopsy of the mediastinal tumor confirmed EHE. CT, PET and MRI findings: Mediastinal tumor 10x12 cm, SUV 16; 9 liver lesions largest 4x3 cm, max SUV 5.7; 5 small subcentimeter nodules in both lungs, none showed up on PET. May 2013 - 2 rounds of Doxorubicin plus Ifosfomide trying to debulk mediastinal tumor. Following scans showed no decrease in size. Very mild, couple mm increase in size of a few liver tumors AND mild decrease in SUV value. June 2013 - Surgery removed mediastinal tumor with clear margins. June 2013 - August 2014 - Relative stability in the liver, few tumors slightly decrased in size. No treatment, wait and watch approach. August -September 2014 - Irreversible electroporation of 5 tumors in the liver done in Miami University Hospital by Dr Narayanan. 3 tumors were killed right away, for 2 the second round of ablation had to be applied. Lung nodules are stable. No recurrence of mediastinal tumor. Continue montoring with chest CT and abdominal MRI every 3 months. May 2015 - MRI showed slight increase (about 3-4mm) in 2 liver tumors. June 2015 - The growing tumors ablated with IRE in Miami. March 2016 - Another IRE ablation. 2 tumors had to be zapped again. Were not completely killed from the first attempt.

DKUS0711	1-Jun-2015	EHE in lungs She has only had an X-Ray, a lower CT and a chest CT and a needle biopsy. She is on no medication and is having no symptoms. She went to the doctor because she had bronchitis and needed antibiotics just before spring break. March 2, 2007 - We found out that she had "something" abnormal on her CT March 16, 2007 - We found out that she has cancer. Aug 2007 - one large tumour measuring 9 centimetres and about 50 small nodules. She was accepted into a study at Sloan-Kettering being administered through the Blumenthal Cancer Center in Charlotte, NC. She started the investigational drug Sorafenib (pills-each 400mg) at the end of June. She takes two pills each morning and two pills each evening. Sorafenib is an antiangiogenesis drug and was designed to incorporate characteristics similar to those of Thalidomide. In the 2 months of treatment, there has been a slight reduction in the size of several tumours. ______ is in good spirits and has no major side effects. Oct 2007 – 4 tumors have been remeasured, and each has shown a slight decrease in size Mar 2008 - ________'s PET scan showed that the small tumours are dead and that only the large one is still active. June 2008 – _________'s last tumour is dying. The SUV (Sugar Uptake Value—essentially how it's feeding) went from 4.7 to 3.8, a 20% decrease. The medicine is working, it's not shrinking the tumour anymore (it has changed less than 1 mm. in size), but it is definitely doing something to make it less active. Still has to stay on the treatment. Side effects - very little hair, having no appetite and being sick on almost a daily basis. Given 3 other options - The options outlined to her were: 1.) Go off the study and if things change, get back on the medicine, as it is available off-label now. However, that would cost $6,000 a month, $1,100 us after her insurance; 2.) Get another opinion. Dr Livingston thinks it may be time to see Dr. Maki at Sloan-Kettering (it's his study) and have him evaluate her situation; 3.) Surgery. It might even be a good time to consider taking that last tumour out. In which case we would definitely want to consider getting another opinion Aug 2008 – Saw Dr Maki - _______ can go off the medicine now! She has to come off of it gradually so it will take four or five weeks. This is so that there isn't a backlash due to a protein build up, I understand this is similar to coming off anti-depressants. After she's been completely off of it for two weeks she'll have a CT scan and if all is well, one every four months for two years, then once every six months from there. Oct 2008 - We got back from Charlotte last night, tired but quite pleased. The CT scan shows that ______'s last living (more on that later) tumor has not grown; it is relatively the same size as it was when the last CT scan was done. She went off the medicine without waking the hibernating tumor and so she gets to stay off of it for now. May 2009 - The SUV number on the last living tumour at the bottom of _________'s left lung is 4.2, same as before. No change in size, no change in its eating habits. This is the first test since being off the medicine last fall where there was absolutely no sign of any growth. Nov 2009 – No improvement, and minimal increase in a few of the tumours. Next appt in 3 months. Jan 2010 - she is doing very well right now. It's been about a year and a half since she stopped her oral chemo treatments and she has gone from fifty tumours bi-laterally in her lungs to only one, which is thankfully dormant at this time. Her next PET scan is April 19th in Charlotte, North Carolina, USA. She is feeling great and other than not being able to find work in New York, all is well with her April 2011 – She is going to Charlotte for a scan this Friday. Otherwise no change. She has had the flu, bronchitis, numerous colds, allergy issues and some infections, not sure if it's related to her immune system and the drugs she's taken for over a year and a half. April 8, 2011 - There's a minimal decrease in the one remaining tumor. Dr. Livingston wants to see her in October and she agreed. October 2011 – ________ and I went went to Charlotte for ________ to have a chest x-ray. We were told everything looked good, but I wasn't able to get the written report until the week of October 14th. The report stated: "Lungs demonstrate multiple circumscribed modules and masses, most prominent in the lower lobes, with the largest in the retrocardiac left lower lobe." We were told two years ago that the nodules would stay there, but that they were basically shells now, that there was nothing in them to worry about. "Visualized airways are patent." "The upper abdomen, osseous, and soft tissue structures are normal." Clearly all good. Impression: No evidence of acute cardiopulmonary process. Metastatic disease, as described on prior CT." Definitely good. It's been three years and two months since she stopped treatment (August 2008). April 2012 - ______ and I went to Charlotte last week for a CT scan. The remaining "marker" tumors (all that are remaining from the 50 + that were in her lungs) are still shrinking. Her doctor shook his head in disbelief and was stunned as this is not the way "these things normally go." Only one of the markers is of any consequence now. It was always the largest but is now smaller than a cough drop. All are still slowly dissolving on their own from the residual effects of the chemo meds she was on over two years ago. Her next appt will be in October and that will only be a chest X-ray. So it's all good! Previously Currently 3.2 x 2.4 cm 2.9 x 2.3 cm 1.2 x 1.0 cm 1.0 x .0.6 cm 0.9 x 0.8 cm 0.8 x 0.8 cm 0.9 x 0.8 cm 0.9 x 0.7 cm Aug 2012 - So we're good to go for another six months, we'll go back in April for a scan this time
DLUS1115	1-Feb-2016	EHE in Shoulder/Neck Late July 2011 - I had surgical clearance for the removal of a bone spur in my left shoulder. I told the NP I had felt a tiny bump in my neck when washing my face. She could not feel it and thought it could be a piece of cartilage. September 2011 – I had water in my ear and felt like I was getting an ear infection. The area in my neck blossomed and I was told to see an ENT. They did a CT scan with contrast and a fine needle aspiration. The cytology came ba benign but the report was rather vague. After several unsuccessful attempts to get on a surgical schedule with this ENT to have a biopsy. December 2011- The new ENT was not as optimistic that it was benign, in fact, he thought it may be low grade lymphoma or squamous cell cancer. January 18, 2012 – I had a biopsy and they originally diagnosed me with stage 4 metastatic breast cancer. When my PET scan, CT scan and MRI's came back clean, except the spot on my neck things weren't adding up to breast cancer. In agreement with my oncologist, my pathology sample was sent out to UCSF in San Francisco for additional review and opinion. February 14, 2012 - I found out that I did not have breast cancer but EHE. Radical neck dissection in 2012, subsentemeter nodules in the lungs are left alone. January 2015 - everything stable, no recurrence. After the first year I was moved to every 6 months screening for my lungs as well as head and neck. The lungs are done with CT w/contrast and my head and neck are done with MRI w/contrast, my abdomen and pelvis via CT w/contrast too. February 2016 - No change, everything stable.
DP0094	1-Jan-2016	EHE in hip, pelvis, lung and limb My mother has had EHE since 1994. She had it first in the hip; she was operated on and everything seemed to have disappeared until summer 2013. August 2015: She was operated on again with a pelvis transplant and an artificial limb. February 2015: a small nodule appeared in the lung, and the last CT in December revealed multiple nodules (the biggest 5-6mm). Now we contacted a doctor in Italy (Padua) and she suggested us to start a therapy with Sirolimus.

DVUS0910	1-Feb-2010	EHE in bone, and liver Mar 2009 - My daughter has already had an above the knee amputation and now they have found a lesion in her liver. Her physician has been consulting with MD Anderson and they are suggesting the Pegasus injection. Feb 2010 - ______ is doing well, she did have some cancer cells show up on her liver so they put her on the Pegasus drug from China and had her liver partially removed. The cells had appeared to have died and her liver has regrown. She is doing well now with no other cancer appearing anywhere. She is finishing her AA degree in college and doing well with her above the knee amputation.
DW0014	1-Jun-2015	EHE in arm ________had a tumor removed from her left bicep. We are doing scans every 3-6 months. 2008 - 2013 - Pain in upper left arm began, as well as a pain that felt like “fire” in her neck and shoulder. Went to doctors at least twice a year with these complaints. _______ was a gymnast and we were told the pain was due to athletic injury. We were also told it was tendinitis. 2014 - MRI, CT, referred to Washington Cancer Institute. Diagnosed as benign intramuscular hemangioma. Georgetown University Hospital removed tumor, changed diagnosis to nodular faciitis then to EHE. Referred to PT. New Oncologist: Dr. Newton, Head of Hematology Pediatric Oncology at Walter Reed. CT/PET scan, MRI are clear. December 2014 - Arm pain started again. January 2015 - MRI, Clear MRI results, referred to neurology for arm pain. March 2015 - Dr. Levy, Neurology, Fort Belvoir, hypersensitive in lower arm, lack of sensitivity in upper arm.
EC0010	1-May-2010	EHE of the right Humerus (primary tumour) Symptoms - Persistent pain in right shoulder muscles (deltoid) just below the joint. Ultrasound and X ray ordered by local GP. X Ray showed a lesion inside my right humerus bone. Damage to the bone was also evident. Aug 2009 – Undergone various scans including CT, Bone, MRI. Scans showed tumour inside the right humerus only. The rest of the body showed no other signs. The tumour had eroded the arm bone from the inside causing a pathological fracture. Scheduled to be operated on my right arm in order to remove the tumour and stabilise the humerus bone. 1 Sept 2009 – Operation at Cabrini Hospital by Mr Stewart Proper – orthopaedic surgeon who had removed the tumour and inserted a titanium rod into the humerus bone (over the full length) in order to secure the bone. Biopsy confirmed EHE. A PET scan was then carried out and confirmed again that the rest of the body is all clear (minor spots only in the vicinity of the humerus bone - residual cell clusters after the operation). Due to the rareness of the condition I was referred to Peter MacCallum Cancer Institute for treatment options and specialists care. 23 Sep 2009 – Booked in for 30 sessions of radiotherapy at Peter Mac Hospital under the care of Prof Sam Ngan and Prof Peter Choong. 7 Oct 2009 – It is recommended that the humerus bone in my right arm be removed completely and replaced with a megaprosthesis. Also some of the tissue and muscle would need to be cut out. They explained this was necessary since the bone is contaminated and that the tumour originated from it. Treatment options including amputation and radiation therapy alone were discussed. Nov 2009 – Prof Choong said the recommendation to remove the humerus bone would significantly reduce the risk of reoccurrence from 60% down to 15%. Completed 20 Radiotherapy sessions. 10 more to go till 2/12/09. Dec 2009 - I have finished radiation therapy early Dec 09, which had literally cooked my arm and later lost most of the skin under my arm (equivalent to a 3rd degree burn). It's healed now and not much pain. The operation is scheduled for mid Jan 2010 at St Vincent’s Hospital Melbourne. Jan 2010 - I feel quite good. The radiotherapy effects are over. No Pain (not very noticeable anyway) and arm is working almost 100%. Prof Choong and Prof Ngan’s treatment plan was to do the radiation sessions to suppress the bad cells form spreading into the rest of my body followed by operation to remove the humerus bone completely. The last MRI after the radiotherapy still showed some tumour inside my Humerus bone, which reinforced the surgeon's proposal to remove the bone. I was hoping for just radiotherapy to be the end and nothing else. Unfortunately it looks like an operation to replace the bone with the metal prosthesis and also take out quite a bit of tissue and muscle. This means, according to the surgeon that I will end up with a sort of disability and my arm will never be the same. I will do my best though to prove everyone wrong! I have gone through quite a battle within my self trying to decide whether I should do the operation or not. I just could not accept the disability. But looking at the big picture, I will have to do it to save myself. There is a 60% risk for the cells spreading if I don't do it, reducing to 10 - 15 % if I go ahead. May 2010 - Had the operation in Feb to remove the total humerous and reconstruct both shoulder and elbow joint. The elbow joint is fully mechanical and the shoulder joint is a metal ball into my existing socket. The operation aimed and hopefully has managed to remove all cancerous bone and tissue and any infected muscle. The result, a lot of pain which I managing with drugs and limited arm movement. I have been under observation under Prof Peter Choong and his team of doctors. I am due to have an X Ray and a CT scan (chest) on 24th May 10. Regular two or three monthly scans will follow to monitor the rest of my body. It has been a hard journey, both physically and mentally, but I am determined to get well though and achieve more than anticipated.
EC0714	1-Nov-2014	EHE in groin and knee Feb 2007 - Two weeks ago I had two tumors removed. Both on same leg, left thigh and left groin. I did have the one on my thigh for awhile, maybe a year at best. And the one on my groin I got for Christmas. I was sick with the flu, like I have haven't been in a long time. I found this lump, like it was a lymph node, swollen. I go to regular check ups at the Woman Kind Clinic, pap smears and such. So in November the Doctor told me the lump in my leg was probably a calcium deposit, I did not worry. Mar 2007 - Surgery was on March 29 at Jackson Memorial Hospital in Miami Fl. Very intrusive. They went back to same two areas and reopened to clean out. Both left upper leg. The one by be knee heeled up pretty quick. The one by groin area not so well. It opened back up when staples were removed, therefore I do have a open wound. They removed 17 lymph nodes, only 4 had EHE. Nov 2009 - Next check up in Jan 2010. Only have to get scans every 6 months now. Aug 2012 - Since then CT Scans and MRI every 6 months. So far so good!!! I wear a compression stocking on left leg for life because of lymphodema, better than losing leg!!!! Great doctor, Dr. Moffatt at the Sylvester Cancer Center in Miami, Fl. November 2014 - everything is good, no recurrence.

EJ7400	1-Feb-2016	HEHE 2000 - Diagnosed with EHE at age 26. I am a patient at MD Anderson. I had swelling in one thigh. Doctors suspected DVT but none was found through ultrasound. I then had an MRI which revealed lesions on my liver, and a blood clot was identified as the cause of my leg swelling and I was treated with blood thinners. A needle biopsy was done and I was given the hepatic EHE diagnosis. At that point I was a patient at Emory University in Atlanta, GA. I had no symptoms and my liver was functioning fine. My oncologist thinks the blood clot was unrelated to the EHE. Upon further testing, several small tumors on my lungs were found. I interviewed several doctors, some of which recommended a liver/lung transplant, but I was turned down. The Emory doctors referred me to Dr. Robert Benjamin at MD Anderson and he did not recommend a transplant. I selected him to be my doctor. 2000-2005 – I returned to MD Anderson every 3 months for about two years to monitor any change, and then I went every six months and then 12 months. I began taking Celebrex in a fairly high daily dose. My tumors changed a bit over the first couple of years of monitoring. They didn’t seem to grow, but they didn’t seem to shrink. 2004-2005 - Liver tumors began to shrink and no change in small lung tumors. 2006 – My oncologist told us we could get pregnant and I stopped taking Celebrex. Our first child was born in early 2007 and the pregnancy didn’t seem to have an impact on the cancer. Post-pregnancy testing showed no change, if anything the liver tumors were further reduced. I had a second child in 2008 and our third child in 2010. Post pregnancy check ups showed no change. 2011 – I continue to have annual check ups at MD Anderson and there are virtually no lesions in my liver and my lung tumors are the same as they were upon diagnosis in 2001. I have not resumed Celebrex and I continue not having any symptoms. Aug 2012 - I continue to have annual check-ups at MD Anderson and they continue to be positive. At this time, I have no active tumor in my liver or lungs - which are the only organs that have had tumors previously. I am taking no medications. In the last year, I was pregnant and delivered a healthy baby girl. My post-partum check ups at MD Anderson reflected no change in my health. Still healthy and tumor free. January 2015 - Everything well. February 2016 - No change, no medication or tumors.
EL1111	1-Oct-2011	EHE in spine and neck June 2011 - Diagnosed with EHE. Tumour on Spine (Base of Skull and down three vertebrae) August 2011 - Diagnosed by surgical biopsy after unsuccessful needle biopsy. Surgeon removed a portion of the tumour. Surgery did not reduce headaches; however remainder of the tumour is causing extreme pain throughout the neck, shoulder and arm. Prescribed morphine and Lyrica for pain. Doctor advised remainder of tumour would be treated with radiation (30 sessions) in hopes of shrinkage to alleviate pain. MRI full body scan and bone scan were performed & biopsy as taken in lymph node in the groin areas and tested negative. October 2011- Pet scan pre-radiation discovers additional tumours in neck area. Unclear if this tumour is separate or related to the spinal tumour. Two ‘shadows’ were also identified in the stomach area but have not been officially diagnosed. Taken off of morphine & Lyrica due to negative side affects (hallucinations, loss of appetite, nausea, contraption and urinating). Currently taking Methadone and Dilaudid to manage pain and have seen positive results so far compared to previous medication. Started radiation treatments on October 15th scheduled for 15 treatments with the possibility of chemo post-radiation.
F*9911	1-Mar-2011	EHE in both lungs 1999 - general pain. Chest x-ray showed multiple nodules in both lungs, CT of the thorax showed many small and large nodular densities. 1- 5 mm in size. Everything else within normal limits. CT Guided Lung Biopsy: Cytology, fine needle aspiration biopsy, left lung mass: Virtually acellular smears, no malignant cells identified. The multiple smears revealed a moderate amount of finely granular, amorphous debris on virtually every smear. There were rare small groups of erythrocytes and leukocytes. No epithelial cells or malignant cells were identified. Because of the lack of epithelial cells, the specimen is essentially no diagnostic. (DIAGNOSIS: GRANULOMATOUS DISEASE) June 2000 - Tests show no major changes. Still assumed to be granulomatous disease. July 2007 - pain in the mid back and the abdomen. Chest X-ray: A subtle rounded density in the left lower chest; CT of the Abdomen and Pelvis: 3.8 cm solid mass in the left lower chest. Multiple punctuate nodules in both lungs. Aug 2007 - CT chest with contrast: small nodules scattered throughout both the right and left lungs. A large mass in the left lower lobe measuring 4.2 in diameter. Also a 2.7X2 cm heterogeneous hypo attenuating mass involving the right lobe of the thyroid. Ultrasound of the thyroid shows complex lesion in the inferior right thyroid lobe. Two complex lesions on the left thyroid lobe. Pet/Ct Scan: Thyroid mass that did not show increased activity on the pet scan. The large left lower lobe mass shows markedly increased activity. There is also mildly increased activity seen in the left hilum. Nuclear Medicine Total Body Bone Scan: There is no bone scan evidence of skeletal metastases. Sept 2007 - Ct Guided Lung biopsy: Diagnosis Pulmonary Amyloid Deposition. The slides were sent to UCLA where they had the same Diagnosis. Thyroid Biopsy: Adenomatous nodule. Oct 2007 – CT Thorax - Stable appearance of lungs with the pulmonary nodules, and the thyroid lesion. Since all other tests were clear, decided to remove the big mass from the lung and to get a better diagnosis. Dec 2007 – Left Thoracotomy with left lower lobectomy and mediastinal lymph node dissectionPathology Report with final diagnosis - EHE. Currently not on any medication. Will have scans done every six months and keep things in check. June 2008 - No changes in her lungs. Also no other lesions were found in the rest of her body. Not on any medication. After having her surgery, it took about two months for her to recover. They removed half of her left lung. March 2011 – Still not on any medication and it’s been 3 years.

FC0815	1-Mar-2016	EHE in liver, lungs, spleen and bones June 2013: Our daughter suffered from a Stage III Nephroblastoma, leading to surgical removal of her left kidney, and a treatment with Vincristine and Actinomycine D, as well as short, light radiotherapy. Since February 2015: She has been suffering from multifocal EHE, with multiple small lesions in her liver, lungs, spleen, and bones. The spleen has been surgically removed. March & April 2015: An unfinished trial to treat her with Vincristine, Celecoxib and Thalidomide (last one was planned but never given). January 2016: Age 7. Since May 2015 she's been treated with the recommended treatment for Angiosarcoma, i.e. Cyclophoshamide, Adriamycine (Doxorubicine), Vincristine, and Paclitaxel. Until September a stop of growth in every place and also a shrinkage in liver and lung could be achieved. Unfortunately she suddenly suffered from mucus in her lung which had to be surgically removed four weeks ago and still has to be treated with Ambisome and Posaconacole the following weeks. Therefore her tumors haven't been treated since September and now finally new growth in her liver can be observed. She suffers from nausea which occurs every few hours if she's not given anything to treat it. What helps is pain treatment like Celecoxib, Metamizol, Paracetamol and finally Fentanyl. March 2016: Put on Sirolomis, immediate relief of symptoms.
FD1115	1-Feb-2016	EHE in lung November 2010 - My initial complaint was about chest pains that I would get 1-2x year since I was 14 yrs. old. Doctors have not found the cause of the chest pains, but because of these pains I had an initial CT scan. March 2011 - Diagnosed with EHE in left lung. One tumour 1.4 cm long confirmed to be EHE by biopsy. A second nodule that was calcified was found. First surgeon recommended removing both nodules since the second one calcified. I am getting opinions from two surgeons, Dr. Eugene Golts at UCSD Medical Center in San Diego and Dr. Robert McKenna at Cedars Sinai in Los Angeles, CA. I am also meeting with an Oncologist – Dr. Dazhenova from UCSD Medical Center . January 2015 - everythig stable. February 2016 - everything stable.
FE1010	20-Sep-2010	EHE in pleura I have no symptoms, no pain, except sometimes perhaps a bother to the muscles in some points of the chest, under the shoulder blades that I imputed to the posture in front of the pc all day. Sept 13 2010: I went to hospital "Policlinico Universitario Agostino Gemelli", Rome, for operation of hernia inguinale. They made a chest xray and they saw the different small pulmonary nodules made TAC + TAC PET+analysis of the blood (also search of the markers): nothing (made exception of the nodules at the pleura, some of the them up 1 cm) Sept 20 2010: made " toracoscopia" and taken 3 nodules. Made the histological analysis of nodules twice, at "Gemelli" and in a specialized center a Verona (General Hospital of Treviso, Department of Oncology, Anatomic Pathology): illness confirmed, it seems that primitive is in the bellows. Immunoreattivi: CD31 + , CD34+
FJ1315	1-Mar-2016	HEHE Spring of 2013. I was diagnosed with HEHE in the liver. I had been having pains in my side and abdomen for many years prior and had gone threw different tests but nothing was ever found and they eventually chalked it up to irritable bowl syndrome. One year prior to dx my appendix had burst and it was found that I had an inverted appendix which meant it was resting on my liver. After surgery they thought the lesions on my liver were abscesses from the infection and would go away with antibiotics. However over the course of the year the pain hadn't gone away and it had become increasingly worse and for longer amounts of time so I went back to my family doctor who decided to send me for an u/s to investigate what I described as a constant stitch in my upper right quadrant. The u/s showed the lesions on my liver were still there and had doubled in size since the previous year and so this led to CT scans a MRI. I was told I had a fatty liver and this could be associated with that or it could be the abscesses hadn't healed but as they couldn't tell thru scans exactly what it was they wanted to do a biopsy. A fine needle biopsy was done and came back inconclusive so another had to be done, this time a core which would give the diagnosis of EHE. I then began to meet with an oncologist who didn't know well anything about EHE and my surgical team. After a lot of consultation they ultimately decide the tumors could be resected and I was very happy to go with that option as I wanted the cancer out of me asap. There were no other lesions found in my body upon lots of investigation such as full body CT scans, MRI and bone scans. August. 2013 - I had 40% of my liver resected at the Ottawa general hospital in Ottawa Ontario Canada by Dr. Martell and his team who were fantastic. June 2015 - Everything clean, no recurrence. March 2016 - Recurrence, one small lesion.
FP6309	1-Dec-2015	EHE in fibula, spine and lungs. June of 2009 - I was first diagnosed with EHE. I was 46 years old, with a tumor in my right fibula. Five inches of my fibula was removed and for the past five years my follow up exams have shown no new tumors. Winter 2014 - I experienced a back strain while shoveling where the pain never really went away. I mentioned it to the orthopedic oncologist when I came for my annual checkup, and a CT and PET scan showed a tumor at T11 in my back and several small nodules in my lungs. December 2015 - I am currently getting radiation treatment for the back tumor and the doctors are going to check my lungs again in January to try to determine growth. I am being treated at Mass General Hospital under the care of two doctors, Dr. Kevin Raskin the orthopedic oncologist who treated the fibula and Dr. Yen-Lin Chen the radiation oncologist doing my radiation treatments. The doctors are not sure how long I may have had these other tumors because they are in areas that they have not been checking, I have been getting lung x-rays but the nodules are too small to show up.
GA1010	1-Oct-2010	EHE of the pleural lining of the left lung. Oct 2010 – diagnosed. Liquid accumulates between the lining of the left lung to the point that the Churchill Hospital (a cancer specialist unit and part of the John Radcliffe Hospital in Oxford UK) have installed an indwelling catheter so that ______ can drain fluid on an “as needs” basis to relieve pain. This is part of her pain management, with the occasional morphine. We are working with a medical consultant who is sympathetic to alternative medicine and in that regard, the Gerson Therapy, which we are following.

GB5907	1-Jan-2015	EHE in arm, now in liver 1/2007 - Noticed a small lump under my right bicep after working out at the gym. 2/2007 - Lump was surgically removed, diagnosed as EHE. 3/2007 - Further resection was necessary due to cancer at the margins. 2007 - 2010: Liver and Lung scans every 6 months. Baseline scans showed small lesions on liver and lungs. Lung lesions have not changed, though there is 1 new lesion. They are all believed to be benign. Small changes in liver lesions were noticed starting in 2008. In August, 2009 a new tiny lesion was noticed on the liver though it may have been there and been missed by other scans. In February, 2010 a new 8mm lesion appeared on the liver. A biopsy was ordered. 3/2010 - EHE confirmed on the liver. All tumors are in the right lobe. Doctors are recommending removal of right lobe of the liver. I'll be seeking second opinions in the next couple of weeks. Oct 2012 - In 2010 I decided to follow the course of treatment recommended by Dr. Benjamin at MD Anderson. This treatment has involved getting CT scans every 6 months and taking 200 mg of Celebrex twice a day. I had 10 small tumors on my liver when I started seeing Dr. Benjamin and I have had no new tumors in the intervening 2 1/2 years. 3 of my tumors continue to grow, though very slowly. One of the tumors has reached a size of 3cm. Dr. Benjamin feels it's time to have surgery to take it out. I am now in the process of deciding what type of surgery to have. I may elect to have all the tumors removed, or at least all the ones that continue to grow. Dr. Benjamin has related to me that he sees a patient who has had EHE for more than 20 years and continues to do quite well. November 2012 - I'm scheduled to have surgery on my liver in 3 weeks and I just want to see if anyone has gone through something similar to what I am going through. 2013 - liver resection. January 2015 - everything clear, no recurrence.
GC0512	1-Aug-2012	HEHE December 2005 - Pain in upper right side. U/s, then CT scan showed multiple lesions on the liver. Biopsy tissue samples sent to Professor Fletcher in Boston (USA) for a second opinion. January 2006 - Biopsy results showed needle points of hepatic tissue containing an atypical infiltrate of vacuolated cells some of which line vascular channels. No evidence of metastatic carcinoma or lymphoma. Confirmation that the liver biopsy was infiltrated by epithelioid haemangioendothelioma. March 2006 - Attended St James Hospital Leeds and underwent MRI, CT and Isotope Bone scans as well as blood and cardiac tests - all the tests required for a liver transplant. It was decided the case was borderline for liver resection and Interferon was prescribed, intended to shrink the tumors in order to operate and to avoid a possible transplant. Sept 2006 – Been on Interferon for 4 months. Scan results are inconclusive – possibly tumors showed slightly less activity. Things much the same here waiting for another CT scan at end of month. Doctors seem pessimistic regardi the Interferon treatment and are now discussing the transplant option. After the scan results we are due to visit the transplant unit at Leeds Hospital for evaluation. Nov 2006 - Interferon now for six months (6 mu three times weekly) and the side effects are getting worse. However CT scan results show no spread and small shrinkage in some existing tumours. Being kept on Interferon for another three months and referred back to Leeds Hospital for further surgical evaluation (possible resection). Dec 2006 - Finished course of Interferon as side effects became too bad. Saw Prof Ian Judson at Royal Marsden Hospital, London, for second opinion. He suggested a course of Sunitinib (Sutent) a drug only just licensed in UK. Also referred to another transplant surgeon. Jan 2007 - Had another CT scan and things are stable. Not decided on Sutent yet but told have choice of simply being monitored or going on drug but do not have to make immediate decision. March 2007 - Saw Prof Nigel Heaton at Kings College Hospital London regarding possible transplant. Said I was a good candidate but wanted to check out ovarian cyst before going further. This was subsequently checked and found to be normal. May 2007 - Latest scan shows possibility of small peritoneal invasion. Have scheduled laparoscopy for June. June 2007 - Laparoscopy showed slight signs of peritoneal invasion but have been told this has probably been there a long time but only just showed up in scan. Again given choice of drugs (Sutent) or do nothing. March 2008 - Have had several CT scans all of which show my condition as stable. However have experienced episodes of right upper quadrant abdominal pain. Had MRI scan to compare to one done two years ago and this showe tumours had grown very slightly in some areas of liver but had shrunk slightly in one area possibly due to the Interferon treatment. Will continue to monitor with both CT and MRI. June 2008 - Her last scan showed a slight increase in her peritoneum but otherwise stable. She is very well and on no medication although for the last year doctors have been advising a course of Sutent (Sunitinib). ________ may start a course after her next CT scan in August. Incidentally she is being scanned every 3-4 months by CT with the occasional MRI (for liver). August 2009 - Just had CT scan – everything stable. Very little change from original scan over 3 years ago. Still not taking any medication. Very well apart from occasional fatigue. June 2010 - Had another CT scan the first for nearly a year as doctors worried about possible radiation effects. Scan showed condition remains stable with slight improvement [calcification] of liver lesions. Still drug free and feeling well apart from fatigue. Have just tested positive for Bartonella [Koehlerae] bacteria which is a cat related infection. I understand other HEARD members have also tested positive. A simple blood test does not find Bartonella. After testing negative we sent bloods and tissue sample to a veterinary testing lab in North Carolina and they confirmed Bartonella diagnosis. Am sending a second set of bloods as based on overlapping DNA sequences they think there is a co-infection with another Bartonella species that as yet they cannot identify. We are now part of their clinical trial. Some people have suggested a possible link between EHE and Bartonella. Feb 2011 - fine Aug 2012 - Still medication free. Had regular MRI and CT scans for last two years. No discernable disease progression although latest scans show some calcification of liver lesions. ***Jane Gutkovich contacted patient's spouse in November 2014 for an update and received no response.

GC0714	1-Nov-2014	EHE in liver 28 February 2007 - Routine surgery to remove my gall bladder, specialist suspected a cyst on my liver. 20 March 2007 - MRI scan which showed 21 small lesions which the radiologists could not identify as they had never seen anything like them before. 5 April 2007 - CT scan which showed that thoracic, abdominal and pelvic organs were normal. 23 April 2007 - Wedge resection of one of the lesions on my liver. 8 May 2007 - diagnosed EHE of my liver, with 20 tumours left remaining. Referred to the Royal Marsden Oncology hospital in London for a 2nd opinion, who suggested a wait and see approach. Discussed transplant. June 2007 - Currently stable, with no change in the tumours. I am completely asymptomatic, my liver is functioning well and I have no pain at all. June 2008 -I am symptom free and scans show no change. Feb 2009 - December ct scan was once again unchanged. May 2009 - my 6 monthly ct scan was entirely unchanged. Mar 2010 - I had my last CT scan at the end of November 2009 and it was entirely unchanged, which was great news of course, my consultant has suggested annual scans [I was having them 6 monthly] so next one due in November unless any problems arise, however I feel very well, completely asymptomatic so I'm very lucky in that respect. Aug 2012 - my CT scan of November 2011 was reported as stable disease, so fortunately no change since my diagnosis 5 years ago. I am to continue with an annual ct scan and 6 monthly blood screening which has always been normal. Nov 2014 --everything stable
GC0814	1-Dec-2015	EHE in liver May 2008: Elevated liver enzymes (ALT & AST) from routine, annual blood test; no external symptoms or physical signs of liver problems. June 2008: Blood test repeated with similar results. Ultrasound of liver done & revealed suspicious growths. July 2008: CT done & then a biopsy of liver lesions; 4 lesions identified, pathology done at Mayo Clinic, Rochester, MN. Aug 2008: Diagnosis of EHE, largest lesion 10mm x 15mm. Advised that my EHE is confined to the liver. Referred to Dr. Lee Cranmer at University of Arizona Medical Ctr., Tucson, AZ (app't. date tbd) Next steps: 2nd medical opinion/pathology review, another CT to determine if there are any changes since 7/08, decide on needed actions/course of treatment Nov 2008: Successful surgery at the Mayo Clinic in Rochester, MN, USA, to remove 3 EHE lesions clustered in one section of my liver (~25% of my liver was resected). My surgeon was Dr. Kay Reid-Lombardo. No chemo nor radiation therapy required after surgery. Dec 2008: CT scans clear and no signs of cancer. Fluid noted around my liver, which is considered normal. Feb 2009: Liver completely regenerated. CT scans clear and no signs of cancer. June 2009: CT scans clear and no signs of cancer - repeat CT scan in 6 months. Aug 2012: I had a recurrence in my liver in 2010. A second surgery took place in 12/2011. Both surgeries were "successful"; however, in April of this year I met with a new oncologist who advised me that EHE is considered "pre-cancerous" because it will not metastasize. A second oncology opinion, in a different medical practice, confirmed this exact same diagnosis. March, 2013: CT scan "clear"—no new lesions in my liver and nodules in my lungs (12 in my right lung, 8 in my left lung - presumably EHE but never have been biopsied) remain stable with no additions or changes. March, 2014: CT scan revealed 2 new—presumably EHE—lesions in my liver: 0.6cm (segment VI) and 0.4cm (segment V). Lung lesions stable. Because my lung lesions are highly suspected to be EHE, I've been told additional liver surgery is no longer an option (i.e. metastasized EHE). Action: "Wait and Watch" mode; MRI follow-up in 6 months. October, 2014: MRI showed no additional lesions; however, the 2 existing lesions both increased in size: 0.6cm -> 1.2cm; 0.4cm -> 0.5cm. Lung lesions stable. Action: "Wait and Watch" mode; MRI/CT follow-up in 6 months, March 2015. April 2015: MRI revealed 2 enhanced lesions in inferior hepatic lobe (17mm x 14mm, previously 11mm x 11mm, and 8mm, previously 5mm). One lung nodule, out of 20, increased 2mm. June 2015: Outpatient debTACE procedure performed 06/16/15. No complications and a quick recovery. CMP 10 days later showed all blood components within normal range. Oct 2015: MRI showed lesions were 15mm x 13mm and 8mm, respectively Dec 2015: Visit to Pulmonologist for an opinion of the increased lung nodule raised no concerns (1 nodule, out of 20 since 2008, increase of 2mm was deemed not to be significant). Follow-up visit in 6 months after next round of scans.

GD1115	1-Feb-2016	HEHE December 2011 - I was 54years old and felt a twinge in the side of my lower back. I was referred to Princess Margaret Cancer Center in Toronto. Upon u/s and many tests, I was seen to have 3 tumours in my liver. The largest measuring 7.6 cm by 4.9. February 2012 - Upon biopsy, I was diagnosed with cholangiocarcinoma. I sent my tissue to Sloan Kettering for a second opinion and they agreed. This is a very serious bile duct cancer. I received 13 rounds of chemotherapy but the tumours never changed. It was only then that a surgeon agreed to do a liver resection October 2012 - I had 80% of my liver removed. A new pathology diagnosed me with EHE August 2013 - my cat scan showed small spots on my lungs (likely metasisized EHE) and then 2 months later, it was back in my liver with three small tumours. I had scans every few months and then in... February 2014 - a clinical trial opened up which I was accepted for, on Tremetinib. I was on this drug for one year with CT scans every 2 months. For most of the time, the tumours either shrank or were stable. I had severe side effe from the drug, particularly with rashes. They had to decrease the dosage from 2mg a day to 1.5 mg a day and finally to 1 mg a day March 2015 - The tumors started to grow again, a few millimeters each few months so I was taken off the clinical trial. May 2015 - My cat scan in showed growth again. The largest is 3.1 cm by 3.1. It grew in the two months by 3 mm. My lungs have not changed at all since first appearing and they are very small. Now I am waiting to decide what meds to take. I have no pain or discomfort. I feel very well and always have, except with the side effects of treatment. I try to watch my diet with eating lots of veggies; little/ no meat; little sugar or alcohol. I also exercise. All this I believe is important. In the middle of my clinical trial, in June 2014, I was also diagnosed with breast cancer. I had a lumpectomy. Thankfully it was stage 1 but because I was on the clinical trial I was not allowed to take the after treatment of surgery such as radiation or medication. I don’t think it is related to EHE, but who knows? October 2015 - One of the tumours grew from July to October. It was 3.6 cm x 3.6 and in October was 5 cm x 4.4. The other lesions were stable. November 2015 - started Sirolimus, 4 mg in November 2015. Next scan in February. February 2016 - Tumors are growing. Sirolimus is not working.
GD9412	1-Aug-2012	EHE in ankle 1994 - at age 37, I observed an abnormal lump in the ball of my right foot. I did not have medical attention for this and it slowly grew larger over the course of 3 yrs. 1997 - while walking, I felt a snap in my right foot, with no pain. Upon sneaker removal, gross swelling occurred. X-rays revealed a lesion that began in the marrow and slowly expanded the bone margins outward until approx double normal size, and the tumors' weakening effect caused the spontaneous stress fracture while walking. Further imaging studies led several doctors to suspect what was later biopsied as an Epitheliod Hemangioendothelioma. After visiting NJ Hospital of Medicine and Dentistry in Newark, NJ, Columbia Presbyterian in NY, and Sloan Kettering, all with unsatisfactory physician or organizational issues, I went to Johns Hopkins in Baltimore. Their biopsy and diagnosis was EHE, and this was confirmed by a second and third pathological opinion from two other institutions They were the first and only institute I visited which did not propose a specific protocol. They provided me case and follow-up studies and suggested I take several months to make a decision on my own. April of 1998 - After much consideration, I opted for a BKA. After outstanding surgery by Dr Frank Frassica, I recovered rapidly and have lived the last nine years with almost no limitations on my mobility. People who observe my gait and do not see my prosthesis do not believe I am an amputee until I prove it to them. I have been free of any recurrence since that time. Recently, I have experienced pain and swelling in my left foot and have just completed radiologic studies which I have not yet received the results of. Sept 2008 - Studies on my left foot were finally confirmed as a simple bunion, so I am very fortunate to have had no recurrence since my initial diagnosis in 12/97 and my BKA in 5/98. Sept 2009 - No change from me. I have had sporadic areas of health concern, but all have been confirmed as non-cancerous with in-depth diagnostic testing. August 2012 - I remain cancer free at this time. Multiple EHE's of the R metatarsals, R BKA. Diagnosed 12/97, BKA 5/98 ***contacted for update by Jane Gutkovich in November 2014 and recieved no response*****
GJ9215	1-Oct-2015	EHE Liver and lungs June 23, 2015 - diagnosed, 23 years old. The ones around his liver are the size of golf balls. He has had IRE ablations around his liver, one in August, they managed to zap two tumors with IRE. October 7th, 2015 - zaped two more tumors around his liver.

GL7913	1-Nov-2015	EHE in T10 vertebrae 1998 - 2011 on and off back pain and spasms in the area of tumor. The pain was sometimes severe, but doctors wrote it off as possible UTI or bladder infections, or that it was all in my head. 2008 - Pain became worse after my pregnancy with my first child. After he was born I began seeing a chiropracter who noticed that I had scoliosis, which my pediatrician had never picked up during any of my yearly checkups during childhood, which we thought was strange. Had x-rays but nothing strange besides the scoliosis was seen by chiropracter. July 2011 - Pain became unbearable during my pregnancy with my second child and after his birth in February, I finally saw a local orthopedic doctor who saw value in getting me an MRI. It showed something strange that was poss a tumor, so I had a follow-up CT scan that showed the tumor clearly. August 2011 - had a bone biopsy at the University of Oklahoma, which came back inconclusive. As scans weren't changing, and as I'd had the pain for so long the doctor believed that the tumor was more than likely a benign osteoid osteoma. January 2012 - as pain continued, I decided to seek a second opinion with Dr. Laurence Rhines at MD Anderson in Houston, TX. I had another bone biopsy at MD Anderson which came back inconclusive as well, but again as the tumor appeared to be stable by scans Dr. Rhines was 99.9% convinced that it was an osteoid osteoma. Dr. Rhines gave me options to either continue dealing with pain from tumor; make plans for radiofrequency ablation which may not work or be possibly dangerous due to the location of the tumor (being close to spinal cord); make plans to have a bone biopsy under general anesthesia where they could obtain more of a sample; or have surgery to just remove the tumor completely. I chose to go with dealing with the pain as I had been forever, because I had a 3 year old and a baby that I wanted to be able to carry around for as long as possible. March 2013 - went back to MD Anderson to see Dr. Rhines because the pain from the tumor was just not going away and I felt like my kids were old enough that they could handle not being carried around for a while. I had more MRIs and CT scans and Dr. Rhines said that there were no changes at all in the tumor and that it was still up to me if I wanted to not do anything or have the surgery to remove the tumor, and I chose to have the surgery after my son's school was out for summer. July 2013 - I had surgery to remove a portion of my T10 vertebrae's lamina and pedicle, and this was stabalized with rods and screws between my T9 and T11 vertebrae. The surgery went very well with no complications. August 2013 - had been waiting a really long time for the pathology results, and that turned out to be because the diagnosis was EHE. I was 34. Dr. Rhines said he believes that all of the tumor in spine was removed by the surgery. There are sclerotic areas surrounding surgery site, but he believes it's just residual bone damage from tumor. November 2013 - August 2014 - returned every 3 months to MD Anderson for scans and also started seeing Dr. Vinod Ravi, a sarcoma specialist there. Everything stable and no tumors showed up in scans of my chest, abdomen and pelvis. Second opinion of pathology by Dr. Rubin confirmed EHE. August 2014 - November 2015 - now scheduled to have scans every 6 months. So far everything is still stable and no new tumors.
GM**11	1-Jan-2011	EHE in liver. Jan 2011 - My brother hasn't got any symptoms. He is fit, looks healthy. They found his cancer while he was doing his medical test for army. His blood result for liver was too high. He had the u/s and contrast. The wide-spread tumor occupy bigger part of his left lobe liver. They also found about 20 tumors size of 0.2-0.8cm on his both lungs but they didn't confirm yet if this is EHE. They gave him some medication for high liver result a while ago and now liver result is good. He is feeling well. They did another blood test to find out if he has got a bacterial infection which has got influence on his tumor. We're still waiting for the result.
GM1111	1-Jun-2011	EHE in both lungs My son is a 30 year old veteran that has just been diagnosed with Pulmonary Epithhelioid Hemangioendothelioma in both lungs after returning from 3 tours in Iraq. Feb 2011 - _____ just had his 1st meeting with his oncologist last week. He will need to get some tests and scans done and then a plan of action will be discussed. June 2011 - Requested article as ________ has an appointment with the oncologist – no update.
GO9211	15-Mar-2011	EHE in lungs and bones March 1992 - aged 29, diagnosis of Haemanglosarkom in the liver and lungs. Chemotherapy was stopped after 3-4 months, without success, and I was given up on by doctors. I managed to recover and stay well for 18 years with a combination of meditation/visualization and sports. The last 3 years were quite demanding. Jan 2011 - aged 48, I was diagnosed with EHE in the lungs and bones. I wasn't surprised as I have not felt 100% for quite awhile. Case was handed over to University Hospital of Bern, Switzerland. Treatment strategy not yet clear. February 23, 2011- Prescribed 50 mg Thalidomid, increasing weekly by 50 mg up to the target daily dose of 200 mg. 1x week I take 20 mg cortisone. Last ten days I spent in the hospital as my left lung collapsed (pneumothorax). Still short of breath but recovering steadily (March 15, 2011).

GR0411	*/*/2011	EHE in liver and lungs and possibly spread to other parts of the body. May 2004: CT of the abdomen and chest showed (1) multifocal and hypervascular later arterial phase enhancing lesions, hypo dense in all phases. Evidence of degenerating tumor (2) at least 18 nodules seen in each lung, mostly peripheral, highly suspicious for metastatic disease (3) evidence of metastatic disease to the spleen. Triple Ct scan to follow. Sept. 2004: CT chest with contrast, CT Pelvis with contrast and CT double-helical abdomen with and with out contrast. Multiple pulmonary nodules in both lungs are re-identified and demonstrate stable CT appearance. A new area of atelectasis is noted in the right lower lobe. Abdomen: Multiple low density confluent liver lesions are redemonstrated in both lobes in the liver. There appears to be interval progression of the disease with some of the nodules or masses getting bigger. Several new masses have also developed. Jan 2005 - ________is not in any treatment yet. Oncologists are gearing towards Chemo (doxorubicin?). One surgeon suggested Bland Embolization but the other said it was not a good idea. His lesions are growing since May about an inch bigger in the liver and in the lungs about a mm (the bigger ones). He has one as big as 3.8 cm and the ones in the lungs about 2.8 mm. March 2005 - Tran catheter Arterial Embolization (known as Bland Embolization) of liver tumors in right lobe posterior. Was done to shrink liver lesions causing local symptoms. Awaiting results. Success of treatment will be measured by a change in tumor markers, decrease in tumor size. If it is successful there will be several treatments every four weeks. First time trying it in tumors such as EHE. Procedure was done at the University of Illinois in Chicago. Oct 2005: -_______ has been on disability for a few months now with chronic pain to his liver. Tumors have increased in size and the only thing that seems to work to shrink them has been the bland embolization procedure. He will be going on a third of that same procedure. It only helps for about 6 months then his pain comes back. Jan 2007 - ________ seems to average a growth once a year. He will be getting another radiation treatment soon. His liver is moving towards the stomach and although he doesn't have any discomfort his liver enzymes are up to 583. The tumors are taking the place of the good liver. The oncologist is concerned about that and also the risk of jaundice. Sep 2008 - _________ received a bland embolization treatment June 2008. This is to help with his discomfort and pain. One of his lobes is giving him trouble because of the tumors. The other lobe works twice as much by enlarging. This creates sensitivity next to the stomach area. Apparently all that is working at this moment is the embolization treatment. He receives this treatment once a year (his tumor growth is once a year). He is not taking anything other than sleep and pain medication. 2011 - My husband was diagnosed five years ago. His treatment consist of Bland Embolization to the liver. He's had five treatments so far and has not taken one since two years ago. It helps to shrink the liver tumors, at least for my husband it has been wonderful, thank God!
GS0015	1-Jan-2016	EHE in the upper gum November 2015: diagnosed. Referred to Stanford to Head and Neck oncology.
HA**10	1-Mar-2010	EHE in bone - polyostotic right leg. Doctor told me I have 8 tumors in my right leg and they just found I have 4 tumors in my liver they're gonna make me biopsy and see if I have cancer in there too. They told me also they're gonna have a below knee amputation. Awaiting results of liver biopsy. January 2010 – Scans showed there is nothing in my liver. But had an appt the 5th with the orthopedist Dr. Pitcher and we decided the best for me is the amputation. He doesn't want the cancer to go to any of my organs, so my surgery is the 26th of January, I'm very very sad. I didnt want to lose my leg but I have to think I have a baby and he needs me. March 2010 – had amputation. Feeling ok. Awaiting prosthetic.
HA1415	1-Oct-2015	EHE in skin 2005 - when I was 20, I was diagnosed with thyroid cancer. Removed thyroid. 2013 - I had a bump appear on the top of my left ankle. I asked my general doctor about it and she said it was a ganglion cyst and referred me to get it drained. I had it drained and that was that for awhile. They had said it was a 50/50 chance it would come back. Well it slowly did and got bigger than before November 1 2013 - I found out we were expecting our first child. The bump on my ankle started bothering me more while I was pregnant but I didn't want to do anything till after I had the baby. Beginning of summer 2014 - I noticed another small bump on my shin. I asked the obgyn if she knew what it might be and she said it looked like an infected bug bite. Well it never went away. I had my daughter on July 9, 2014. I decided to get the bump on my ankle taken care of. I went back to the doctor and they did an X-ray. Then they sent me for an MRI. That was inconclusive, so they had me do an MRI with contrast. It was then thought that it was not a ganglion, but an epidermal inclusion cyst. So I was referred to a surgeon to have it removed, Dr Chang at Orthopedics Physicians Anchorage. He saw the other bump on my shin and said he thought it was the same thing and was going to remove it also. November 6 2014 - I had the surgery to have them removed. Well I was told that after they sent it to the lab that they found out it wasn't what they thought. The local pathologists couldn't determine what they were and they were sent to the Cleveland Clinic where it was determined what they were. I was being referred to an oncologist (Dr Rabinowitz at Alaska Oncology). That Wednesday, I had a full CT scan to make sure there were no other tumors in my body. There weren't. I was sent to Seattle to meet with Dr Conrad at Seattle Cancer Care Alliance. January 15 2015 - Dr. Conrad wanted to go back in and get clear margins. That surgery took place. I had another MRI after surgery - that showed no tumors present. The tumor board decided to not have me do any radiation because of the placement of the larger tumor on my ankle - the radiation would be harsh on my joint. So I am on a watch and see plan, which is being supervised by Dr Rabinowitz locally. I have an MRI every 3 months. So far they have all been clear. I just had my most recent one on September 28th.

HA4315	1-Sep-2015	EHE in liver and lungs. I am 72 and live in Yorkshire, UK 11 May 2015 - Ultrasound detected 'something' on liver. A followup u/s told me it was a birthmark. 28 May 2015 - CT scan revealed lesions on my liver and nodules on my lungs. Several nodules both lungs eg: 6mm,5mm, 6mm likely small volume metastases. Several lesions on segments 4,5,6 of liver. One lesion 2.7 cm. June 2015 - Saw consultant oncologist Dr Raj Roy at Castle Hill Hospital, Hull on 9. 17 June 2015 - First liver biopsy back to see Dr Roy. 29 June 2015 - (Biopsy ineffective). 1 July 2015 - Second liver biopsy. 20 July 2015 - Dr Roy diagnosed EHE on and referred me to Professor Lodge at Leeds Liver Unit, St James hospital, Leeds. 20 August 2015 - Saw Prof Lodge in Leeds. Possible treatment options discussed: Transplant, (not advised over age 70); surgery; chemotherapy. 1 September 2015 - Another CT scan and MRI scan at St James, to asses if the tumours have grown since the scan on 28 May. 10 September 2015 - Got the results from the registrar: 5 pulmonary nodules, largest 6mm. Unchanged!! Liver lesions in segments 4,5,6 and 8. Next scan review in 6 months.
HA8815	1-Jan-2016	EHE in liver and lungs. 1988 - Year of birth. July, 2015 - Diagnosed. Scan reports note several tumors throughout liver. Subsequent CT of lungs noted tumors, not sure of size or number. November 2015 - Had subsequent MRI of liver which noted change in tumor size. December 2015 - Started low dose of Cytoxan and steroids for 4 weeks (one week on, one week off). Scheduled for scan at end of January 2016 to check results. January 2016 - scan showed stability. No known autoimmune problems or other cancers. Additional info: Family history: father –prostate cancer, thyroid nodules-benign; paternal grandfather-prostate cancer; paternal grandmother-thyroid nodules-benign; breast cancer.
HA9514	1-Jan-2016	EHE in vulva December 2014 - Found a lump (age19). Gave her antibiotics and sent her away. After further follow-ups it had grown rapidly and was causing her severe pain. They were treating it as a cyst (blocked gland). April 2015 - they finally removed it. July 31 2015 - (age 20) she couldn't sit down or sleep as it was in her vulva area right side. They told us there are still some lumps in her tube they didn't remove. _______ can feel them like peas in pod. Nothing more said, no treatment offered. October 10 2015 - they wrecked my world with a letter. We don't have a doctor, we don't know anything else except they're sending her for a CT scan. Going to see Dr Jones at Masden. January 2016 - surgery
HB0812	1-Nov-2012	EHE in peritoneum Oct 2008 – diagnosed, then sent to St George hospital in Sydney for a Peritonectomy in early December. Feb 2009 - started chemo but gave it up in late March as the side effects were too insane. He is now experiencing intense back pain. Apr 2009 - ________ had a CT scan at Easter time that has areas of opacity in his bowel, which could or could not be tumour. Six months after his peritonectomy, he should be thinking about going back to work one day a week, but he is unable to get out of bed, totally unnatural. He is still in great pain. July 2009 - _______ had more surgery on Saturday to reverse his colostomy. While in the process of doing that, Prof Morris found more tumour, and thus the operation became more involved. He is recovering well, if slowly....For the past 5 months, ________ has been unable to get out of bed due to intense pain in his rib area of his back. February 2010 - _______ is cancer free at the moment. He had his last scan in January and it has come back clear. He is now just struggling with nerve pain caused by his surgery. Although he was started on steroids about 6 weeks ago and this has increased his appetite, which in turn has increased his energy levels, which in turn has increased his ability to hold the pain medication inside him. So maybe we have turned a little corner. Although I think it will be quite some time before he can return to work... Nov 2012 - My husband was diagnosed 4 years ago with EHE in his peritoneum. He underwent a peritonectomy and has had ongoing problems with pain ever since. Over the last year, the tumour has grown over his left ureter, causing his left kidney to fail. Just last month, he was hospitalised again with kidney failure in his right kidney. The oncologist we saw in early October has said we will just wait and see what happens with the tumour, as it has grown 2 mm in a year (but it has grown in the wrong place)..... *****contacted for update in January 2015 by Jane Gutkovich but she recieved no response.

HC0112	1-Aug-2012	EHE in lung and liver 2001 – 2007 - A fluke x-ray of the shoulder revealed a portion on the lung had spots on it - been monitored by Dr. V. Mohan - Pulmonologist – St. Elizabeth's Hospital, Belleville, IL. Jan 2007 – liver change – darkening & grouping. Liver biopsy - sent to a Mayo Clinic – all benign. Feb 2007 – Bone scan, MRI, Cat scan…Diagnosed EHE. March 2007 – Dr Adkins mentioned two drugs Thalidomide and Interferon A. He felt very strongly in getting a 2nd opinion. Met with Dr. Bryan Meyers – Jacqueline Maritz Lung Center – No lung biopsy at this time, but Dr. Kevin Korenblat called saying I would be a great candidate for liver transplant and would like me to go to the Mayo Clinic. April 2007 – Phase I testing at the Mayo Clinic for liver transplant, which consisted of blood work, urine test, ultrasound, bone density, chest x-ray and electrocardiogram. Met with Dr. Kimberly Watt of Hepatology & Liver Transplant to discuss if I was a candidate for transplant. Dr. Watt's feeling was no since the tumors had spread from my liver to lungs. After reviewing my case in clinical I was not a candidate for liver transplant. Went to MD Anderson, Houston to the Sarcoma Center, met with Dr. Joseph Ludwig, who prescribed Celebrex. 200 mg twice a day. Dr. Scott Akuno, from Mayo Clinic agreed Celebrex was a good start. May 2007 – Had a diagnostic mammogram done, found calcifications or tumors on both breasts. My doctor wanted to do a breast biopsy, but I decided to wait until my follow-up appt at MD Anderson in July. July 2007 – MD Anderson for a 3 month check, met with Dr. Ludwig - change from my April slides. As far as the mammogram, I need to do a follow up in six months and they are thinking its calcifications. Dr. Ludwig's asst told me th they have never seen EHE spread to breast tissue. After much discussion, Dr. Ludwig gave me an option of having my next 3 month check in St. Louis or come back to Houston. So we decided to alternate checkups between St. Louis and Houston. I've been of Celebrex now for 3 months and still feel GREAT!!!!! June 2008 - Been on celebrex now for 14 months and responding very well. My last followup was in April and some of the tumors have increased in size minutely, some are discoloring, some are shrinking and most importantly no new growth. As far as some the tumors increasing in size my doctors don't seem too concerned. I still have 3 month checkups between St. Louis and MD Anderson. Feb 2011 - I've been on Celebrex twice a day for 3 ½ years now and it's working great. Celebrex stops blood vessel growth so therefore the existing tumors aren't growing because they aren't being fed by new blood vessels. I started out with CT scans every 3 months and now I'm being scanned every 6 months with very minute growth to the tumors; feeling awesome. Aug 2012 - I alternate follow-up appointments between MD Anderson, Houston and St. Louis Sitemen Center, Missouri. I've been on Celebrex 5 years with little to no change. However, in March doctors started monitoring a tumor in my liver which was growing. On August 10th I did have surgery to freeze the tumor. As we don't know the outcome, I am due back to MD Anderson on Sept 11th for follow-ups.
HC7514	21-Feb-2015	EHE in Liver/Bile Duct Aug/Sept 2013 - RUQ pain began. April 2014 - Fatigue, unexplained rashes on abdomen and face, facial flushing, and just a general feeling of being unwell and episodes of severe abdominal pain led to me finally seek the advice of a GI. Several tests (including an abdominal ultrasound) revealed little but some gallstones and mild gastritis. Insisted on consult with surgeon and he suggested we remove my gallbladder. June 2, 2014 - Cholecystectomy was performed, at which time he discovered a large mass and some other smaller tumors in segments 4 and 5 of my liver. Biopsy was performed (wedge) and preliminary pathology was a benign bile duct hamartoma. However, 3 weeks later at a follow up visit, I was advised that my tumor had been sent to the Mayo Clinic for further review and the diagnosis was changed to EHE with possible focal transformation to angiosarcom Was then referred to the liver tumor clinic at the Univ of WA Medical Center in Seattle. In the interim, I had a CT and MRI of my abdomen which measured the largest tumor at 8 X 6 X 4 cm with multiple small lesions in the surrounding tissue. July 8, 2014 - Consulted with Dr Yeung (surgical oncologist) at UWMC Liver Tumor Center. He recommended a central hepatectomy to remove the tumors. I had a CT of chest which revealed several very small nodules which they decided to call "nothing" as they were very small and if they classified them as EHE, then resection surgery may be in jeopardy. Recommended just watching them. July 10, 2014 - Had 55% of my liver removed in 7 hour procedure. In the 5 weeks between surgeries, the tumor had grown to 10 x 7 x 5 and was adhering to my diaphragm. Pathology again confirmed EHE. No angiosarcoma mentioned in second pathology report. No major complications February 2015 - Follow up care has involved Celebrex at 200mg twice daily and CT/MRI scans every 3 months. Abdominal pain has lessened but not resolved. All other symptoms are unresolved. Other medical conditions include Graves Disease (thyroid ablation in 2001), Hashimoto's thyroiditis, Rheumatoid Arthritis, Fibromyalgia, IBS, EBV and HHV6 reactivations. Family history of cancer- paternal grandmother- colon cancer in 1970 which she survived.
HE0815	1-Jan-2016	HEHE Dec 2008 - I felt pain in my upper right quadrant. After talking to a few people I thought maybe it was a gallbladder issue so I contacted a GI Dr. (Dr. James Singer) who scheduled me to do an endoscopy and an ultrasound. The results of my ultrasound showed lesions on my liver. (My endoscopy results showed some stomach erosion, but the Dr was not too concerned). Jan 2009 – Had CT scan and then later CT guided liver biopsy at Banner Thunderbird Medical Center. The pathologists at Banner Thunderbird were unable to make a diagnosis and sent my biopsy results to the Mayo Clinic here, w diagnosed EHE. I was then referred to a haematologists/oncologist (Dr. Volk) who had never heard of the disease before who sent me to the office of Dr. Koep, Cashman and Brink who after reviewing my CT scans determined I would need a liver transplant. Currently I am in the process of getting on the transplant list. July 2009 - I did transplant evaluation. My liver function is normal so currently although I am on the list I wouldn't be transplanted. I met Dr. George at Dana-Farber in Boston and she was not in favor of a transplant and advised taxol, once a week for 3 weeks and one week off for 4 to 6 months to see if it stablizes, however she advised to first get new CT scans and if there is no growth to take a wait and watch approach. George also suggested I visit with a genetic counselor since I have a family history of cancer, including a cousin would was diagnosed with sarcoma in his 30s. Oct 2009 - I am currently doing chemo because my last scans showed some of my tumors grew significantly. I am still planning to do a liver transplant though I may do chemo-embolization before that. I am now working with doctors at the Mayo clinic here in Phoenix and Scottsdale. Jan 2010 - I had a liver transplant and have been doing well. Aug 2012 - I have not responded in a while, but that is a good thing, because I have been busy with a normal life again. I take rapamune, 7mgs a day. Pre transplant I did chemo - taxol - didn't work and I did carboplatin (sp?) and something else, not sure if it worked because I was transplanted within the time I was doing chemotherapy. January 2015 - Everything well. January 2016 - Innumerable nodules in lungs. Largest grew by 3mm in the last year from 7mm to 10mm and the second largest is 4mm growing 1mm more. Still taking 5mg Rapamune per day along with anti-rejection medication. Otherwise in good health and feels well.

HJ**14	1-Nov-2014	EHE in her liver and lungs. Was on Interferon. Was going to have a liver transplant but couldn't because they found that it had spread. ________ is on Vinblastine 3 times a week and will soon be started on thalidomide. She also has gravol, vitamin K, domperidone, lansoprazole, colance, and celebrex on a regular basis and other meds as required. She is being treated at CHEO (Children's Hospital of Eastern Ontario) Ottawa, and was in Sick Kids Hospital in Toronto where she was going to have the liver transplant and couldn't. May 2005 - Miami at Jackson Medical Center – University of Miami. The doctors and staff there have been amazing. _______ arrived here last Wednesday and was put on the list for a liver transplant on Friday. On Monday they operated. They doctor came out and said "we have nothing but good news" there was no metestatic disease in the abdomen – this was one of the reasons that Sick Kids in Toronto wouldn't do the operation because of this metastatic disease. Anyhow it is Thursday and everything seems to be as good as to be expected at this point. She has some fluid on her lungs that has been making her feel short of breath but they seem to be pretty confident that it is all under control. She is still in ICU but we hope that she will be on a regular ward soon. ______ remains very positive a strong willed. She still has a long road to recovery with this operation but her strength and positive attitude has been very visible. Nov 2006 - _______ is doing very well. The only problem she has had is the metastatic spots on her lungs have increased and a few have also increased in size recently. At this time she does not want to take any medication. She tried thalidomide and celebrex for a short time but they made her tired and had other side effects. She went back to school and is progressing but does find it difficult at times. She has more energy and is feeling great. ______ has been given a new lease on life. November 2014 - Everything stable
HM1115	1-Jan-2015	EHE in liver and lungs Diagnosed September 2011. May 2011: Started with an appendectomy at my annul OBGYN check up. OB nurse called me to say that I had blood vessel growth on my liver. It took four months waiting on this test and that test to be diagnosed with Cholangiocarcinoma. September 2011: I ended up asking for a second opinion and chose Barnes Jewish Hospital in St. Louis, Missouri. Dr. Steven Sorscher is my oncologist and Medical Director of the Siteman Cancer Center, West County, St. Louis, and is the doctor who diagnosed me with EHE. I am on hold for a liver transplant due to insurance. The treatments plans are wait and see, Celebrex or Thalidomide. I have been told that only 10% of my liver is affected. My lung spots are very small but there are several of them. To date have had 3 sets of MRI and CT scans showing little to no growth. I am due my next set in February 2012. Oct 2012: I am doing the same as I was last year January 2015: Everything is stable.
HN0015	3-Mar-2016	EHE in Foot Autumn 2015: 15 years old. 1 cm thickened skin on outside of midfoot that appeared to be a callus for several years. Soon doubled in size, developed purplish fluid and became painful. Initially thought to be a cyst, was removed and diagnosed as EHE. Calcified nodules were seen on lung, but assumed to be due to histoplasmosis infection. Dec 23 2015: Had wide resection and muscle graft. Initial tumor was 1.5 cm located within the skin and subcutis of left midlateral foot. March 3 2016: Clear of tumor in foot, no others found. Undergoing CT scans every 3 months to monitor lung nodules for changes.
HN1011	1-Mar-2011	EHE in arm August 2010 - ______ noticed a lump on the inside of her right bicep. There was no pain associated so she put it off as a cyst or inflamed lymph node. Early October 2010 - Went for physical in with Dr. David Augustine at Holy Family Memorial in Manitowoc, Wisconsin. MRI done and came back as a potential sarcoma. Then went to Dr. David King at Froedtert Hospital in Milwauke WI, he performed a biopsy and confirmed EHE. Feb 8 2011 - Surgery to remove lump. _________ had a CT scan and is awaiting the result to see if EHE has spread to her organs (or the organs spread it to her arm).
HN1415	1-Jun-2015	EHE in lungs and liver March 2014 I had my son by emergency c-section. I was discharged from hospital as normal. After a few days I started experiencing some discomfort, I had shooting pains just below and kind of behind my right rib cage. I spent 2 weeks in hospital undergoing a number of investigations. I was spiking temperatures (fever) and had infection markers in my blood. I was eventually diagnosed with pneumonia as they found shadowing on the lungs. I was treated by IV antibiotics and was discharged after my temperatures (fevers) were back to normal. Once at home I still didn't feel well, I was experiencing fevers every evening and was lethargic and still had pain. Back to the hospital, underwent a number of investigations to try and find the source of the infection. I was told the pneumonia has cleared up. I was put on broad spectrum IV antibiotic to treat general infection. During the MRI scan they noticed some shadows and lesions on the liver. I underwent a liver biopsy and a CT scan and then diagnosed with Heptapic EHE. I had another CT scan of my thorax to see if any lung involvement. I was then discharged from hospital as my infection markers had come back down to normal in my blood and I was no longer having the fevers. The Drs didn't locate the source of the infection and they still are not sure if ever linked to the EHE. May 2014 - I saw the liver Dr.. He advised me it has spread to my lungs, it was cancer and it was aggressive and my only treatment option was a liver transplant. He advises they believe the increase in hormones/blood flow during pregnancy may have caused this cancer to surge. London Kings College pre-transplant assessment carried out. It was there they told me that as I had 9 possibly 10 lung nodules they felt I wasn't a candidate for transplant and there was no literature to support transplanting in EHE patients with that many lung nodules. They fear that the anti-rejection drugs I would be on for the new liver would have an adverse affect on the lung nodules and cause the cancer to grow. I advised them I was certain I had seen of patients on the EHE Facebook page who had had lung involvement and they said this may be the case but not as many as I had. They said they would only consider me again for transplant in 6 months if I underwent some treatment that shrinks the lung nodules down. During this hospital stay I had another scan and was told the tumours do not appear to have grown. This was in a 2 month period. I asked hi it's aggressive and he says it's appears to not be behaving aggressively. July 2014 - further CT scan no change in the tumours from May. August 2014 - saw Prof Judson and discussed treatment options. Waiting for the next scan. September 2014 - scanned with IV contrast. The scans had shown the cancer was stable so prof Judson talked about my options. He advocated the watch and wait approach. He said I could try Celebrex but he felt it better to leave all treatments 'in reserve' in case they were ever needed. He advised he wanted to rescan me in 6 months time. He advised we could revisit transplant if it ever got to that point but my body currently has the EHE under control so he didn't want to mess with that.

HP**12	1-Jul-2015	EHE in shoulder tissue History - was born and raised in central Nebraska on a farm. At 16 I had a mole which I injured under my football shoulder pads, it turned into a scar looking thing on my shoulder. Have twice had it frozen off. 20 years later - I injured it again, frozen off again, but it grew back in a couple years again and this time with the slightest bump it would rip open and not really heal for 6-8 weeks and then when it was healed it had a flakey ring of d skin around the outside edge, the size of a nickle. July 2009 – removed again, and sample sent to UCLA, and diagnosed as EHE. Oct 2009 - Had surgery on my shoulder to remove the tissue around where the tumour was. He also ordered a pet scan, it was clear. Feb 2010 - The tumour was removed from the skin on my shoulder. The margins were clear. No other tumors were found at that time. Aug 2012 - Last November I went for an annual screening and had a clean bill of health cancer wise. July 2015 - No recurrence, everything is clean.
HR1415	1-Jun-2015	EHE in lungs July 2014 - I was diagnosed at the age of 69. Multiple nodules in the lungs. The doctor just told me it was on the border line. I have scans every six months. So far everything stable.
HR3915	1-Dec-2015	EHE in Lungs Early July 2015 - diagnosed at 76 at Loyola. Multiple small lung nodules. September 2015 - scan showed no growth.
IC5312	1-Feb-2016	EHE in Spine October 2011 – I am a breast cancer survivor since 2005. I went for a check up at my urologist for a small problem and they took a CT san. They noticed a mass on my spine and advised me to see my oncologist. My oncologist, Dr. William Sikov is located at Breast Center Women's & Infants Hospital, Providence, RI.He immediately thought it was breast cancer and I had the following tests at Rhode Island Hospital; CT, PET scan, MRI's with T4, T8/9 & T11 the worst being T8/9. I then had a needle biopsy which did not show cancer or anything they could recognize. Dr. Sikov sent my biopsy sample to Emory University Hospital for a diagnosis. January 16, 2012 - I have been diagnosed with EHE, so I asked for a referral to Dana Farber where I saw Dr. Morgan and Dr. Gainor and they confirmed that I had EHE. The doctors recommended radiation to shrink or even get rid the tumour, so I have gone back to Rhode Island Hospital and met with a radiologist, Dr. J. Hepel. He has recommended that I have "CyberKnife" robotic radiosurgery with 3 treatments to shrink the tumour but as it is so close to the spinal cord and the vertebra is compromised they are treating it with the utmost care. I have not had a CT or MRI before they can program the machine, but I saw Dr. Hepel on January 25th and should know more by January 31. February 2012 - Operation on spine Feb 10, 2012, they didn't realize the damage the tumour had done and the bone was very soft so they implanted a cage in the T8 then 2 rods, 5 plates and 11 screws to keep me together. I left hospital Wednesday feel more comfortable at home although am in pain and discomfort just have to find the right sitting, sleeping and general position. My follow up is Thursday with the surgeon to remove staples, I think there about 50 down my spine. This has been very emotional for me and find myself crying for no reason but I guess that is all in the process too. Once staples removed and healing on the way they are talking radiation so will update on that wh the time comes. Not sure of my prognosis as no one seems to be able to say much right now, I guess only time will tell. I had a good recovery and then had CyberKnife Robotic Radio Surgery (radiation) on my T4 , T8 (this was the largest tumour) and T11 the other two spots were smaller tumours. CyberKnife is a very precise radiation that does not effect any other organs so much safer on the body than regular radiation and less time consuming, the first session was 3 treatments on the T8 area which also included the bottom of T7 and top of T9 they were 45mins each, then t T4 was 3 treatments of 30mins each they took it slower there because of the esophageus, the 1 treatment of the T11 for 1hour, and it was over....only side effect I had was fatigue the next day. April 2012 - Completed all the treatments. June 15, 2012 - Follow up MRI (May 15, 2012) showed no new growth and all stable. Next MRI in 3months. Other treatment to strengthen the bone in the spine is Zometta infusions once a month, had my first on Friday (June 15, 2012) and have them scheduled monthly for 12 months, no side effects to date. Feeling my strength returning by walking daily and starting a swimnastics program in July for a month to gain more strength. Sometimes feel tired but not too bad and am looking forward to gaining my strength and stamina. Do not know if I have EHE in any organs, was going to have a CT scan in 3 months to see if I am clear but really not sure if I will as there is nothing they can do for it anyway and if it isn't affecting me. Feel I have been very lucky to have a good team of Dr's even though none have ever seen or treated this before I think they are doing a pretty good job on me. I have a positive outlook on the future and hope that anyone reading this will feel more positive about their own situation too. November 2014: stable. February 2016: Stable, on Zometa every three months.

IE0810	1-Feb-2010	HEHE with multiple nodes (around 12) in liver. October 2007 - Lesions were found during a check for pain during the 6 month of her pregnancy. Doctors advised against a biopsy because of the pregnancy. 3 January 2008 - ________ had a Cesarean to our healthy baby boy without complications. Jan 2008 - Diagnosis made with needle biopsy and CAT scan. Biopsy confirmed by three Italian pathologists. Neoplastic construction from circle-like with abundant cytoplasm and with intercellular lumina and vascuoles. The neoplastic cells are isolated or join in the form of a necklace or cord [in cordone in Italian]: both the isolated cells and those that come together in a cord are surrounded by both fibrous and myxohyaline stroma. There is the presence of focal areas of necrosis of non-continual and atypical cytologic. Immunohistochemical Markers: CD43+ and CD31+ (in the neoplastic cells); Actina 1A4+ (in the fibrous component of the PERITMORALE stroma) CAM 5.2-, CK7-, AE1-AE3, CD45-. We have been given the advice of wait-and-see or Interferon Alpha. ______ has no symptoms; sometimes she feels her liver pulse or stretch a bit. Sometimes she feels it is heavy. June 2008 - ________'s well. The big lesion (2.8cm) seems like it may or may not have grown a few millimeters in over 8 months. June 2008 – nothing to report. DEC 2009 - FEB 2010 - because of slight (.25cm) growth of largest node in liver was causing extreme pain in shoulder twice in a month, and slight growth of other tumors (less than .1 cm), _______ started a treatment of Interferon (ROFERON -A: 3000UI / .5ml three times a week by injection). Normal side effects of shivers and sweat in beginning, much less now; some tiredness the day after Interferon injection but tolerable. Since treatment in DEC, no alarming pain. Feeling of the node and liver tenderness where the node is located to even light touch (resting arm on the node, for example). Minor shoulder and liver pain (1-2- / 10) about 5 times a week. Feb 2010 - Last MRI of lower abdomen and liver show no growth. We are waiting for the 6-month mark from Interferon.
IW9307	1-Jun-2015	EHE in liver, lungs and bone 2004 - He started going threw puberty at age 11 with rapid growth and complained a lot at that time of joint pain. He was diagnosed with Osgood Slaughter. Inflammation around both knee caps. July 2007 - complained of bump on left side of abdomen, being tired all the time and bone pain. August 2007 – Ultrasound showed positive for mono and anaemia. Liver functions normal except low alk phosphateas and high Gpt/alt. Told all due to the mono. October 2007 - Repeat ultrasound shows liver still enlarged. Paediatric gastro intestinal specialist states _______ has an extra lobe in his liver based on ultrasound. November 2007 - _______ wakes up Thanksgiving morning with severe left abdominal pain and shortness of breath. Cat scan shows many tumors in both liver lobes. Initial diagnosis is Hepatic Cell Carcinoma. Liver biopsy shows Hepatic EHE. They also think on Cat scan that he may have two small lesions on one lung and possibly a bone lesion. At this point we have slides out for second look in Utah. We have docs looking at cat scan at Emory, Dana Farber, ucsf, U of I and U of C. Dec 2007 – 2 treatment options for ________. Dana Farber- Dr Klement would like to try medical approach as soon as we get urine results back. She feels the liver tumour is large enough to warrant treatment. Chicago surgeon would like to do liver transplant. (After reviewing his med records with the paediatrician we were reminded of two xray's he had 5/06 & 7/06 for lump on left side of abdomen (guess this was already the tumour). _____ is symptom free at this time. The therapy will be guided by the levels of angiogenic growth factors in urine. We are still waiting. If VEGF elevates Taxol/Avastom combo. If BFGF elevated Thalidoide/Celebrex. If both elevated maybe Sutent. Feb 2008 - repeat cat scan on 1/31/08, 9 week since first ct scan. He has been on 500mg azithromycin daily for the past 4 weeks. We have left Children's Memorial and are now receiving treatment at University of Chicago. Radiologist impression is as follows: Infiltrative tumour or infectious process, with areas of necrosis and calcification throughout the liver. Numerous pulmonary nodules, stable since the prior CT. Lucent lesion in the right transverse process of T6 is probably a benign finding given the intact cortical margin and lack of other osseous lesions. His liver is twice the normal size and half of it is tumour. We were so set to go ahead with a transplant, but we are content with the idea of waiting to see how he does with medical treatment first. ________ is feeling pretty good except he is tired a lot. He has gained 4 pounds which we take as a good sign. March 2008 - _________ is being followed at the university of Chicago and doing reasonably well: fatigue, mild but persistent RUQ pain, o/w ok. Based on my investigations, the infectious disease experts there thought enough of these findings and my theory to recommend ________have a prolonged trial of intensive antibiotic therapy. He's finished two weeks of iv gentamicin plus oral doxy and rifampin. now the gent is replaced by azithromycin and the three drugs will continue until mid-may (~3months total) when we'll repeat his CT scan. Based on tumour volume, we'll decide whether to proceed with liver transplant or not. May 2008 – Latest cat scan - everything remains stable and the healthy part of ________'s liver is about 20% larger than before. Most of his blood work has also remained stable or improved though his iron still remains low. Sept 2008 - _______ is doing well. We have chosen a wait and see attitude since his CT scans have remained essentially unchanged since last November when the diagnosis was made. His liver functions are nearly normal. His or lab abnormalities are an iron deficiency anemia, slight prolongation of the PT and elevated CRP. January 2010 - _______ is currently on the liver transplant list. He is always tired and just in general does not feel very well. The major reason we decided to go a head with the transplant is that _______ had an upper GI. It showed the liver tumour pressing on his stomach. ______ has had a very poor appetite and when we saw how little room the tumour gives him in his stomach we decided it was time to get it out. The tumour is not in his stomach just compressing his stomach. May 2010 - _______ had a liver transplant on May 10th 2010. He is doing extremely well with no recurrence. His blood work, CBC liver panel are all normal. He is now 17 and getting ready to start his Senior year of High School. His appetite is still not great but he has gained some weight and his activity level is great. He still has spots on both lungs but the Radiologist says they change all the time. Some old ones are gone and new ones appear. June 2015 - Post-transplant course was entirely smooth except for an episode of drug-induced liver injury caused by a trial of Celebrex. He has recovered from that after a brief period of high dose steroid. Shortly after that a rib lesion that had been stable seemed to get bigger and required a segmental rib resection. One wonders if the drug induced liver injury was causally related to the rib lesion's growth since it presents as liver inflammation and required high dose steroids (immunosuppression).
JJ1213	1-Apr-2013	EHE March 2012 – 22 y/o daughter has EHE. She was dx in March of 2012. April 2013 – Currently being treated at Dana-Farber in Boston, MA

JK5413	1-Oct-2015	EHE in liver 2010 - tumours were discovered on my liver. This came about after routine bloodwork showed high liver enzyme markers and a follow up ultrasound showed something on my liver. A CT scan confirmed numerous tumours (4 initially) and in various lobes of the liver. At first they were suspected as colengiocarcenoma (?) bile duct cancer, then possibly secondary colon cancer tumours…..they weren't biopsied at that time, as the specialist felt it could cause big problems if they were cancer tumours. When I didn't become ill - and they didn't grow, it was decided to just sit, watch and wait. I was given a 3 year plan with MRIs every 6 mos. Nothing changed…..and at my 2.5 year appointment with the doctor, we agreed that after the final MRI, we would just agree that they were weird cysts on my liver and leave it at that. Not sure what happened over the next 6 mos. April 2014 - the final MRI showed both growth of existing tumours and increase in number of tumours. A decision was made to do a biopsy August 2014 - it was confirmed that I had a rare cancer in my liver…..EHE. No one in Victoria had seen it before…..the oncology department had not seen it - and knew nothing about it. (So….I never did see an oncologist). I tried different venues to find information on it, but could not find anyone who knew anything about it. Eventually, we flew to Chicago and saw the head of transplants at the University of Chicago. He brought my scan up on a huge screen and showed me where they could see a ton of little tiny tumours in addition to the 8 or 9 that were visible on other scans. The largest was 3.7cm and others were 2.4, 2.7 and then smaller. (In hindsight, I think that the tumours had been increasing every year as the first mri showed 4 tumours, then six months later, 6, a later one 7, etc. etc. When I would ask about them, I was told it is difficult to see the tumours always and that sometimes they are just missed the scans). He suggested that a transplant was my best case scenario. I also went to Dana Farber in Boston, but that was a complete bust; a waste of time and money. I had mailed 33 pages of documents and scans a month prior to my appointment - but when I arrived at the clinic the morning of my appointment, they didn't have one of them….they ended up being in a file in the international admittances area of the hospital. Somebody had dropped the ball. There was never an apology - and the doctor that we saw was more interested in chatting about the research he was doing on different sarcomas than he was in helping me find answers to EHE. I met with the liver specialist in Victoria upon our return to Canada. I had spent a month doing my own research on this cancer and discovered there was one lady in Vancouver who had been transplanted for EHE 10 years earlier by Dr. Scudamore, at Vancouver General Hospital. An appointment was made, and so my path to liver transplant began. I was officially added to the transplant list in October 2014. May 25, 2015 - after 3 "dry runs", had a complete liver transplant. Prior to the operation, I requested some of my liver be sent to Dr. Rubin. I have never been on any drugs prior to the transplant. I was never in severe pain, but I could 'feel' my liver more and more as time went by and could not sleep on my right side without serious discomfort. I would break out in a sweat for hours during the night, but would never have a fever. I know there are different opinions on the importance of diet when one is battling cancer. I went on a dairy, wheat, sugar, alcohol free diet for almost 4 years….whether that helped to slow the growth of the tumours or not is a discussion in the making. I know that the last 6 months before I was biopsied and diagnosed with EHE, I had started drinking alcohol occasionally and eating pretty well whatever I wanted in anticipation of being cancer free… who knows if that started the growth of the tumours. T one thing I can attest to is that I was without a doubt the healthiest liver transplant patient they had seen. I was in ICU for only one day and out of the hospital in a week. I do feel the diet I followed made my body as healthy as it could be. I know we are all different and each of our bodies reacts to EHE in a unique way, but I believe the diet was instrumental in my body's ability to handle the transplant as well as it did. I was 56 when the tumours were first discover 60 yrs old when I was finally diagnosed with EHE….and 61 when the operation took place.
JL9015	1-Dec-2015	EHE in Liver and lungs October 2015 - Diagnosed at age 25 due to chance - found by CT scans after accident. Tumor at liver is 6.5cm...there are 3 tumors in lung and I'm happy that they are still very small (<1cm). Tumors haven't grown wihin a few weeks. So no treatment so far. Next scan in December 2015. December 2015: CT didn't show any change. No treatment at the moment but scans every three months.
JM5807	1-Jan-2016	EHE in both lungs and liver. June 2007 - Presented for first physical in 5 years - something showed on the chest x-rays and he was sent for a CT Scan. Referred us to an Oncologist who did a Liver biopsy and he was diagnosed with Epithelioid Hemangioendothelioma. Referred us to MD Anderson. August 2007 - Saw Dr. Patel and he told us the wait and see approach, we are scheduled every 3 months for the first year. No pain, no symptoms, no treatment at this point. Dec 2007 - Went for 3 month check, tumors in lungs have not changed, but there is change in the liver - most of the tumors have grown 2 to 3 cm. Dr. Patel suggested Avastin. He said it was up to us and so we decided to wait until our next appointment to see how things are. Still has no symptoms or pain. May 2008 - Things are still the same, his cancer is growing in the liver and has been since diagnosis. He started Celebrex but Dr. Patel wanted him to do Avasitn and we are just scared to do that right away. June 2008 - My husband is just on Celebrex and has been for only 3 months, we go to MD Anderson tomorrow for our next checkup. I keep seeing Avastin popping up from time to time with people saying the doctors say they will try that next if this or that doesn't work. Our doctor, Dr. Patel at MD Anderson has only wanted us to try the Avastin and has pushed it since day one. However, with ________ not being physically sick yet and with us having some trips and things planned we decided against that for now and to try the Celebrex, the Celebrex was at our request not Dr. Patel's. He did tell us we would need to try it for 6 months to a year if we wanted to see if it works. We will probably reconsider the Avastin if things speed up. September 2008 - Tumors still growing, waiting for one more checkup to see if they continue and then make a decision to try something at that time. January 2009 - Tumors did not have any new growth for the first time in 18 months, so he will continue on Celebrex in the hopes that this is what has stopped the growth for now. May 2009 – Tumors are still growing slowly. Will continue on Celebrex until we go again in November. Our doctor did mention this time that they are having some luck with the embolizations and that would be something to consider the larger tumors. There are two tumors in the liver growing close together that could possible merge so we will wait and see a bit longer. November 2009 - Tumors did not have any new growth continue on Celebrex. January 2010 - My husband is still on the wait and see approach and we go every 6 months, we go again in May. In October when he went there was no change. He has liver pain and right shoulder pain which has to do with the tumors in the liver, the right shoulders nerves are connected there. He does work if he is not physically ill at that time. He gained some weight when he quit smoking and that was a year and a half ago and he is now walking and eating better and losing some weight so we are just going to wait and see, he thinks some of his pain is from being overweight. Feb 2011 - My husband is on Celebrex at MD Anderson in Houston, and is on the wait and see approach now for almost 4 years, with tumors mostly stable. November 2014 -- stable. January 2016 - No change in tumor size. Celebrex 200 mg 2x/day.

JM6013	1-Jun-2015	EHE in Liver/lung Dr Susie Bae, Peter MacCallum Melbourne Australia Dec 31 2013 - Diagnosed. Initially went to my GP of 25 years, with liver pain, nausea, 10kg weight loss symptoms for 3/4 months prior to seeing GP. Ultrasound revealed multiple liver lesions on both right and left lobes largest being 2.6 cm x 2.2 and multiple lung lesions under 2mm. Two weeks after initial GP diagnosis EHE was diagnosed. A liver needle biopsy on largest liver lesion was taken. This lesion is in a difficult spot, entry to the liver therefore liver transplant was ruled out, vascular surgeons saying they did not know how to get around this lesion. First suggestion was chemo for six months 3 weeks on 1 week off but I suggest that I have another CT before starting chemo to determine growth time. There was no growth in 10 weeks so I opted to wait and watch approach. Jun 2015 - I have only had one significant growth on my lungs of 2mm. I have significant pain daily and struggle to digest food but have maintained my weight over this last year.
JM6410	1-Jul-2015	EHE in liver and lungs. Childhood diseases: varicella, rubella, pertussis. No traumatic injuries. Tonsils removed at age 6. Only other history: folliculitis of the scalp; multiple basal cell skin cancers (scalp, abdomen, back, face). 2009 (March): sensation of chest discomfort, “heart pounding: in the chest.” E.R. visit showed elevated lipase, bun/creatinine. Ultrasound showed mild hepatomegaly. Diagnosis was mild pancreatitis and mild hepatomegaly. Follow up with an abdominal MRI/MRCP = negative for masses. Lab values returned to normal within 1 month. Had been on omeperazole 20mg for several years for GERD. Tried to wean off without success. 2009 (December): episode of elevated BUN/Creat (Cr = 1.8). Think it may have been medication induced (use of Motrin, Bactrim). Stopped all medications, increased fluids. 23 hr urine, repeat chem. = normal within 5 days. Restarte omeperazole 20mg daily. 2010 (Aug/Sept): experienced vague, mild left upper quadrant pain and what seemed to be an increase in gas/gas-like discomfort under the left rib and sometimes the right rib cage. Symptoms were suggesting possible gall bladder issues. Repeated an MRI/MRCP = pancreas normal; two small liver lesions first noted, approximately 0.5cm. Only abnormal lab – lipase = 68. We all decided the risk of a biopsy outweighed the benefit. Liver lesions were most likely hemangiomas. 2010 (December): Continued vague mild LUQ pain, gas, intermittent nausea (but not enough to make me lose weight) and a little less energy. Only abnormal lab – lipase = 69. Put myself on a bland, lo-cal diet. Physician friend ordered labs, EGD/colon and CT of pancreas and liver. 2011 (January): CT completed and showed four nodules on liver; 5mm nodule left upper lobe apical region; no bulky lymphadenopathy; 1.3 exophytic lesion seen at the upper pole left kidney posterior aspect. Biopsy pathology determined the liver lesions to be EHE. 2011 (February): Dr. Steven Curley performed a right partial hepatectomy to remove liver nodules. Post-surgery diagnosis: four nodules 0.5 – 2.2 cm in section 6. All margins clean. It was theorized that the lung tumors may regress now that the liver tumors were removed. 2012 (January): first reappearance of a 0.5cm nodule close to the area of surgical resection suggesting the possibility of recurrence. Follow up PET scan: no hypermetabolism. 2012 (April): first nodule appears slightly more dense. A second nodule seen on the left lobe. 2013-2015: new nodules developed and growth of existing nodules, mixed with periods of no growth. Nodule sizes = 0.5cm to 2.5cm. Lung nodules remain stable. Considered additional surgery, radio ablation, and/or chemotherapy with low dose Cytoxan. Have stayed with the “watch and wait” approach. Currently: Nexium 20mg daily (self-prescribed for GERD), healthy diet, multivitamin, curcumin a few times each week. Acupuncture, meditation.
JS6313	1-Jun-2015	EHE in spine and liver 1995 - I was 32 years of age when I, for no reason at all, no injury, no trauma and no explanation suffered a broken rib, collapsed lung and was admitted to our local Hospital because I just couldn't breathe. They decided that as I had no idea why this had happened that they would do a bone scan. At that time it was picked up that I had a "lesion" in my C2 vertebrae. I was then told that I had bone cancer. My rib showed no lesions, but they decided back then that I had bone cancer and I was told that they would have to do a bone marrow test and confirm the diagnosis. This was performed whilst I was in hospital for the two week period... the results were negative. They took the bone marrow from my hip bone... and as I was so young.. this was an extremely hard and extremely painful procedure to endure. I then was told that I didn't have bone cancer and that they didn't know what it was... I was told to go on with your life and just don't worry about it..... GREAT!!!!! So for the next ten or so years that's just what I did... no doctor would biopsy the bone as they would have to go through my spinal cord and so because of the severe risk of paralysis they decided against doing the biopsy. June 2015 - My Non Hodgkins has been completely cured. I had my last appointment with the ENT last week and he said that I am cured. I have seen a new oncologist about my EHE, one who has no other patients with this disease and he advised me that this is not a "true" cancer... I said that it was and I am now on a "watch and see" approach. I have seen various doctors.... Dr Thompson in Melbourne to discuss IRE treatment, a doctor to discuss SIR treatment (radiation to the liver) and also a doctor who wants to do a liver resection on me. I cannot have a liver transplant or go on the register to transplant as I have NHL. So I have decided not to do any treatment at all. My last scan in December 2014 actually showed shrinkage of nearly all my tumours and even some had disappeared completely. Only one had increased in size, a small bit! The doctors feel that perhaps the lesion in my neck may also now be EHE as it is not a "normal" looking lesion and I will never know as they will never be able to biopsy it. They feel that the tumours in my liver are the secondary tumours.
JS7414	1-Jun-2015	EHE in lungs 2012 - at the age of 38, I had a X-ray on my chest to look for a broken rib. They found something on my chest and I went for multiple CT scans. Had about 6 nodules on my lungs anywhere from 4mm to 8mm. Regular CT scans every 6 months to see if there was any change. The first few scans showed slight growth of about 10 percent on some of the nodules. They started scanning me every three months and showed slight growth on some of nodules. I was getting scans at the BC cancer clinic in Vancouver BC. After 2.5 years they finally decided to do a biopsy. This is when I was diagnosed with EHE. Due to the non aggressive behavior of the cancer they decided to take the wait and see approach. June 2015 - I have had about 3 scans since dx and my last one showed I was stable. I have about 10 nodules now, the largest being about 12mm. I have no symptoms. Due to the large number of family members afflicted with cancer, I was accepted into the hereditary genetic testing program. They did a blood panel test to see if I was a carrier of any of the 14 major cancer causing genes. My tests came back negative which was great news.

KA6215	1-Oct-2015	EHE in liver and lungs 2011 - I was diagnosed in and I was 49 years old. October 2015 - In 2011 I had one tumor (5 cm) now I have 3 tumors in the liver (6 cm, 4 cm and 1 cm) and many metatases in the lung (since 2011). No treatments (watch and wait). No sugeries. No other medical history before 2011, but know I have non melanoma skin cancer (removed by sugery).
KB1115	1-Feb-2015	EHE in liver and lungs When I was in high school I had stomach pains that felt like severe gallbladder attacks . Doctors couldn't figure out what it was. Early 2000's - Into adulthood the the pains continued my right shoulder would also go numb when I was running/ exercising, and it started to do that as well when I wasn't exercising. It seemed more frequent. I felt that I may have had more "allergic" type reactions to what I thought were soaps and perfumes, but I noticed it wasn't all the time. 2008 - After the birth of my first daughter my stomach aches came and went about every few months. December of 2009 - It wasn't until after the birth of my son December of 2009 that the pains became severe. (I had not problems with any of my pregnancies and gave birth naturally). 2010 - My shoulder went from a numb feeling to a nagging numb almost pain. I also remember then, I would flush. My chest would burn. Almost felt like sunburn, and my cheeks and neck would get itchy and hot/red. It continued randomly through the year. 2011- the symptoms started happening at least once a day; and the ladies at work started noticing between that and my arm pain my right hand " my dominant" started to not grip so well. I visited the hospital and they didn't see anything in the scans. Fall of 2011 - everything was so frequent. I became more concerned with that nagging pain in my side, and arm and as to why I was "flushing" the way I was. Halloween, my body was in so much pain I could barely talk. I drove to the hospital crying I was hurting so bad. They scanned me again and I told them "you need to look at my gal bladder!!!" So they did. They found the lesions in my liver, and upon being rushed to Duluth Mn. Which was a larger hospital, was admitted for 5 days and diagnosed about 2 weeks later after the biopsy was sent to UW Madison and Mayo, and Marshfield Clinic. I was diagnosed with EHE over the phone and referred to an Oncologist. There were tumors noted in my liver and nodules in my lungs also noted, not knowing if they were related or not. December of 2011 - I had a liver Resection done at Mayo in Rochester MN. 75% of my liver was removed. The recovery wasn't so bad. I remember night sweats, and fever type symptoms, and what I call phantom "gal bladder" attack pains. October 2012 - I had an ablation done at Mayo of 2 small areas near the resection site that seemed to have grown. January 2014 - I had a regular follow up. Along with a weird feeling after the PET scan. He thought that everything looked normal; There may have possibly been growth along the ablation site, however we did do an ultrasound and a CT and it seemed as though the surfaces were the same as my liver. Then I really started to feel sick. We found out I was pregnant. The pregnancy was textbook, however, I started to have the flushing of my face and chest. My chest and neck were as if the sun had burned me and It would last for days. At one point I feel my collar bone was almost to the point of being raw. I had a "burn" scab on my chest. My legs and arms seemed to break out as well with this weird rash and it came and went for a few months. I thought our house had bed bugs, or fleas, or something and everything we did, I was still having a reaction to. Finally it seemed to go away. Then my side started to hurt. Scans after pregnancy showed 7 areas that may be concern on liver. I was put on transplant list at Mayo. Taken off the transplant list because the stable nodules in my lungs seemed to have changed. October 2015 - scan showed stability.
KR5412	1-Mar-2016	EHE in the liver 2001 - I had a total abdominal hysterectomy for excessive bleeding. The uterine pathology report found endometrioid adenocarcinoma 0.3cm non invasive tumor. I did not receive treatment (radiation or chemotherapy) for it. July 26 2012 - diagnosed at 58 years old with EHE. Multiple (at least seven) tumors in the liver. The larger tumor sizes: 9 cm x 4cm, 2.2cm x 4.3cm, 3 cm, 1.8 cm 2/8/16: CT scan: the tumor sizes are: 9.3 cm x 3.7 cm, 7.3 cm x 3.5cm, 2.8 cm confluent with other masses, 4 cm. They have grown slightly over the past 3 1/2 yrs. I have had no treatment. I I have no other autoimmune diseases. Additional information: At the time of my initial diagnosis in 2012 the only reputable experts I could find on EHE was Boston Children's Hospital - Harvard Medical School. The Vascular Anomalies Center at Boston Children's Hospital is a world known center that has treated children with EHE. Since 2012 I have sent my biopsy specimens and all of my diagnostic tests including CT scans, PET scans, etc. to them. The Vascular Anomalies Center has had two Interdisciplinary conferences on my case since 2012.
KS8614	1-Oct-2015	EHE in Liver Diagnosed at 26. Since January 2012 - I had been losing a lot of weight. Between May-July 2012 - I had extreme upper right quadrant pain on 3 separate occasions. The pain was so severe I went to a&e but they told me it was inflammation and to come back if it happened again. September 16, 2012 - I went to a&e as my eyes were bright yellow. I was admitted that evening. I was told right away that I had obstructive jaundice and that this would need to be investigated to see what the cause was. They took bloods and I had an X-ray, ultra sound scan, MRI scan and finally a CT scan over a week. After my CT scan I was told that they were 99.9% sure I had liver cancer. The CT scan showed 3 large lesions. They were pressing against my bile ducts, which explained the jaundice. At this point they were unaware of the type of cancer I had. So I still didn't have a definite diagnosis. After 4 weeks of being in hospital, 2 biopsies and an ERCP they let me go home. October 22, 2012 - I was called back into clinic to be told I had a rare liver tumour, EHE. The consultant, who had never heard of EHE, told me there was nothing he could do for me. The tumours were placed in positions that meant he could not operate. He referred me to the Leicester Royal Infirmary to see an oncologist, Dr Esler. She had heard of EHE. Dr Esler referred me to the New Queen Elizabeth hospital in Birmingham where the option of a transplant was mentioned. February 2013 - My consultant, Dr Elsharkawy, put me forward for a transplant assessment. I had no treatment. My condition seemed to worsen. I was losing weight and the stent that they had put in to open up my bile duct had gotten blocked. The tumours seemed to be growing. My quality of life was poor and at this point my only option was a transplant. My twin brother had been worked up to become my live related donor. May 8, 2013 - my twin bother donated his right lobe of his liver to me. My whole liver was infected with EHE.

L*1010	1-Aug-2010	EHE in lungs August 2010: diagnosed EHE of the lungs. Started like I had a cold earlier in the year. Finally in June went to see my regular Dr and they ran various tests. Had a bad cough that would choke me at times. It also affected my voice and clearing my throat. This lead to a Barium Swallow on June 21st which showed an aspiration and a hernia which lead to having an xray on the 24th which showed spots in my lungs on the xray. Saw Pulmonary specialist (Dr. Lischner) and Oncologist (Dr. Kalaith).
LB8512	1-Jun-2015	EHE in Liver, Lungs and Lymph September 2012 - I had what I thought was a stomache ache, accompanied by a difficulty taking deep breaths and a shooting pain in my right arm. The CT came back with over two dozen spots across both lungs and at the very bottom of the scan, my liver was partially in view and there were spots picked up there as well. Biopsy that was sent to UCSF came as EHE. Within two weeks, I had an appointment at UCSF Cancer Center with GI oncologist Dr. R. Katie Kelley. PET CTs were ordered for end of November and end of January. In the meantime, she referred me to the liver transplant program. February 2013 - my tumors were stable over a 4 month period. At that time I was started on Nexavar (sorafinib). My beginning dose was 400mg/day (half a full dose of 800mg). I tolerated it well and then when I went up to 600mg a day, I was hospitalized at the end of February with severe abdominal pain from a very small liver bleed, thought to be from the medication. We stopped it for a month and then slowly put me back on until I plateaued at 400mg/day. We tried to increase it one more time in May and the same thing happened so I stayed at 400mg/day for the rest of the year. Early 2014 - we VERY slowly started to increase again and eventually I tolerated 600mg/day fine - however 3 weeks after I started this dose, I had an allergic reaction of "hand/foot syndrome" which 20% of patients who take Nexavar get - severe blistering on the palms and bottoms of feet. My doctor pulled me off of Nexavar permanently at that point. Through the year and a half I was on Nexavar, there was not shrinkage of the tumors but there was little to no growth either. June 2014 - I became active on the transplant list. September 28, 2014 - I received my transplant, just under two years after going on the list. My surgery went well - I had a complication with a blocked artery so they had to open me up for a second surgery 4 days after the first to make me a new artery from a donor artery. The second surgery went well also and I was out of the hospital after 8 days total. Recovery went very well - I was on prograf, prednisone and celcept to start. During surgery, they found that the cancer had spread to my lymph nodes (they removed a lot of them but once it's in the lymphatic system, it's pretty much there to stay). Lymph nodes showed up on PET scan as well. They also found a few tumors in my abdomen. June 2015 - 30 days post-op they switched me from celcept to Everolimus. By the time I was 4 months post-op, I was on 3.5mg twice a day of Everolimus, 1 mg a day of prograf and 5mg a day of prednisone. I've had one bout of rejection after my doctor tried to cut my Prograf to .5mg a day - this was recently so I'm still recovering. I am currently being weened off of Everolimus (temporarily) because they discovered I have an incisional hernia and will have to have this surgically repaired once I'm off of Everolimus for 4 weeks (slow wound healing). In terms of metastasis, my lung nodules remain stable. I've had three sets of scans and all tumors remain stable within the margin of error.
LC8697	1-Jun-2015	EHE in Lungs and Liver 1997 April: Pain associated with nausea. Abdominal u/s showed a hyperechoic nodule of about 2 cm on the third hepatic segment. A thorax-abdominal CT scan with contrast confirmed the presence of hypodense nodule on the 3rd hepatic segment and micronodular lesions spread to both lungs. A needle biopsy of the liver mass was done, diagnosing epithelioid hemangioendothelioma. 1997 October: Lungs biopsy confirmed the pulmonary localization of the disease; normal on sizes and course of the hepatic veins and the portal vein. Not intra hepatic biliary dilatation. Normal spleen, pancreas and kidneys. Chest RX: Discrete expansion of the lungs. Bilaterally, widely over the lungs, numerous small parenchymal nodules with a variable diameter from 3 up to 5 mm more evident in the mantle. No signs of pleural effusion. It was undertaken a therapy with Interferon alpha-b (IntronA) 1 million/unit/m2 for 2 days; increased to 2 million /unit/m2 for another 2 days and then increased again to the current dose of 3 milion /unit /m2 per day. 1998 February: U/s confirmed unchanged tumor in segment three. Found two small reactive focused adenopathies, one with a diameter of 9 mm at the hepato-duodenal ligament and the other one more voluminous (diameter 15 m located in front to the vena cava. Good compliance to therapy with interferon. Normal blood tests. 1998 November: Hepatic ultrasound: it confirms the presence in the third segment of the liver of expansive round formation whit about 27 mm of diameter, defined margins, hypoechoic, with small central calcification. The lesion was hypervascular. Compared to the previous ultrasound examination this one shows an increase size of the nodule. It has confirmed the presence of a 8 mm diameter round lymph node located in the hepato-duodenal ligament. It was performed a biopsy of the nodule. Histological examination: epithelioid hemangioendothelioma - pulmonary nodules probably increased in size and contrast. May 2000: percutaneous radiotherapy of the lesion on the 3rd segment of the liver, with a slight progression. Lung disease stable. 2000 November: on CT appearance of dubious image at the level of the hepatic segment VII. Lung disease stable 2003: Stereotactic radiotherapy on the 7th segment of the liver (VII 24 Gy). Between 2003 and 2011: CT unchanged, ______ was in fairly good conditions. 2011: Pain in the left knee. The MRI showed a focal lesion: exclusive radiotherapy to the left femur. 2012 October: appearance of abdominal pain and CT scan finding adenopathy in the celiac-mesenteric region. 2013 July: exploratory laparotomy, partial resection of the omentum, removal of retroportal and mesenteric adenopathies, as well as celiac ganglion alcoholization. At abdominal exploration multiple peritoneal nodules not visible on examination were found. Histological examination of the disease nodules resected confirmed the diagnosis of epithelioid hemangioendothelioma. The pain has not decreased after surgery. Treated with antiCOX2 analgesic. After collegial re-evaluation, given the histological diagnosis, in the absence of configurable illness and obvious signs of evolving disease on CT scan, it was decided to propose to the patient a future checkup (follow-up), postponing the start of a possible anti-cancer medical treatment to allow for evidence of disease progression.

LJ**15	1-Jun-2015	EHE in the liver I live in Ottawa, Canada. February 2014 - had a lump on my rib, Dr. sent me for an abdominal ultrasound...they found spots on my liver at that time. April 2014 - Next step was a CT scan. It came back indeterminate. (Lump went away on its own) saw spots on my liver. MRI was done in April 2014, it came back indeterminate, another MRI was done to try and find out what it was my liver, it came back as indeterminate, showing signs of cancer and signs of no cancer. May of 2014 - a liver biopsy was order and done. May 28th, 2014 - I was told I had a very rare cancer called EHE. June of 2014 - Met with my surgeon a few times. August 21 2014 - Liver transplant was original plan but I was able to have 70% of my right lobe liver resected (9 tumors removed and sent to Dr. Rubin, fresh and frozen). Spent 1 week in the Toronto General hospital. After about 10 days, my right lung was giving me severe pain, it had filled up with fluid and collapsed, I spent another 6 days in the hospital getting it drained slowly. November 2014 - I had another CT scan done. Liver was great, one spot showed up on right lung, they thought it may be related to the tubes from the drainage of the lung. February 2015 - another CT scan showed 3 lymphnodes or spots, two over 1cm. CT scan in 3 months to see. June 2015 - I just had my latest scan and all 3 spots in my right lung have disappeared. :)
LK7701	1-Feb-2016	EHE in right foot, liver 2001: At the age 24, a lump was felt in my right foot between the big toe and toe next to it. It was taken out and pathology came back as EHE. Since then I was told to get CT scans to check my chest and liver...turns out I have multiple nodules. I had a lung biopsy done which came back inconclusive. Ever since I'm scanned on an annual basis except for 6 years in the middle, when I went through 2 pregnancies. There was quite a change in nodules and volume of right lung after 2nd pregnancy (2009). Since 2009 there has been no change whatsoever and I'm being monitored on an annual basis. December 2015: I started feeling pain near my arch area of that same right foot, which presented as edema in the bone. I had a biopsy done and pathology came back as EHE. I had to do a full body PET scan and luckily all other areas showed clean. My oncologist recommended (based on his discussion with Dr. James Wittig, the orthopedic oncologist who performed the biopsy recently and surgery 15 years back) to proceed with a surgery to remove the bone and replace with bone graft and fusion.
LL1415	1-Jun-2015	Tumors in liver and lungs. Doctor Olav Yri and Jan Oldenburg, oncology department university hospital of Akerhus, Norway. November 2014 - She got her diagnosis after liver biopsy. Pressure pain in stomach and she could even palpate tumors in the liver region. She has had the pressure pain for about 2 or 3 years before she got a diagnosis. She started treatment with adramycin (doxyrubin). After 12 doses/weeks she got a new scan. No change in the lungs (spots) and some of the tumors in the liver had grown 2mm and 3 mm. She does not know the size of the tumors. New treatment - Paclitaxel (taxol) now for 6 weeks and a new scan. If no effect the doctors were talking about using Sirolimus.
LL9311	3-Jul-2011	EHE in stomach tissue 1990 - I had felt a hard, grissly lump in my abdomen in an area above my left leg, the fleshy part of my tummy. I went to my doctor who determined it was a swollen lymph node and nothing to worry about. However, 6 months later it was still there. The doctor repeated the same 1993 - 3 years on, the lump had grown and now felt like a rock hard, large marble. I said I was not happy and was sent for a biopsy, where the surgeon was certain it was just a lymph node. However, on my return visit to the hospital I was told it was not what they expected and had only removed a sample of it for analogy. The remainder needed to be removed - this was done swiftly the following week and involved major surgery. The tumour was near to my bowel but the surgeon was happy it had been excised with a clear margin of healthy tissue. I was diagnosed with EHE and it was decided that no further treatment was necessary given the limited knowledge of this cancer and the fact that it was typically slow-growing. I had scans for the following five years (proposed for 10 years originally) but as there was no reoccurrance I was given the 'all-clear'. 2011 - It is now nearly 18 years on and I am in good health, albeit overweight, which I am trying to control with exercise and a healthy eating approach. I have been blessed to have 3 healthy, happy children during these years.
LS1011	1-Mar-2016	EHE in liver and lungs July 2010 - Found the EHE by a "fluke" really.....sudden chronic onslaught of diarrea in Feb 2010 caused my gastro doctor to order a colonoscopy which was unsuccessful, so he ordered a colonography next. Everything was fine except the radiologist was alarmed when he saw numerous nodules/spots on my lungs (noticed during the above test). Then all the testing started....bronchoscopy, CAT scan of brain, PET scan, liver scan, and then a liver biopsy which landed the EHE diagnosis. They have only seen two nodules in my liver, but numerous ones in my lungs (however these did not "light up" during the scans. Only the one in my liver did.) The diarrea is now gone and I really have no noticeable symptoms of this EHE. I have been referred to a specialist since my oncologist knows nothing about this cancer. I visit a Dr. Savage at Wake Forest's hospital Aug. 4 and am also going to Dana Farber Aug. 17 in Boston. No idea what has caused it. I am very active, eat pretty healthy, practice some Yoga, and have a prayer life. My husband and I have 3 daughters.... June 2011 – Currently going for scans every 3 months to monitor the rate of growth. So far so good- minimal, if any growth. March 2016 - Even though liver tumors remain stable. There is a tumor in the kidney that grew from 6mm to 1.6 cm in a few months.
LS6297	1-Jan-2016	EHE in Liver. Diagnosed and transplanted in 1997. No recurrence. Jan 2016: No tumors 18 years post liver transplant.

MB**15	1-Jun-2015	EHE in lungs and sacrum. I was diagnosed at 21 years old. I was taking sorafenib for 8 months and was getting CT scans of my chest to see if there had been any changes. But this drug did not seem to do anything. My tumors did not get any better or any worse, So I was taken off. Since I have been taken off I get CT scans approximately every 6 months and PET scans once a year. My doctor is taking the "watch and wait" approach. Because I have been stable for a long time, they have decided to just keep an eye on things and not treat with any drugs.
MC0514	1-Jan-2016	EHE in both lungs, both nodes of the liver and in the Medium Stinum which is a Lymph node. She has fluid built up in the plural sac around her right lung. Oct 2002: - Stomach pains and vomiting, suspected appendicitis. Discovered 2 spots in right lung and spots on both nodes of the liver. Sept 2003: - Fluid built up since one year - drained. May 2004: - Fluid has returned - thicker and could not be drained. Oct 2005: - EHE diagnosed from Mayo Clinic after 2 liver biopsies. From 2002 to present the tumors have increased in size. They are small in the lungs, but bigger in the liver. The largest is the size of a quarter. Nov 2005 - EHE is still in her Liver but it has started to regress. The DR's are concerned about the fluid around the plural sac and the Pet scan did show activity. It has been over a month and we are still waiting for treatment recommendations. ______ continues to attend college and does not let this disease control her life. Currently asymptomatic as we wait for second opinion and treatment from Children's hospital in Boston. Dec 2005 – Will commence with Interferon injections in January, for 6 months. The interferon is being used to stop the activity in the Lymph Nodes around the right upper chest area. Apparently the tumors are not in the lungs but rather in lymph nodes. But she still has fluid build up in the pleural sac. The tumors in the liver where they took the biopsy are still inactive. She had a Cat Scan and blood work last week. The results of the cat scan found spots in several locations, some pre-existing ones are growing, and there are new ones in the pleural sac around right lung, right lymph nodes and left lung. _______'s Dr at Kaiser told us that Dana Farber Cancer Institute (Children Hospita Boston, MA.) will look at her records this week. Nov 2006 - ________ had another Cat Scan and Pet Scan. The Oncologist sent _______to a Pulmonologist to discuss a collapsed right lung. She is scheduled to have a Bronchoscopy January 5, 2007 to determine if there are any obstructions in the right lung. If there are no obstructions she will commence with a Thoracoscopy Talc Pleurodesis to re-inflate the lung. Tumors in the Lungs, Liver and Medium Stinum are still growing slowly. Dana Farber, Dr Giannoula Klement, suggests that we start some form of drug therapy but not until after the fluid has been removed and the right lung is functioning properly. _________ also is nauseated every day, it comes and goes. Mar 2007 - _________ met with Dr. Klement at Dana Farber Cancer Institute in Boston, MA. She works on the Vascular Anomalies department and specializes in EHE. Her recommendations for _________ are to start her on Thalidomide and Celebrex. Taken for 12 months. _________ has shown symptoms over the past several months. She has had episodes of nausea and had fluid build up around her right lung that caused her lung to collapse. She had a Thorocodomy, and Decortication to remove the fluid around her right lung in February. The Dr's think the fluid build up was caused by the tumors and the nausea was from the fluid around her right lung. June 2008 - ______ has been taking Thalidomide, and Celebrex for 9 months now. The drugs are working for her. The tumors are gone in her lungs and have been shrinking in her liver. Before she started taking the drug the tumors were consistently growing. The medication does make her tired, and she can only take 300mg of the drug due to side effects. The drug has caused temporary distortion in her eye sight at 800mg. Since reducing the dosage she has not had any more side effects. ________ is now 22 years old and the tumors are under control. Aug 2012 - My daughter, who is now age 26, continues to stay in remission. She was diagnosed 11 years ago. She is currently under Dr care however has not taken any drugs for over 3 years now. Nov 2014 - Stable January 2016 - Stable, no medication.
MC7111	1-Jul-2015	EHE in Liver and Lungs (too small to biopsy) 2009 - Diagonosed with Crohn's disease (I was 40). I had an abscess in my abdomen and required a bowel resection. A CT scan and MRI showed something strange in my liver. Visually, it had the characteristics of a benign hemangioma (a tangle of blood vessels). We agreed to keep our eye on it. Fall of 2009 - After my Crohn's surgery to keep my Crohn's disease in check, I began to take an immunomodulator called Mercaptapurine or 6-MP, which is actually an oral chemotherapy drug. My GI doctor was Geanina Anghel at the Allegheny Center for Digestive Health. I was followed with MRIs every six mos. Each time, she noted the hemangioma in my liver, but it was stable so we were not worried. After one year on 6-MP, it was clear my Crohn's disease was active and Dr. Anghel suggested we Add Humira to the 6-MP. At the time, temporary, concurrent therapy was thought to be the most effective way to reverse the effects of Crohn's disease. Humira is a powerful biologic immunosuppressant drug, self-administered with shots every two weeks. I was followed with blood work and planned an MRI at 6 months into the Humira therapy. The blood work showed puzzling elevated liver numbers. I wish I had more specific info on this. Let's just say the GI doctor was puzzled as to why my liver numbers were elevated. At the 6 mos. mark, I had an MRI and she saw that the "hemangioma" had nearly doubled in size. A liver biopsy was ordered at West Penn/Allegheny Hospital in Pittsburgh. The lab there found the EHE in the liver tissue. I was immediately removed from all Crohn's drugs. The theory is that the previously stable tumor was "activated" by all of the immunosuppression therapy. It was growing rapidly. I was lucky that my case was one of the rare candidates for resection. My tumor was large and in tact in my left lobe, with one other possible small tumor on the right side of the liver. I contacted the UPMC Liver Cancer Center and requested to see Dr. Wallis Marsh. October of 2011 - I had a left lobe hepatic resection. They also ablated the other small tumor they found, and continue to watch that one. It seems to be stable and it is unclear if what they see on imaging is tumor or scar tissue. It's way on the right corner of my liver, difficult to biopsy, so we just watch it. I was also encouraged to see an oncologist named Dr. James Orr at Hillman Cancer center of UPMC. However, when I met Dr. Orr, I didn't get the feeling he knew any more about this disease than I did at that point. After my surgery in a search for more answers, I made an appointment with Dr. Jeffrey Morgan at the Dana Farber Cancer Institute. Dr. Morgan said that Dana Farber was treating about a dozen EHE patients, some with chemo, some were watch and wait. He suggested a derivative of Thalidamide called Lenalidomide. I asked if he had seen success with EHE patients on that drug. He said, "No, you would be the first to take it." At that point, I was still pretty fresh from surgery and decided to wait for another round of imaging before I decided that I needed medical management of my EHE. July 2015 - Since then, my liver surgeon, Dr. Marsh, orders MRIs of my liver every six months and occasional CTs of my lungs to watch my EHE. So far everything has been stable. There are and always have been possible nodules in my lungs but they are too small to biopsy.

MH0008	1-Aug-2012	EHE in lungs and liver 2001 - Diagnosed with pregnancy asthma during my second pregnancy. This condition cleared for a number of years. 2005 - Saw my doctor with a lump on my hand that had been there for quite some time maybe 6 months or more. He said it was a thrombosed vein and not to worry. 2006 - Pregnant again and the asthma came back with a vengeance. Very morning sick and I lost a lot of weight. I only put on about 3 pounds during my pregnancy in total and my son was born at 9 pound 8 ounces. Had periods of trouble breathing and was put on steroids and nebulised. I had a terrible cough that would not go. I developed what I now know to be clubbing in my fingers and toes. I thought that it was hormonal. After my son was born the thing on my hand got worse and I had it removed and biopsied. They said that it was fine. We now know that it was EHE in the vein. Early 2008 - The cough still wont go and the asthma meds are not helping. I asked my doctor for chest x-rays to be done, which showed multiple nodules and white shading around the heart in both lungs. The radiologist suggested that it was Sarcoidosis. I was referred to a lung specialist. A CT scan and a double wedge resection or open lung biopsy was done in May, and diagnosed EHE. I have asked for a second opinion. June 2008 - Bone scan showed no cancer in the bones. It did however pick up that I have HPOA which is a rare bone disease that is caused by prostaglandins not being able to be cleared form the lung and your bone then grows layers like an onion. The most noticeable symptom being finger clubbing. I would like to hear from any one else that has finger clubbing. CT scan showed no real changes to the tumours in the lungs. Liver clear and brain clear. July 2008 - MRI on back. They can't decide if a tumour is in my spine or not. It will need to be rescanned later to see if has changed. Still getting a lot of pain in my upper back. February 2009 - Cancer has spread to the liver. There are 3 tumours all about 6mm in diameter. They are painful and I knew that they were there before it was confirmed by scan. I have seen the Heptologist. Dr. Jonathan Koea who previously worked in New York and actually operated on 4 or 5 patients with EHE in the liver. He suggests that I should have the tumours Microwaved. He says that he can stick a little probe into the liver and then microwave the tumour directly. (Started on a Trial of Tamoxafen for three months – was not effective!) April 2009 - Yet another CT scan. This time the cancer in the liver is growing. It has to come out. The lungs are still stable. May 2009 - Surgery. The surgeon was able to microwave 2 of the tumours but the third was up under my gal bladder and had to be resected along with the gal bladder. This incredible surgery was all done through key holes in my abdomen. June 2009 - Saw my chest oncologist and he is happy with the surgery. He thinks there is a good chance the cancer is in my spine as the pain just keeps getting worse. We need to do another MRI. Oct 2009 - The cancer is back in my liver. It grew in 3 new places since surgery, and my lungs are no longer stable. The surgeon won't opperate again at the moment and probably not again in the future either. My oncologist has been in contact with several doctors in Melbourne and they have all suggested Taxol. I am waiting for an online consultation from the Dana Farber Institute in Boston before making a decision. My pain levels are quite high at the moment as my back is getting worse. February 2011 - I started chemo as the disease in my liver continued to progress. I had 4 cycles of Taxol and Carboplatin. These were given every 3 weeks. They did not help rid me of the cancer in my lungs or liver. October 2011 - I then started Thalidomide starting at 100 mgs per day and increased up to 300 mgs per day. I continued on thalidomide for 9 months until my cancer started to grow again. July 2012 - I stopped taking thalidomide. I am going to see a liver specialist on the 30th of August to discuss SIRT. (Selective internal radiation treatment). This will only help in the liver if it helps at all. My lungs have been reasonably stable over the last 4 years.
MJ4908	1-Jan-2016	EHE in upper left thigh and lung. Summer – Fall 2008 - dry cough, I thought to be brought on by Lisinopril. Oct – Dec 10 2008 - tests performed at Lourdes Hospital, Binghamton, N.Y. Oct 2008 – bad upper respiratory infection and severe coughing, went to my primary physician. On second visit was given orders for a chest x-ray. Oct 2008 – X-Ray - no acute chest disease but small nodular opacities are found. Nov 2008 – CT - Bilateral pulmonary nodules are found to be indeterminate for malignancy. Dec 2008 – PET SCAN – no abnormal uptake in pulmonary nodules. Mass seen in the anterior left thigh, muscular compartment, deep to the rectus femoris muscle. Even though pulmonary nodules show no hypermetabolic activity, they are suspicious for a neoplastic process due to the thigh mass. MRI result – find a 4.1 x 2.6 x 2.4 cm mixed signal intensity mass. Tissue sampling recommended. Consult with Dr. Timothy Damron. Jan 2009 – Needle Biopsy – EHE diagnosis – epithelioid cells are strongly positive for markers CD34 and CD31. CT preformed, consult with Dr. Shah, radiology oncologist. Biopsy to be preformed on lung nodules and checking on pathologist report of leg mass for mitosis. Feb 2009 – Lung biopsy showed 2 nodules, each 1.1 cm, confirmed EHE in the lungs. Smaller nodules also detected. I decided to have the leg mass removed but wait on the lungs. Operation preformed by Dr. Timothy Damron to remove mass in leg. There are clean margins, no radiation ordered. April 2009 – Went to Sloan Kittering in NYC for a second opinion. Met with Dr. Mary Louise Keoman. She stressed I should receive chemo as the cancer had metastasized into the lungs and could come out in a 3rd location. I discussed what I read in the case histories through HEARD and felt I should wait to see if the nodules grow. She agreed since the nodules are so small. I will stay with my doctors at University Hospital in Syracuse and she is availab as a consult. June 2009 – CT done, everything stable. Healing from leg operation is going well, MRI of the leg will be done July/Aug. Jan 2010 - I am doing well, the cancer is still in my body, but I get periodic testing. There has been no regrowth of cancer in my thigh and the nodules in the lungs are stable. May 2012 - Had MRI on left thigh and CT scan on lungs. No recurrence of cancer in the leg and nodules in the lungs show no growth so will just continue to monitor. Oct 2014: Wide resection of the left thigh mass was performed on 3/3/09. Now 5 years cancer free at this site. Lung nodules are being monitored yearly and remain stable as of 11/13. January 2015 - Everything is stable in the lungs, no re-growth in the thigh. January 2016 - No change in condition.
MK8915	1-Oct-2015	Liver and lungs June 2014 - I was diagnosed after an appendectomy. I was 25, am 27 now. I do not know exactly how many tumors I have. I know there are lesions all over my liver and lungs at this time.

ML0015	1-Feb-2016	EHE in liver and lungs January 2015: Diagnosed. Prior to this she had a melanoma in her eye 20 years ago, non hogkins lymphoma 10 years ago. February 2016: Scan in a month to see if EHE is porgressing. Also diagnosed with primary breast cancer (December 2015), and primary thyroid cancer in January 2016, so she has had a tough time.
ML1515	1-Feb-2016	Diagnosed with EHE in 2015 age 50. May 2015 - the meidastinal tumor was 5.9 x 7.4 x 6.3 cm (from pet scan) and 2 in my liver 1.1cm and 1.6cm (from biopsy). June 2015 - Started chemotherapy - Taxol 3 weeks on and 1 week off. Aug 22 2015 - after pet scan tumor measured 5.9 x 8.3 x 8.4cm. But what they don't know is if the growth was from 5/8/15 until I started chemo on 6/10?. I do not know that original size of the tumor from 1/2014 (the Dr never told me I had EHE) so it grew large until 5/2015. My last chemo was 8/12/15. Sep 2 2015 - start Doxcil. 1 week on 3 weeks off for three cycles and then have another PET scan. Okuno and Silva discussed that if Doxcil shows no sign of shrinking tumors I would probably qualify for a clinical trial. My blood work has all been good. November 2015 - Visited with Dr. Ravi at MD Anderson and came up with a plan December 2015 - Pet scan showed a decrease in the SUV (hot) cells - going to do another set of 3 Doxcil. February 2016 - Had last IV chemo in January - going to see Dr. Ravi middle of February to discuss recent Pet scan and what the next steps will be.
MN0915	1-Jun-2015	EHE in Liver. April 2009 - Routine check up made without any specific symptom. Some liver lesions (mm). Needle Biopsy confirmed EHE. No metastasis April 2010 - Liver resection in Bologna (Ospedale Maggiore) after consulting with Miami Hospital (I don't know the name of the surgeon). April 2011 - New lesions - same number (5) more or less same dimensions (millimiters, max 16) as before resection. July 2011 to June 2015 - on waiting list for a liver transplant at the Ospedale Molinette Torino - Prof. Salizzoni. I am undergoing checks every three months - no medicament - up to now all is dormant.
MS0214	1-Feb-2016	Hepatic EHE 2001: -Tumors in the liver were found incidentally. Not treated -- thought to be hemangiomas. Had periodic checkups (MRI); tumors did not seem to grow (biggest was five centimetres). Dec 2002 - Had a baby. Liver Biopsy because tumors grew and joined in a way hemangiomas do not grow. Hepatic EHE diagnosed. Nov 2004 - Feeling fine, never had any symptoms. Now, right liver lobe is completely invaded and the other lobe has two small tumors. Currently testing for further metastasis to determine treatment (liver transplant?). Looking for specialists in Europe or USA who have treated EHE. Jan 2005 – (in response to a member's query about liver EHE and fevers) - I have EHE in my liver and I also had fever on and off. It was one month after I had my baby. Doctors didn't know I had EHE two years ago so they thought the fever was because of an infection and I had a curettage. After that, the fever went on and off the same and I had lots of antibiotics. No infections were ever found. So finally, I left the hospital, I relaxed at home and the fever disappeared. I never had fevers since. Now doctors know that I have EHE and they ask me if I feel tired or if I have lost weight of whether I have fevers. The fever was due to a period of EHE liver tumors' growth March 2005: - (in response to a member's query) I consulted Dr. Folkman because of his pioneering work that led to the discovery and development of antiangiogenic therapies. He told me about Interferon alpha maintained for one year and reinforced with doxycycline, zolendronate, rosiglitazone, tarceva or avastin. To conclude that these procedures are all experimental. I have changed my diet (biological products) and am practicing relaxation which helps a lot. Aug 2005 – Confusing times – Doctors had suggested a liver transplant. Now, they have doubts due to the stains in both lungs. They say they are not growing now, and maybe they would if I have a new liver. Some oncologists say I should try thalidomide, which I should buy abroad because in Spain it is impossible. Don't know which way to go!! Oct 2005 - Tumors in liver have less activity than before and they seem smaller. One of the tumors in lung had grown. I think it is due to the biopsy of the liver, disturbing it. Starting on Avastin weekly. They suggested thalidomide, but decided on Avastin. I feel fine, I have a normal life, I follow a diet based on organically grown food, I do some relaxation and exercise. I am also having some treatment from plants (viscum album subcutaneous) and an antigenous from my own urine (also subcutaneous). Nov 2005 - I still have tumors in the liver and some subcentimetric ones in both lungs, which are stable. I have no pains, no symptoms. I am having twice a month a dose of Avastin. It seems it has no side effects at the moment. I am feeling fine. Sep 2006 - Still symptom free - taking Avastin since last September. Recent CAT scan some months ago and it showed no growth and tumors seemed less vascularized. EHE was accidentally discovered five years ago (my doctors also think it was there for years), but I had a baby four years ago and that was the reason why tumors in liver grew. Aug 2007 – Fine. June 2008 - CAT scan in April - tumors are not growing. I am on a special diet - no fat, more fruit, vegetables, whole grains, (I thought it would be a good idea to take care of what I eat) and I also try not to get angry so often. It seems it works. Avastin seems to be the best. That is what I had for a year (two or three years ago). July 2009 – stable. Scans reduced to 6 monthly. Feeling fine. March 2011- Stable and in remission for 5 years. I've been on the medication Avastin. Aug 2012 - there is no change. I have a CT Scan every six months and everything is the same. Spots in lungs did not grow, some spots in liver seem to have reduced and I feel as well as always. I do not follow any treatment, apart from Avastin I had during 2005. My new oncologist has your address and he told me he has two more cases of EHE at hospital, a woman aged around 40, in her liver, and a man, in his bones. November 2014 - there is no change. February 2016 - No change in condition.
MS1515	1-Oct-2015	EHE in liver and lungs. August 2015 - diagnosed. She has 6-7 lesions in her liver, 2 of them are 2.4cm x 1.8cm (being the largest) and some very small nodules throughrout her lungs (difficult to see on the ct scan, biggest being 7 mm).

MS8715	1-Dec-2015	EHE in liver and lungs. December 2015 - Diagnosed at 28. Incidental finding of abdominal pain related to Crohns found in her ileum which was also a new diagnosis with this visit. No change (fingers crossed) for the past 3 and half months. 6 lesions in her liver, the biggest being 2.1 cm x 1.8 cm. Scattered nodules throughrout her lungs, all sub cm, biggest being 7 mm. PET scan revealed two "active lesions." One had an SUV value of 3.6 and the other was 4.9. No other activity found. PET scan was from the skull to the thighs. No elevated cancer markers. No abnormal lab besides a slightly elevated WBC (probably related to her Crohn's) Recommended treatment, wait and watch.
MS9614	1-Oct-2015	EHE in liver. September 1996 - I gave birth to my beautiful first daughter. I returned home and on around the 5th day I started to have a stomach ache. I was able to distinguish a mass under the skin when I pressed on the right side of my body. the time I didn't know that that was where my liver was located. I was sent for scans which revealed lesions on both lobes of the liver but of a type that they had never seen before. My blood tests came back extremely bad and I fou myself hospitalised within a week of my baby's birth. This was the beginning of three months in 6 different hospitals in Paris as many, many doctors and radiologists tried to figure out what was wrong with my liver and I went from being told that I had a chronic liver condition, to leukemia, to angio-sarcoma and that I would be dead in 3 months. We finally took everything to London. First I was seen at The Royal Marsden by Dr. Ian Judson who realised that I had EHE which at the time was so rare that they didn't even call it a cancer. I received chemotherapy (I don't remember the name of it) to slow the growth and I was referred by Dr. Judson to Mr. Nigel Heaton at King's College Hospital for possible transplant as the cancer was primary in the liver and had not visibly spread anywhere else as yet. I was seen, the diagnosis was confirmed, my chemotherapy stopped and within 7 weeks of being on the transplant recipient list I received the call. April 21st, 1997 - My transplant was at King's College Hospital, London, England. The operation was done by Mohammad Rela on Nigel Heaton's team as he was off that day although he was my consultant. I know that I was put on the urgent list and I think the fact that I was young (32 years old) and with a little baby all helped. I was told not to try to have more children for at least 5 years as of course they had no idea what the effect of immunosuppressants might be on the fetus. Six months after my transplant I was pregnant with my lovely second daughter who is my 'transplant baby' and my extra gift.
MT9012	1-Oct-2015	EHE in Liver. November of 2012 - My lesions were found on my liver and at that time there were only 3 visible. I was 22. December of 2012 (only a month later) - there were over 15 lesions visible. For about a year I went through multiple scans, blood work and even THREE biopsies. After the first two, the doctor said I was fine and could live with them. I wanted them out anyways so he requested another CT scan to choose which ones to take out. It was after that scan that he realized he made a mistake and the 3rd biopsy confirmed it was EHE. January of 2014 - My diagnosis was right before my 24th birthday. As for size, I haven't been told lately anything about the measurements but I know before my biggest one was 4 cm I believe. Also, when I was pregnant my cancer seemed to be stable, however when I gave birth the transplant team told me there was significant growth October 2014 - During my appointment with my oncologist, she told me that my CT from September 30 2014 showed ZERO growth since my scan in January beginning of this year (______ was born a month prior to that scan). It's good news it hasn't grown lately but it has consumed about 80% of my liver since November 2012. Currently considering transplant.
MV7712	1-Oct-2015	EHE in liver, spleen and lungs. Treated by prof. dr. Patrick Schöffski at UZ Leuven Belgium Sept 2012 - diagnosed, at age 35 years. Tumors in liver (about half of liver affected), spleen (+/-10 cysts size between 0,5 and 2cm), lungs (several tiny cysts). September 2012 – May 2013: waiting for liver transplant, aborted in May 2013 because tumor was too agressive (had already affected peritoneum). June 1013 – September 2013: metronomic cylclofosfamide and steriods: did not work, tumors still growing. October 2013 – February 2015: Votrient (Pazopanib): did stop tumors from growing, but blood parameters started going crazy in February 2015. April 2015 – now: Avastin (Bevacizumab): already 2 CT scans showing tumors do not grow. other cancers: October 2010: melanoma on calf, complete resection
MW8615	1-Aug-2015	EHE Diagnosed 2015 at 29 incidental finding on chest x-Ray when broke arm.

NM9212	1-Aug-2012	EHE in right shoulder 1992 - Persistent pain in shoulder, severe, dull pain in entire right arm for 2 years (esp. during pregnancy) that would not go away with ice or heat. No swelling, no physical signs from this large 5cm tangerine growing in my arm. Until 2 years ago, the pain would come and go, something I could live with. 2005 - I knew something was wrong but kept putting it off 2007 - found out I was pregnant, and pain became so bad, I cried myself to sleep. Began acupuncture immediately (never had this treatment before, believe in it thoroughly) for last 7 months every week to help ease the pain while pregnant. No pain or symptoms anywhere else in body. July 2007 - After giving birth 14 weeks ago to a premature baby, I wanted to get to the bottom of the pain. So I went to my MD in Greenville, SC who conducted an x-ray and from there it I went to an orthopaedic oncologist. October 2007 - Had a open biopsy. It was sent to Mayo Clinic in Rochester, MN who diagnosed it as EHE. No signs in my other bones, only a very small "cyst" in my liver, too small to consider, however, they are calling it a "cavernous hemogiomia". Will watch it and will do another CT scan in 3-4 months to see if it is growing. I have an appointment with the Mayo Clinic in MN for a 2nd opinion on 10/25/07. For now my orthopaedic oncologist, Dr. Bryan Moon with Steadman Hawkins in Greenville, SC as well as other colleagues of his, are recommending radiation. If I went in for removal, it would mean a complete right shoulder replacement, resulting in limited range of motion of my arm. June 2008 - I was diagnosis with EHE in November 2007. I went to the Mayo Clinic in Minnesota for a 2nd option and after ALOT of testing, they discovered it was only in my right hummerus, a blood tumor, malignant. They took out the tangerine size tumor, scrapped my bone, packed it with cement, place an 8" plate on there and off to Radiation I went. No Chemo. Took 6 weeks of radiation at home. Went back up in February for 4 month check up, all is well so far. I go again in 2 weeks for my 7 month check up. They did however find "bone islands" throughout my body. They took biopsies of these in my liver, which was not at all pleasant, and removed one in my hip bone, but still nothing cancerous came out of it all. During my stay at Mayo, they checked my lungs, spleen, liver and other bones for other signs of EHE. I really think they were stunned that it was no where else. March 2011 - I am 3 ½ clean from EHE. I had my right humerous bone removed and underwent radiation for 2 months. I am currently not on any medication at this point as they labelled it focular malplasia. Aug 2012 - Dr Shives in Rochester MN , Mayo clinic has been watching with nothing new. I do have focal modular spots in my liver, but it seems non related. I go next month for my 5 year appointment. ****Jane Gutkovich contacted November 2014 for update and received no response***
NT0014	1-Feb-2016	EHE in artery above heart & in liver (?) May 2014 - A tumor in the artery right above the heart was operated on but coudn't be removed. They only took a part of it. Biopsy came back as EHE. September 2014 - Radiation of the tumor in the artery shrank it a little bit from the original size size 6 cm. One small 1cm tumor appeared on CT in the liver. Biopsy came back negative. October 2015 - 2 liver tumors removed. February 2016 - liver is clean, the main tumor in the artery stable.
OJ816	1-Mar-2016	EHE in the lungs February 2016 - Patient diagnosed at 35 years old. He currently only has the disease in his lungs. About 15-20 nodules they said, and they are currently growing. He is on Pazopanib. He's had a PET and CAT scan. We originally we to the doc because he was having pain while breathing and had fluid in his lungs. That comes and goes. He is a little fatigued and has some muscle pain, but that is it. HIs blood work is normal.
OM8408	1-Jan-2016	EHE in liver Apr 2009 - Lesions in liver incidentally discovered by abdominal ultrasound through workups for elevated total bilirubin (~3mg/dl). Subsequent CT scan showed hypodense liver lesions, about 7, the biggest around 30mm. Gastroscopy, colonoscopy, lungs, breasts – ok. Elevated marker cancer 15.3 (~29U/ml). Clinically asymptomatic, feeling great. May 2009 – laparoscopic biopsy June 2009 – diagnose – neuroendocrine cancer July 2009 – hospitalized, looking for the source of tumours in liver – capsule endoscopy, USG, brain CT, chest CT (the biggest lesion around 40mm). Tumours just in the liver. Recommendation of treatment – liver resection and radiation. Aug 2009 – hospitalized, resection not feasible because tumours are in both lobes. Histopathologic material taken in May checked again by other specialist, diagnose EHE. Positive for markers CD34, vimentin and negative reaction to the presence of antigen LCA, cytokeratin, EMA, serotonin, chromogranin. Lack of proliferative activity in addition to the reaction with Ki-67. Doctors say the only option for treatment is transplant. PET scan showed only two active lesions. Occasional mild liver pain. MRI showed the biggest lesion ~50mm. Sep 2009 – changed diet – NO sugar, almost no meat, a lot of veggies, juicing every day, supplements: Reishi mushroom, bioflavonoids (Flavon Max+), Silybum marianum. A lot of flax oil, trying to follow the rules of Dr Budwig's diet. Transplant is not for me! Oct 2009 – MRI showed no change since August. Occasional mild liver pain, no need to take painkillers. Blood test: elevated bilirubin, cholesterol and marker CA 15.3 (~32U/ml). Everything else in norm. Jan 2010 – MRI result: one lesion diminished from 3,x3,6cm to 3,6x2,7cm. Other tumors in right lobe: 3,1x2,8cm; 4,3x2,4cm; 1,3cm; 0,8cm; in left lobe 1,9x1,4cm. Blood tests: Ca 15-3 32,5U/ml, elevated bilirubin, everything else in norm. I work full time since Dec '09 and feel great, from time to time feel mild liver pain, nothing changed in this matter. July 2010 - MRI showed small regression. Tumors in right lobe 1) 3x2,9cm (was 3,6x2,7cm); 2) 2,7x 2,4cm (was 3,1x 2,8cm); 3) 3,8x 2,7cm (was 4,3x 2,4cm); 4) 1,3cm; 5) 0,8cm and in left lobe 1,5x 1,4cm (was 1,9x1,4cm). I feel very good, I have the impression that pain occurs less frequently than before. I still juice every day and keep my diet. I work full time, sometimes it's stressful but apart from that I lead a healthy life style. January 2015 - Tumors stable since diagnose, no action taken. January 2016 - Pregnant, due date in mid-May. Feels healthy.

PG7909	1-Oct-2015	EHE: Liver, lungs DIAGNOSIS + DOCS and INITIAL EXAMINATION RESULTS: 2008: December: Persistent cough that would not go away with treatment and shortness of breath, chest Xray showed numerous tiny nodules on both lungs (initial diagnosis: Sarcoidosis), following CT also revealed several lesions liver, surgical biopsy of lung tissue (January 2009) confirmed EHE. Age at day of diagnosis: 29. Initial CT and MRI results: several very small nodules (5mm or less) in both lungs (+ densification of lung tissue interpreted as disseminated metastasis or lymphangiosis carcinomatosa), slightly enlarged hilar lymph node, several hypodense liver lesions (largest about 17x14mm). TREATMENT 2009: February – May: Paclitaxel (initial dose: 150mg per week, dose was reduced to 120 mg per week due to increasing toxicity) + Avastin/Bevacizumab (400mg in a two weeks interval) – chest and abdominal CT scans after three months (May 2009) showed relatively stable lung nodules, increasing structural changes of the pulmonary framework and slightly growing liver lesions. Change of treatment because of increasing toxic effects on body and blood work. 2009/2010: May (2009)-April (2010): Caelyx/liposomal doxorubicin (initial dose of 70mg in a three weeks interval, dose was reduced to 60mg due to increasing toxic effects on blood work and body) + Avastin/Bevacizumab (600mg in a two weeks interval) – chest and abdominal CTs (3 months interval) showed decrease in size of liver lesions and relatively stable lung nodules. Change of treatment after one year because of increasing toxic effects. 2010/2011: May (2010) – February (2011) :Avastin/Bevacizumab monotherapy (1100mg dose in a two weeks interval). Relatively stable disease in lungs and liver for a period of about nine months. When scans (3 months interval) showed progression of liver lesions in February 2001 = change of treatment. 2011: February – May: Return to low dose of Caelyx/liposomal doxorubicin (37mg, three weeks interval), CT after 3 months showed stable lung nodules and a slight progression of some liver lesions. Increase of toxic effects (blood work, skin, general physical constitution) = change of treatment. 2011/2012: May (2011)- February (2012): Low dose of Endoxan/Cyclophosphamid (oral medication, 200mg p.o./d). Lung problems – persistent cough, bronchitis. In July, 2011: Pneumothorax (part of left lung) + surgery. Scans in February 2012 showed stable lung tumours and slight progression of liver lesions. Due to the slight growth and because the liver function tests showed a consistent increase of liver values = change of treatment after 9 months. 2012: February – April: Temodal/Temozolomide (oral medication, 50mg p.o./d). Scans in April (2012) showed no significant positive improvement = lung nodules stable, persistent slight growth of liver lesions, no improvement of liver values. This resulted in a change of treatment after three months. April 2012 – until today (October 2015): Afinitor/Everolimus (oral medication, 5mg per day). Progression of liver lesions stopped. Slow but consistent improvement of liver values. Regular Scans (monitoring interval = 3 months, then changed to 6 months) during the three year period of treatment with Afinitor/Everolimus showed: stable lung nodules, stable liver lesions ~~(~~ change of appearance under treatment with Afinitor: liver lesions seem to be less sharply defined), hilar and infracarinal lymph nodes are (still) slightly enlarged. Next scans are due in December 2015.
PH0415	1-Jun-2015	EHE in cheek and lungs 2004 - at the age of 26, _______ found a very small lump in her cheek. The lump did not show up much on scan. Head and neck surgeon decided to remove it. Biopsy results eventually came back as EHE. She was monitored every six months and had surgery for local recurrence. She was never scanned during follow up and was eventually discharged after 5years. 2012 - _____ had pneumonia which did not clear up quickly. A CT scan revealed multiple nodules in both lungs? TB? Sarcoidosis. No one even thought of EHE. After 6 months of visits to hospital x Rays, scans, bronchoscopy she eventually had a VATs procedure and biopsy confirmed EHE with multiple bilateral lung nodules measuring up to 7mm on CT scan. Our local hospital was unable to deal with this and referred her for follow up under the care of professor Judson at the Royal Marsden. Jun 2015 - Professor Judson 'watches and waits' though she does take Celecoxib. She was for the first two years seen every 3 monthls but now every six months. ______ has always suffered with pain in her right shoulder and beneath her right shoulder blade which no one seems to think is related to the EHE? Sometimes the pain is severe and she has in the past taken morphine,naproxen, paracetamol. She has now come off this regiment and takes Pregabolin, a neuropathic drug, and sometimes paracetamol.
PH9615	1-Oct-2015	EHE in liver. 19 years old. Healthy healthy kid. We had three years in a row where he didn't go to the doctor for anything except his sports physical. Started having pain in his side when he moved to his apartment for the school year. We thought it was a strained muscle and told him to take some Advil. It stayed there but wasn't bad, until September 12, when the pain couldn't be tolerated. Sept 12 2015: At the ER, they did an xray and blood work to see if it was gall stones. His blood work was (and continues to be) 100% normal. No rise in LFT or WBC at all. On a chance they did an ultrasound and found the lesions. The doc said they needed to do an MRI. Sent us home with follow up with PCP for order. Said the pain he had was gas. (?!?!?!) Sept 16 2015: MRI said the same thing: lesions in the liver, more then 15. Sept 23 2015: CT guided biopsy. Sept 28 2015: Pathology: EHE. Sent results to Mayo because our hospital hasn't seen it before. Our local cancer/hematology center had no idea and said University of Michigan. Oct 3 2015: U of M visit. Just did an initial eval of _______ and told us that liver transplant would be the cure... If it hasn't spread. Ordered a CT chest Oct 4 2015: CT chest done. Results from local hospital and films sent to U of M.Provider at U of M: Dr Ted Welling. ________ continues to have intermittent moderate to severe pain in his side. Waiting to see what's next.
PL1212	4-Jul-2012	EHE in foot 2012 - Towards the end of last year I finally decided to check out a painful lump that had developed on top of my left foot. It was above my big toe and the first. An MRI scan came back fine but nevertheless I went into surgery just before Christmas to have the lump removed. The biopsy has shown that in fact there was a 'low grade rare tumour' called Epithelioid Haemangioendothelioma. As I understand it, this is a tumour located in the wall of a blood vessel within the soft tissue. I am scheduled to be operated on again in a few weeks in order to remove tissue over a wider area of my foot to check that the cells are localised. ****Jane Gutkovich contacted January 2015 for update and received no response.

RA0510	1-Jan-2010	EHE in liver and lung 2005 – after constant pain in liver region over period, eventually had surgery in 2005, when EHE in liver was diagnosed. 2006 - Tumors continue to grow, so doctor suggested either a liver transplant or a big liver resection. I ran around getting second opinions from NC, to NY to LI. Everyone said the same thing. So I decided to have the big resection in Oct of 2006. March 2008 – Latest scan shows tumour has appeared. One tumour that is 2cm long. This time it only took 6 months for a tumour to come back. Last surgery it took 1 year. Also, after testing bones and lungs, discovered two small tumour on my lungs Jan 2010 - I was put on Thalomide for about 5-6 months which seems to stop some of the tumors in my liver from growing but others still continued on the same pace. The side affects of the medication were too much for me so I am taking a break right now and planning on a pregnancy. After my pregnancy we are going to look into trying Avastin or this new drug they are testing right now at the hospital I go to - Wake Forest Baptist Hospital Cancer Center in Winston Salem, NC.
RC8015	1-Feb-2016	EHE in left thyroid, lymph nodes and attached to carotid artery July 2015 - age 35. Diagnosed with thyrpid cancer, had left thyroid removed. The pathology reports from that surgery indicated I had EHE on the left thyroid, in lymph nodes and also a tumor attached to the carotid artery. This tumor was unable to be surgically removed. September 2015 - Starting in September I had 31 EXT radiation treatments and 18 doses of Taxol. The tumor disappeared. No autoimmune problems.
RJ**12	3-Apr-2012	EHE in liver. November 2011 - He has had zero symptoms. His tumours were discovered at a routine scan as a follow up to a kidney being removed in 2009. A 2010 scan did not show any tumours, but sarcoma doctor felt they were probably there, but so small they were overlooked. _______ had 2 core biopsies at Lacks Cancer Center in Grand Rapids, MI that were inconclusive. We were referred to the University of Michigan Cancer Center at Ann Arbor, MI. A third core biopsy was done at UM that diagnosed EHE. We then met with a sarcoma oncologist at Univ. of Michigan Cancer Center and she confirmed the diagnosis of EHE and she told us that resection of the tumours or liver transplant is the treatment for a 'cure' or Interferon to keep the tumours under control. April 3, 2012 - MRI with double dose of dye to determine if two tiny lesions are EHE or not. If they are not, they plan to remove the 2.1 cm and 1.7 cm tumours that are confirmed EHE. If they determine there are 4 tumours, we will need to pursue a transplant. The doctor does not feel with _________'s Rheumatoid Arthritis that Interferon is a good option. Our local oncologist said there are three hospitals that excel in sarcoma and they are Mayo Clinic, MD Anderson in Houston and Sloan Kettering. ******Contacted by Jane Gutkovich in January 2015 for update and no response has been received.
RM**15	1-Feb-2016	EHE in liver and liver with small nodules in lungs. 2002 - have been on Interferon and Gleevac.......with no success. A natural chemo in Europe called Ukrian, helped but got too expensive. May 2009 - Currently on Sutent and my tumor has not moved in over 20 months. I am a naturopath and a physician's assistant, and adhere to a very strict alkaline diet. I work full time and also give lectures on cancer. July 2009 - I'm still on sutent and also on taxol. The tumor is tryng to close down one of the main vessles in my liver. I may need stents. Oct 2009 - I am being worked up for a transplant - I will know if I am a candidate soon. I am also on Taxol and off Sutent Dec 2009 - Transplant. July 2011 - Reoccurence in April 2011. Had RFA, took it out, Nov 2011 - progression off cellcept,,,,,,,onto Rapamune 1mg. Jan 2015 - Stable for 3 years. March 2014 recurrence 1.5x1.5 cm. Feb 2016 - No change. On Rapamune since 2011.
RM1215	1-Jan-2015	EHE in liver and lungs. October 2011- began having sharp pains in left side (previously had this sharp pain in 2006 & 2007). In 2006 & 2007, CT scans, MRIs and ultrasounds showed nothing except one or two liver cysts. Those appear to be simple cysts. My gastroenterologist thinks it may have been something muscular. I had previously been diagnosed with Crone's Disease in 1999 after having symptoms every 5 years since 1983. I then went on Imuran which put my Crone's into remission. I stopped taking Imuran in 10/2011 when five liver lesions were discovered which were not there in 2007. While on Imuran I had blood work every 3 months which was always perfect and remains that way now. December 2011- referred to Dr. David Koch, liver dr. at Medical University of South Carolina. January 2012 - Liver biopsy performed at MUSC. February 2012 - Results were given to me – 5 liver lesions DX: HEH (EHE in liver). Dr. Koch recommended a liver transplant and referred me to an oncologist – Dr. Andrew Kraft at MUSC. CT scan performed the next day and found 10 subcentimeter nodules in my lungs. March 2012 – Lung biopsy performed and confirmed metastatic EHE in lungs. Doctors at MUSC have indicated liver transplant is probably not an option now. Appointment scheduled week of 3/11/12 to discuss further. April 2012 - I saw Dr. Robert Benjamin, head of the Sarcoma Unit at M.D. Anderson Cancer. He put me on Celebrex, 200 mg twice a day. January 2015 - Very minimal growth in the liver tumors and the lung tumors are stable.

RM8213	29-Jun-2015	EHE in liver and lungs. Diagnosed at age 31. Edwin Choy, MD, PhD, Director of Sarcoma Research at the Division of Hematology Oncology at MGH, Boston. 3/2013 - Persistent cough that would not go away - Chest x-ray. 3/28/2013 - Needle Biopsy of Liver - EHE 4/22/13 - Lung Wedge Biopsy left upper lobe - EHE, low-grade, multiple nodules ranging from 0.1 to 0.6 cm., left lower lobe - EHE, low-grade, 0.3 cm. 5/15/13 - Brigham and Women's Hospital, Dana-Farber for second opinion. David D'Adamo, MD, PhD - confirmed diagnosis with their pathology department. 7/1/13 - Needle Biopsy of left back shoulder - 2.5cm mass in left back shoulder - soft and squishy without discoloration. Diagnosis: Skeletal muscle and fibroadipose tissue. 8/19/13 - MRI Liver - numerous arterially enhancing lesions in the liver. The largest 1.5 cm. Spleen - Stable small hemangioma in the spleen. CT Chest - Unchanged innumerable lilateral pulmonary nodules with largest on right measuring 6mm and left measuring 8mm. MRI and CT Scans every 3 months unchanged. 6/23/14 - Scan showed interval slight increase in the size of multiple lung metastases (for example measures 8mm compared to 6mm). No new nodules. 9/2014 - Began Interferon injections 5X a week for 3 months. Flu-like symptoms and joint pain. Felt lousy. 12/15/14 - Scans stable. 3/9/15 - Scans stable. 6/29/15 - Scans due.
SA0815	1-Jul-2015	HEHE Early 2008 - When I was 27 years old I was getting regular heartburn and feeling run down often. I wasn't thinking much of it all as I was working and living a busy lifestyle. Mid 2008 - I then had 3 bouts of abdominal pain that lasted for around 3 days each time. On the third bout I saw a doctor and had an ultrasound. The Ultrasound found multiple large lesions across my liver. A follow up CT Scan and biopsy diagnosed me with Hepatic Epithelioid Hemangioendothelioma (HEHE). Unlike some other cases, mine was growing fast around 10% per month. A PET scan revealed no other lesions in my body, simply the ones in the liver. Therefore a liver transplant was recommended. November 2008 - I was lucky to be called in for the transplant. Unfortunately once they opened me up they found hundreds of very small lesions across my peritoneum. They were so small they did not come up in any of the scans. The surgeon described it feeling like sand paper under his fingers. With this new information, the transplant was abandoned as the belief was that the new liver would not last long with the EHE having spread and therefore it would be a success – successful liver transplants are generally deemed to be those that survive 5 years or more. (Luck would have it that there was another liver recipient available in time to benefit from the liver assigned to me). Early 2009 - My oncologist then started looking at various medical options to trial. I also did a copious amount of research myself. From all the options available at the time, Sorafenib was deemed to be the best bet. I was on it for approximately 6 months over which time we saw no reduction or stabilisation of the disease, instead it continued to grow. I also suffered many side effects to my skin, hair, hands, feet and mouth. So we decided to stop the Sorafenib. Over this time the lesions on my peritoneum we're still undetectable to any scans (ultrasound, CT and PET) so my oncologist and liver specialist felt that they probably were not growing. They believed that they may not ever grow as EHE is a vascular tumour and prefers organs such as the liver. With this in mind, both my oncologist and liver specialist re submitted by case to the transplant committee and thankfully I was re-accepted to have a transplant for the second time. August 2 2009 - I underwent a successful liver transplant. For the first 6 to 9 months I was on medications such as Prednisolone and Tacrolimus. My specialist didn't want to give me Cyclosporin because I believe it can promote certain cancers. Mid 2010 - My specialist started to move me from Tacrolimus to Everolimus because as well as being a light immunosuppressant, it also shows some cancer fighting properties. For the first 12 months we played with the dose every 6 months and we have since settled on 1.5mg twice per day. Over time I was also weaned off Prednisolone. May 2012 - Unfortunately, after completing my regular 6 month scan we found that the HEHE has returned in my liver. There are a few small lesions in each quadrant of the liver, but not nearly as big as the first time. After recommencing regular 3 month scans we realised that the lesions are not growing and are in fact stable. When the recurrence was diagnosed we also found two small lesions in by hip bone. These have not been biopsied (confirmed as EHE) and have not caused any pain or issues. They have also been completely stable over this time. July 2015 - Since the beginning of 2013 I have only been undergoing annual scans accompanied by blood tests every 6 months. We have seen no change to the lesions in the liver and my bloods have been stable for over 3 years. As always the lesions in my peritoneum still don't come up in any scans, they have only ever been seen visually.
SB6405	1-Nov-2015	EHE in liver and lung June 2008 - Having been diagnosed with EHE 3 years ago, with many lesions on liver and lungs. I have had no treatment, but have CT scan every 3 to 4 months, to monitor things. So far there has been no change, in fact some of them may have even got smaller. I have my next scan tomorrow, and if that is all fine, then I think they may then do scans 6 monthly after that. Sep 2008 - I have now gone from 3 month to 6 month scans. Aug 2012 - I am due for my next scan(MRI and Xray) in a few weeks, so will update further then. (My last scan was actually MRI plus xray, to reduce the risks from too many CT scans). Nov 2014 - No treatment, very few symptoms. Remained pretty stable for 9 years. initially scanned 3 monthly, then 6 monthly, and now annually. June 2015 - No change, everythig is stable. Sep 2015 - CT Scan show no progression Nov 2015 - Intermittent stomach aches (probably unrelated to EHE) but no sign of progression; signs of tumor shrinkage and calcification on liver observed.
SCOO0809	1-Oct-2009	EHE in back and liver 2008 - diagnosed. Oct 2009 – treated with 50 mg with Sutent. for 4 months – no change.

SD9705	1-Mar-2005	EHE in lungs Feb. 1997: Noticed broken blood vessels and bruising around right bicep and shoulder. Dec. 1997 - Feb. 1998: Severe pain and burning in upper right quadrant of my chest and right shoulder. Sought treatment from chiropractor for tendonitis. Feb. 1998: Noticed right arm was achy and seemed to be slightly swollen. Pain increasingly severe. Feb. 20, 1998: Right hand and arm severely swollen. Blood clots discovered in right arm and jugular vein. Numerous angioplasties performed to eliminate clots. Feb. 25, 1998: A mass is noticed in my right subclavian vein. The mass appears to completely occlude blood flow to jugular vein, resulting in multiple blood clots. Full biopsy of mediastinal region scheduled. Feb. 26, 1998: Full biopsy performed. Mass more solid than expected and surgical procedures more extensive than expected. Vertical incision made across collarbone region and portion of my collarbone removed to facilitate access to the mass. Feb. 1998 – Mar. 1998: Biopsy results determined the mass is cancerous but of unknown origin. Diagnosed as EHE in March. Twenty tumors noted bilaterally in lungs. April 1998: Sternum split to facilitate resection of primary mediastinal mass. Resection performed and vein graft implemented to rebuild the veinous pathways removed with the primary tumor. Lung biopsy confirmed nodules in lungs are EHE. June 1998: First chemotherapy administered (two-day protocol) of four cycle BTIC regimen. First day: Ifosfomide. Second day: Ifosfamide, Adriamycin/Mesna, Mitomycin C, Cysplatin. 3 days of IV fluids. Neupogen shots 2x daily. Hospitalized 2nd week after treatment b/c of infection. July 1998: 4 wks later, second treatment; same protocol for chemotherapy and follow-up treatment. Oral dosage of Cipro taken to prevent infection. Shots of Procrit given to boost red-blood count. Aug. 1998: 4 wks later, third treatment; same protocol for chemo and follow-up regimen. Platelet count extremely low and transfusions required. End of Aug. 1998: 4 wks later; fourth treatment; same protocol for chemo and follow-up regimen. Platelet transfusions again required. Sept. 1998: Second visit to Mayo Clinic. Tumors in lungs have stabilized; chemo discontinued. Mar. 2005: Frequent check-ups (CT Scan and Chest x-rays) to monitor size of tumors in lungs. Still stable.
SF0712	1-Aug-2012	EHE in liver June 2007 – I am an ultrasound technologist and during a routine day adjusting the image on a machine was scanning myself and saw several lesions that did not appear benign. Blood work came back normal, so I felt not much to worry about and we had only seen about four lesions on ultrasound. July 2007 - MRI revealed 11 lesions total in the right and left lobe Aug 2007 - Liver biopsy pathology at MCV- unknown, so sent it to AFIP in Washington, diagnosed as HEHE. Saw hepatologist Dr. Todd Stravitz MCV recommended more lab work, suggested consult with transplant surgeon Sept 2007 - saw an oncologist Dr. David Trent Virginia Cancer Inst. Recommended wait and see. Had CT of chest, abd and pelvis, no other lesions, as well as a bone scan that showed normal Nov 2007 - Saw Dr. Robert Fisher at MCV recommend treatment, then Nexevar. An MRI showed no change at which time I saw liver oncologist Dr. Ray Lee MCV - wants to try Nexevar. Thanks to your registry I realized that too had been tried with little to no success. Nov 2008 - I went to MSK in April and saw Dr. Robert Maki who was great and agreed we should wait and see. He said at this time there is nothing proven to work. He had said if we saw 1-2 lesions that were growing would could consider Radio frequency ablation. I just had an MRI May 22 and it showed slight growth in 1-2 lesion as well as a new 6mm lesion. So my oncologist here wants another MRI in 3 months. So feeling great. Labs normal. July 2009 - I continue to have an MRI every 6 months and have seen no significant changes. Aug 2012 - Had most recent scan Feb this year remain stable with lesions only in liver. *****Jane Gutkovich contacted November 2014 for update and received no response.

SJ0414	1-Feb-2016	EHE in jawbone July 2004 - routine dental x-rays showed small tumor in left jawbone Sept 2004 - biopsy confirmed EHE. Oct 2004 - tumor removed from jawbone, along with part of the jawbone itself and 2 teeth. Bone replaced with metal support. Surgery performed at UNC hospital in Chapel Hill, NC by Dr. Shockley, ENT and Dr. Blakey, oral surgeon. Follow-up bone scan was clean. Resumed normal life. Aug 2005 - follow-up chest x-ray showed multiple abnormal spots on lungs. CT scan and PET scan showed a fist sized tumor in the liver (among smaller tumors in liver and lungs) and it's causing severe pain. Biopsy of this tumor confirmed EHE. Using 25-50 mcg Fentanyl patches for pain. Awaiting results of full body bone scan/head scan. Several doctors at UNC hospital, Chapel Hill, NC are consulting others at MD Anderson, still others in Boston and New York. Full body scan revealed a spot on the skull as well as one in the knee. Met with Dr. Benjamin at MD Anderson last week, who said she is in good health aside from the pain. Advised to stop Fentanyl and take Celebrex for the pain. He said the pain is probably from when the tumor (in the liver) bleeds. He believes the tumors will regress on their own. They think that her EHE started in the liver, and based on similar cases (that started in the liver) the tumors will produce scar tissue that will eventually slow their own blood supply. He said he could go in and cut the blood supply manually, but does not want to since she is in good heath (liver function and otherwise). So until her health is negatively affected, no treatment is the best option. Will meet with him on a regular basis to scan and monitor the tumors' growth. Best of all, he said to go back to normal life with no restrictions. March 2007 - Since 10/2005, ________ has been taking Celebrex (200 mg) once daily since briefly suffering from pain in her liver for a few days in 08/2005. Celebrex was prescribed by Dr. Benjamin to control inflammation. (It should be noted that the drug in general is being researched for cancer prevention.) Since then she has not experienced any pain or ill effects. She goes to M.D. Anderson in Houston every six months for scans. On her visit in 10/2006 they reported that one tumor in her liver was marginally larger, but her overall condition was the same as the previous visit in 04/2006. I must remind everyone who reads of _______'s case to note that she is a healthy 26 years old, so Dr. Benjamin does not want to intrude on her health unless her body is losing functionality or it is otherwise deemed necessary to treat the tumors. Additionally, we have no idea if the Celebrex is having a positive effect since the cancer known to be slow-growing. June 2008 - doing well. Saw Dr. Benjamin in April 2008 and her tumors in the liver and lungs are stable and have not grown for 2 years. She has been on Celebrex 200mg per day during this time. The doctor also said he only needed to see her yearly instead of every six months May 2010 – stable Aug 2012 - My daughter __________ was recently checked at MD Anderson,12 months after her ablation of a 3 cm tumor in her liver. I am thankful to say the tumors in her liver are "dormant " and the lesions in her lungs are stable over 7 years. She will go back for re-check in one year. She has been on Celebrex only. She has the low grade malignant tumor. Nov 2014 - Stable. Feb 2016 - 100mg Celebrex 2x/day. Everything stable.
SJ9014	1-Nov-2014	EHE in hand 1990 - painful area in hand. Mentioned to family doctor at routine visits - Nothing was visible so we didn't pursue testing. 1993 - Small but visible, painful mass in hand. Saw an orthopedic hand surgeon who diagnosed it as being a tortuous ulnar artery and recommended surgery to tuck it back in place. As the surgery was not a necessity I choose not to do it. 1994 - Returned to the same hand specialist with more pain and mass getting larger. Given same diagnosis and same treatment option and assured it was not anything more serious. I chose not to have the surgery at that time. 1994-2000 - Because of increasing pain and the mass continuing to get larger I went to see a vascular doctor who diagnosed an ulnar artery aneurysm, and referred me to another hand specialist. During this time period, for various reasons, I saw an additional 4 hand specialists. The only thing they all agreed on was that it was a rare ulnar artery aneurysm. 2000 - In Sept. I had surgery at the University of Pittsburg to remove what was believed to be an aneurysm. When I went back to the doctor for a two week follow up, I was told the pathology report came back and it was diagnosed as EHE. The margins were not clear and resection was recommended. Saw several oncologists all with varying opinions for treatment. Jan 2001 - treated at the Cleveland Clinic by Dr. Kenneth Marks, Orthopedic Oncologist and Dr. Richard Crownover, Radiation Oncologist. I received radiation therapy was and followed with MRI to my hand and chest X-rays for next 5 years. Jan 2007 - I am doing fine. Sept 2007 – doing fine. Feb 2008 - So far so good ------ no changes. Jan 2010 - I am well although I am experiencing some symptoms that are concerning to me so far nothing new has been found. I am extremely frustrated in trying to have my symptoms medically evaluated. Nov 2014 - no changes, everything is good
SL0310	1-Feb-2010	EHE in liver June 2003 - When I was 38, they found my cancer because I had pain in my stomach and they took out my gallbladder. I thought there was something wrong with me for 6 years before I was diagnosed. I was put on Interferon for 6 weeks, my liver was completely full of nodules. My only chance to survive was a transplant. Since I had EHE I was at the bottom of the transplant list so I needed a live donor. My best friend was a match and she gave me 60% of her liver, what a wonderful friend. I was in hospital for a year and a day after my transplant - it was so long and horrible! I had my transplant in Denver, Colo at University Hospital. After my transplant I was doing really well until a line in my neck came out and my body was filled with blood and fluids. Everything that could go wrong did! They put me on a breathing tube an in an induced coma for 6 months, I had so many infections. I almost died four times and it just wasn't my time, plus I am a fighter. My life has changed quite a bit since my transplant! I am a much better person and I do enjoy life so much more now. July 2008 - I am doing fine from the transplant all my blood work came back fine. I will have my five year anniversary July 15th Jan 2009 - I am still doing well, I am going on 6 years with my new liver. So far my EHE has not returned. I am on two immuno drugs, Prograf and Rappamune and 20 other drugs a day. I cannot work because I still cannot walk very well and I have had 18 surgeries on my stomach. I am an extreme case, most people don't have the complications I have had. Feb 2010 - I am almost 7 years post transplant and doing okay.

SM1215	1-Jul-2015	EHE in leg and lungs 2011 June: I was age 32 and 3 months pregnant and started having pain in my right leg, gastrocnemius. Tried to find a doctor that would treat a prego lady was troublesome. 2011 August: diagnosed as a tumor, but the doctor thought it was benign. Doctor decided that it would need to be removed, but we would wait until I delivered or I could not tollerate the pain. 2011 December: I delivered the baby with minimal complications. None due to the tumor. 2012 January: Doctor removed tumor surgically. He sent it to pathology but they couldn't figure out what kind of tumor it was so they sent it back east somewhere for further testing. 2 weeks later the results from the pathology came back and was confirmed EHE. 2012 February: Doctor wanted to go back in surgically and make sure that he got all of the affected tissue. No further treatment or scans were ordered at that time. Doctor contacted me in 2014 and told me that I needed to have some updated scans. At that time I had to switch doctors due to insurance. So I switched to Huntsman Cancer Institute in Salt Lake City, Utah 2014 April: Scans, MRI and CT. MRI of leg results came back no regrowth of tumor. CT was done of lungs. Results came back that there was at least 8 tumors in my lungs, ranging in size from 1/4 inch to 1/2 inch. 2014 May: Huntsman wanted more testing and imaging of tumors but I found out I was prego again. So no testing or imaging for the duration of the pregnancy. 2015 April: Testing at Huntsman, MRI and CT. MRI of leg came back and no regrowth. CT of lungs was good also, no change in size and no new tumors. But the CT got the top part of my liver, and there was something that needed further inspection. Scans are scheduled. No treatment so far.
SS0915	1-Jan-2016	EHE in abdomen, lungs and lymph node Jan 2009 - Might possibly have spread to lungs, awaiting results to see if it's that, or bronchitis – related scar tissue. Went to doctor originally for pain in abdomen, x-ray showed spots. Catscan and Petscan Confirmed. Originally diagnosed as Angiosarcoma, second opinion (from Harvard) said EHE. Feb 2009 – latest scan - doctor noticed a mysterious spot on a lymph-node (outside of the liver) that he is concerned about. It must be probed for biopsy before any future treatments are considered. March 2009 - ______ had a lung biopsy done, spent 4 days in the hospital, just got home yesterday. Unfortunate results. The spots biopsied were indeed cancer. Meeting with doctor tomorrow so he can tell us what options exist. May 2009 – Cat scan was good – no changes since last time Nov 2009 - ________'s tumors have not grown or moved at all! She's completely changed her diet, and eats' only healthy, healthy, healthy! The doctor told us we don't need to keep coming back for tests every 2 months, we're stretching them out to 3 months now. _________ does have some pain now and then on her right side, and gets tired easily, but also works like a dog at all she does! She looks great and if you didn't know about her situation, you'd never be able to tell. Apr 2010 - _______ is doing just great. No/little growth for 15 months now, and she rarely has any pain. January 2015 - everything is stable. January 2016 - Everything is stable.
ST0814	1-Jun-2015	EHE in liver and lung Nov 2008 - ______ has been sick since July and was just diagnosed with EHE. It's all over her liver, and in her left lung. She has bad shoulder pain, and stomach pain. Discussing option for transplant, or 8 weeks treatment. She has been going to Childrens Hospital of Philadelphia (CHOPS) and had recently got a 2nd hospital involved, DuPont in Wilmington, DE. They have confirmed the diagnosis. Dec 2008 - commencing 6 to 8 week course of AVASTIN then to rescan her to see if it helped but they are putting a plan B in the motion of a liver transplant. Jan 2009 - the Avastin didn't work. Pet scan last week showed no change on the liver, but some on the lungs got bigger. We are now starting Interferon. The pain on her liver side is very severe; her shoulders are hurting all the time. And she has trouble sleeping June 2009 – liver transplant, we tried about three different chemo's before that and it didn't work, it made her real sick. Feb 2011 - My daugther has had EHE for two years now. Both liver and both lungs. She has gone through so much. Then they finally had to do a liver transplant on her 6/09. Now she is fine. Nov 2014 - Lungs are stable. Liver is clean. June 2015 - There's few back in liver one is 6 mm that grew 3 mm in few months. Her lungs are filled only 3 show very very small growth. Watch and wait.
TA0016	1-Mar-2016	EHE in liver March 2016 - Diagnosed with EHE, 6-8 tumors in both lobes of the liver, largest 5cm, suspicious lymph nodes.
TA0815	1-Jan-2015	Hepatic EHE July 2008 - Lesions in liver incidentally discovered by abdominal ultrasound through workups for mildly elevated total bilirubin. Subsequent CT scan showed characteristic liver metastases, but liver biopsy proved to be primary hepatic EHE instead. Presently clinically asymptomatic, awaiting diagnostic imaging studies to see if resection is feasible, and exploring other treatment options. January 2015 - There has been slight decrease in tumor size since the time I was diagnosed. NO treatment. Last MRI in 2014 showed stability.

TB7913	1-Jun-2015	EHE in Spinal Cord At the time of my diagnosis, I was a 33-year-old female with fair health. In 2012 - I had various female problems. I thought the back pain I was having was caused by these issues. Towards the end of the year, I had gotten to a point where I could barely stand up straight. Neither OTC or narcotic pain medicine would work. March 2013 - my right hip began to ache. I mentioned this to my PCP and an X-ray was ordered. The results were negative. My PCP attributed my pain to me being overweight. After begging the doctor to order an MRI, the results from the scan revealed a hemangioma at L2 and what appeared to be an osteoid osteoma at L5. After my consultation with the neurosurgeon, a CT of my lumbar and cervical area was ordered, as well as a bone scan and EMG. The cervical area CT was normal. The lumbar CT revealed a possible osteoid osteoma or osteoblastoma at L5. My EMG showed significant nerve damage at the L4-L5 nerve roots. Due to the location of the tumor, I was scheduled for an open biopsy/laminectomy in late May. After 2 weeks of waiting for pathology results, the local hospital informed my doctor that the specimen had to be sent to the Cleveland Clinic for further testing. One week later, the pathology results revealed that the tumor was an Epithelioid hemangioendothelioma. 2014 - I had 3 rounds of radiation. Earlier this year, I had a pain pump installed. January 2015 - I was being treated with sirolimus (1 mg/day) until I started to experience lymphedema in my extremities. At this time, I still have lymphedema and I don't know what will be Dr. Adams' next steps.
TC6312	1-Jun-2015	EHE in liver and lungs. September 2012 - severe URQ pain. Initially thought to be gallstones, but an ultrasound showed lesions in my liver, so a CT was ordered which showed lesions in lungs as well. 4 tumours in my liver ranging from 6.1cm to 2.1cm. I have 20 or so tumours in both lungs all under 3mm. Biopsy ordered, inconclusive, second biopsy showed EHE. MRI to follow and bone scan and PET Scan. Three months later CT again to measure any growth. No growth so decided to wait and watch. Scans every 3 months for a year, and after that every 6 months, alternating between MRI AND CT 2015 - Feeling very well at the moment and blood tests are very good.
TL0310	1-Dec-2010	EHE in aorta, lungs, liver and right breas Dec 2003 - Surgery to remove tumour. Surgeon only able to take biopsies. Diagnosed initially with a para ganglioma, this was double checked 6 months later and found to be EHE. Main tumour is around the mid thoracic aorta with metastases in the lungs. March 2004 - diagnostic 1131 MBIG isotope scan. Tumours failed to take up isotopes. Coughing up blood, difficulty in breathing and severe pain – was hospitalised as blood clots were found on the lungs April 2004 - PET scan to test suitability for Imatinib (Gleevec treatment). May 2004 - Started taking Imatinib tablets - experienced bleeding gums. July 2004 - another isotope diagnostic whole body octreotide scan. Subsequent scan showed tumours had taken up a little of the isotope though tumours had not changed in size. Have lost 3 stones in weight. Difficulty with eating due to nausea and food getting stuck in oesophagus. Cut out dairy products completely, substituted with soya milk and soya yoghurt. Taking vitamins, minerals and food supplements: Soy Isoflavones, primrose oil and sage tablets (for night sweats), Omega 3 fish oils, Garlic, Aloe Vera and Calcium tablets. Also, Revenol food supplement in tablet form and Reliv liquid. Medication - Methadone for pain relief; Efexor to help prevent night sweats; Warfarin to keep the blood thin and stop it from clotting. Currently not feeling too bad, but cant work. Try to walk at least a mile a day. Oct 2004: CT scan shows that the tumour has not grown very much. Oncologist won't advise chemotherapy and the Consultant Radiotherapist says radiotherapy would 'cook' my gullet and oesophagus, so not sure what to do with me. Nov 2004 – NEW YORK for 3 weeks - The Cabrini Clinic is one of the few hospitals that offers stereotactic body radiosurgery, a form of radiotherapy, which targets the tumours and does little or no damage to surrounding tissues. Body radiosurgery focuses treatment on the cancer area and because the radioactive beam is focused more precisely, often higher doses can be given; therefore, treatment is carried out frequently with fewer doses in a shorter period of time. Consultation with Dr Lederman, then CT scans and discussions led to several sessions to treat the main tumour around aorta and the two tumours in left lung over the 3 weeks... March 2005: - latest CT scan today shows the three tumours have not increased in size. Feeling good. Reduced pain killers, off methadone completely and now just taking tylex (paracetamol). Also, not having night sweats any more. Sleeping better, more energy. I am sure that the treatment I had at Cabrini Clinic in New York was effective. (In response to member's enquiry) - I have been on the Gleevec (Imatinib) for almost a year. It is very expensive over here UK - about £18,000 per annum for one 400 mg tablet per day. Some side effects - but not as drastic as chemotherapy. June 2005: tumours have not grown, but have some fluid on my right lung (the good one) so awaiting for a bronchoscopy. I have put on 2 stones in weight (lost 3 initially). Feeling much better and only taking tylex occasionally. However, the sweats have returned both day and night - trying acupuncture. Aug 2005 - My tumours haven't grown and I am feeling well, so it was decided to leave me on Gleevec. Doctor decided against bronchoscopy, as I appeared to be well, though I thought it was needed to check the fluid on my right lung. Overall, I feel great; better than I've felt in ages. The acupuncture has started working and my day and night 'sweats' have reduced, which is wonderful. Life is almost back to normal. Oct 2005 - Still on Gleevec. 400 mg. Dec 2005 - Feeling really good at present. Started part time work. April 2006 - The primary tumour, which is wrapped around my aorta, has shrunk from 17 mm to 12 mm. Aug 2006 – one more tumour - on the spine between thoracic vertebrae 6 and 7. I've been told that because I had such a high dose of radiotherapy in New York, I would not be able to have any more. The Oncologist is talking about surgery on the spine. Considering a new treatment called HIFU - High Intensity Focused Ultrasound (website address www.hifucancertreatment.co.uk). It is not available under our National Health system, so would have to pay for it, if it is suitable - around £12,500 sterling. Still feeling fine - walking 2 to 3 miles most days. May 2007 - I'm doing fine - have conflicting medical opinions though. The clinicians in UK say I have a tumour on my thoracic spine, around vertebrae 6 & 7. Oncologist and his team in New York disagree, saying they think the hot spot is from the radiotherapy I had in November 2004. Had a PET scan - now the UK clinicians are saying it is inconclusive. The drug I've been on is Imatinib (Gleevec). Long term use has shown that some patients have had corona heart failure. I have been on it now for over 3 years, so am having a break. Haven't been prescribed anything else. So at present am only on warfarin because of 2 pulmonary embolisms I had back in March 2004. Otherwise feeling OK. Sept 2008 - I was taking the cancer drug Gleevec (also called Imatinib), however, I read some alarming reports of people who took it having heart attacks, so have come off it. The only drug I take at present is warfarin to thin my blood. I had 2 pulmonary embolisms in March 2004 and was very poorly - have been on warfarin ever since. On 26th June this year I had an MRI scan. This shows slight growth on the main tumour, although this could be scar tissue. Secondary tumours on lungs and liver are currently static. Scan showed up a lesion on my spine, however, the Consultant who treated me in New York says it is from the very strong radio therapy I had back in November 2004. The scan also showed that I have pneumonitis (inflammation) in the lining of the left lung - also probably from the effects of radiotherapy. This is giving me some pain, which I'm able to manage. Nov 2009 - had a PET scan in July - didn't get the results until October, so thought all must be well. Unfortunately the cancer has now spread to my right lung; have 2 small tumours - one is 5 millimeters and the other 7. The Oncologist doesn't want to treat them - just 'watch and wait' as they are very slow growing. Feb 2010 – I have been having problems with swallowing since Jan 2009. A pet scan carried out in February 2010 showed that my primary tumour has grown and is pressing on my oesophagus making it narrow and causing me

TM0810	1-Oct-2010	EHE - Lungs and skull base tumour of the Clivus and Petrous bones. Dec 2008 - just had a tumour removed from my head by way of a suboccipital craniotomy. The pathology report indicated EHE. I am waiting for my surgeon to present my case to the brain tumour board of Mount Sinai Hospital in N . Jan 2009 - My case was presented to Mount Sinai's ENT and Brain Tumour boards in NYC and It has been determined that I need radiation therapy. It will be done 5 days a week for 5 weeks followed by boost of pinpoint fractionated stereotactic radiosurgery. I did have a PET/ CT scan done with and without contrast and no other tumors have been identified. I will have repeat scans every three months and as needed. I am returning to work on Monday following 6 weeks of post-op recovery. Surgically I feel well however, I am still having daily headaches and occasional blurred vision. Mar 2009 - I have completed 6 weeks of conventional radiation. I have 4 weeks off then I have a repeat MRI and if indicated I will have stereotactic radiosurgery for the remaining tumour. Oct 2010 - I now have four new lung nodules found in my right lung when I went to to Emergency department for severe sharp pain in my back. The nodules are 3 mm so now I'm being monitored every three months for growth. They will not biopsy the nodules due to the small size of the nodules. I am certain the constant dull pain I feel is do to EHE of my lung. I am anxious and scared sitting and waiting for these tiny nodules to grow large enough for them to biopsy safely. The clival tumour remains stable with no further growth noted since my treatment.
TM1212	1-Oct-2012	Diagnosed with Stage 2/3 EHE behaving like an angio sarcoma because of a higher grade than typical in EHE (2/3, KI-67 40%) 2012 - My mass was discovered due to a slip and fall in the bathroom that started compressing my sciatic nerve. Mass has since been removed on October 24, 2012 but EHE has spread to my lungs. I have 4 nodules in my right lung and 2 in my left lung. Doctors here are recomending aggresive chemotherapy options include adriamycin/ and gemcitabine/docetaxel. I have an appoitnment with Dr. Wagner at the Dana Farber Oncolocy Center in Boston, where Kris Carr is being monitored.
TR1015	1-Jan-2015	HEHE End of September 2010 - My father went for a regular checkup and abdomen ultrasound was slighltly suspicious. CT Scan was recommended and after reviewing the scans doctors ordered a liver biopsy. Biopsy was carried out at a leading institution in Mumbai, India and they provided the diagnosis as soft-tissue sarcoma with no subtype. Multiple lesions were reported and the largest one was about 6.8 cm. in the left lobe. To get the subtype we had the biopsy slides sent to me and I had them reviewed at University of Michigan. December 20, 2010 - doctors confirmed it was a HEHE (Hepatic Epithelioid Hemangioendothelioma). Doctors in India have a lot less experience so I am trying to understand the treatment modalities. Given that HEHE is rare and indolent and my dad is asymptomatic, does a wait and see approach make sense? Oct 2012 - He is on a "wait and see" approach. His tumors have grown slightly but doctors are not advising chemo treatments yet. Surgery is not an option for him. January 2015 - Stable. Scan in March.
VD1015	1-Oct-2015	EHE in liver Diagnosed 2010 Age: 32 Years. 10 tumors in the liver without metastases in other organs. The tumors had a size from 2cm-6cm. No treatment with chemo or other therapies, just wait and watch. I just take dexamethason (20mg per day) against my pain in the stomach. 2011 - a successful Liver Transplant. Til today no recurrence or metastases with EHE. 2012 - at the age of 23 years I was diagnosed with a Hodgkin-Lymphoma Stage 4B. I had a chemotherapy (Beacopp eskaliert with 8 Cycles). October 2015 - I’m in complete remission. Also I was diagnosed with Hashimoto Thyreoiditis in 2009.
VG0114	1-Oct-2015	EHE in Liver and lungs May 2014 at age 12 diagnosed. She has 4 tumors in her liver ranging from 1.75 cm to 5.75 cm. The largest 2 have shrunk nearly in half since treatment but have remained stable the last few scans. She also has 20 plus tumors in each lung ranging from 1-5 mm in size. June 2014 - She began 4 mg sirilomus, and increased to 5 mg in June of 2015. She is with Dr. Karen Fernandez with St Jude clinic in Peoria Il and she consults with Dr. Adams. October 2015 - __________ scans again in November. She sees a pulmonary functioning specialist in December due to a poor result on her pulmonary functioning test in Aug.
VJ0715	1-Jan-2015	EHE in my liver and Lung Diagnosed January 2007. First treatment was chemotherapy with adriamycin and ifosfamid but this doesn´t work. The next option was Lenalidomid 30mg/day. This slowed down the growth of the liver Tumors. The Tumors in Lung are without a change since 01/2007. Also no new Tumors were found since lenalidomid therapy was started. Because of the slow growth of the liver tumors that has taken almost 65% of my Liver, we decided to make a Liver Transplant. Sept. 12, 2008 - Transplanted. I stayed in Hospital for only 10 days. I have no pain and I start to work this week. On the last scan the Lung tumors are without any change. The new Liver looks very good without any dark spots. So i am hopeful and start my new life without cancer. Aug 2012 - after my transplant in 2008 there is no sign of a reccurent tumor. Tumors in lung are still stable. All is fine. Still on Rapamune immune blocker. January 2015 -stable, no reccurence
VW1111	1-Sep-2011	EHE in Lungs September 2011- Diagnosed at the Virginia Piper Institute in Minneapolis, Mn. I am their 1st case of EHE that they have seen. I first went to the doctor because I was having problems with my voice. After eliminating allergies, reflux, post-nasal drip, I went to an ENT to have a scoping of my throat and found out my right vocal cord was paralysed. I had a CT scan of the neck and chest to make sure there was no damage to the vocal cord nerve and that is when multiple nodules were found in my lungs. I have approx. 16 nodules in my lungs, not all are cancer some are calcified. I also have 3 enlarged lymph nodes in my abdominal area, two behind my stomach and one left of the liver. I have been having slight symptoms: lack of energy, nausea and night sweats. I have been an active & fit person to this point. I went through 3 months of tests and procedures before being diagnosed with EHE. I am going to Sloan Kettering in Manhattan, NY for a second opinion and will come back to Minneapolis for treatment.

WA0611	1-Nov-2015	HE Winter 2006 - a lump on the left side of my neck was diagnosed as a lymph node. Jan 2007 – Lump still evident. Biopsy diagnosed Hemangioendothelioma. Referred to Dr Edward Levine. Aug. 2007 - surgery to remove the vascular tumour which the cancer had spread to 1 and 1/2 lymph nodes. He also removed 11 nodes on that side of my neck. A week later the test results showed they got everything and the radiologist suggested no radiation at present, but a wait and watch approach every 6 months. Jan 2011 – Due for scans, bloodwork, etc next month. I have noticed in the last 6 months + that I have more headaches (have had them my whole life tho) and out of nowhere occasionally I will get an unbearable pain. Doctor is aware of it and not concerned. November 2015 - All clear, no recurrence.
WB0715	1-Jul-2015	EHE in Liver and possibly lungs 2007-2014 - Annual stomach aches, from discomfort to severe pain. June 2014 - Finally saw a GP who suggested an ulcer. July 2014 - Ulcer medication unsuccessful, gallstones suggested, referred for an ultrasound. Sep 2014 - Ultrasound revealed a large 7cm tumour in the right lobe of the liver and 2 smaller tumours in the left lobe, which had begun to join together. Initial suggestion, which I was not informed of, was secondary cancer. Sep – Nov 2014 - CT scan, MRI and biopsy at the local hospital did not result in a diagnosis, the doctor was puzzled and referred me to a Liver Unit in Cardiff, Wales. Dec 2014 - Diagnosed with EHE by an MDT in Cardiff and 3 nodes mentioned in lungs. January 2015 - Tumour in right lobe of liver resected, with clear margins (45% of liver removed). April 2015 - Tumours in left lobe of liver resected, with clear margins. July 2015 - Bone scan is clear, I will be scanned every 6 months to check for recurrence in the liver and any change in the lung nodules. All doctors seen are reluctant to class the nodules as EHE so far, but admit it is possible. The nodules are too small to biopsy or resect. I have been symptomless, apart from the aforementioned stomach ache, roughly once a year since around 2007. It has been suggested that it was caused by the tumours bleeding and irritating the organs in the abdomen.
WC6715	1-Apr-2016	EHE in lung and pleura March 2015 - 48 years old non-smoker and non drinker, extremely fit and healthy. Developed flu like symptoms with a bit of a fever and the doctor said it was a virus and gave him antibiotics. A week after he finished the antibiotics had the same symptoms so was given another round of antibiotics. A week after the 2nd round, developped severe cough. June 2015 - blood tests, X-ray and CT scan. He was told that it looked like he had cancer on his right lung. He then had a CT guided biopsy and a bronchoscopy where now the top lobe of his right lung had collapsed and the surgeo Mr Adrian Pick from Melbournes Cabrini Hospital - said the tumour had to be removed. July 23 2015 - They had to remove the top and middle lobe and after analysing the 9cm tumour, found it to be EHE. Our surgeon thought that patient should have radiation treatment ASAP as he said there were no margins and although he removed everything he could see, that there would still be microscopic cells left. Our oncologist professor at Peter MacCallum in Melbourne, Anne Hamilton, decided on the watch and wait approach. PET scans 12 weeks after operation showed a small lesion at the same site and fluid in pleura and chest cavity. Then the pain started. The pain kept increasing and got quite severe. We were told it was possible nerve pain, possible pain from fluid or referred pain from the tumour. We sought another opinion from oncologist Dr Vinod Ganju from Frankston Private - Southern Oncology. As the pain was ever increasing Dr Ganju ordered a PET, MRI & CT where if was found that there was more fluid and the lesion had grown. He was organizing treatment with pazopanib and that's when the Drs from Peter Mac decided that chemo would be the better approach, so patient commenced 3 cycles - weekly 3 weeks on, 1 week off with Taxol (Paclitaxel). Patient coped well with the chemo with the pain almost disappearing during the whole of the first cycle but then pain returned on each week off. CT scan after the 3 cycles showed that chemo effect was minimal and what was thought to be the fluid was actually the tumour. The doctors had difficulty working out whether it was fluid or solid but whatever it was it was filling up the chest cavity and pushing and squash the organs around it causing pain and discomfort. Following an ultrasound it was determined that the tumour was part fluid and part solid - they described it like being a full sponge. After a round table discussion it was determined that the best course of action would be radiation therapy. The surgeon plus another from Peter Mac said surgery was not an option at this stage to try and remove the tumour given its part fluid/solid state and how big it is. February 18 2016 - Radiation therapy began and there will be 10 sessions. A CT review will probably happen 4 weeks after the radiation therapy stops. April 2016 - The radiation stalled growth and now he has just started pazopanib. Since radiation finished he had some great weeks then went downhill with a lot of fluid buildup and severe pain in certain areas.
WD3815	1-Dec-2015	EHE in lung December 2014 - Something suspicious was found in a routine, follow-up chest x-ray for my lumpectomy in 2013. March, 2015 - I had a CAT scan followed by a PET scan which further defined the area in question and confirmed SUV of 4.5. April 22, 2015 - EHE Diagnosed by needle biopsy. Confirmed also by Mayo Clinic. May 29, 2015 - Resection Age:77 Tumor location: left anterior mediastinal surface of upper left lung lobe Tumor size:6.0 x 5.5 x 2.4 cm, Tumor depth: N/A, Low grade, Surgical margins: Tumor involves multiple surgical margins, Procedure: *Marginal resection* At the same time, a typical carcinoid tumor (1.4 x 1.0 cm) (low grade) was removed from my left lower lobe lung. I have had no further procedures done since the surgery. A CAT scan is scheduled for December, 2015. Watch and wait. December 2015 - Everything stable. Previous cancers:Melanoma in upper left arm (1999).Wide-margin excision.Very small size.No further treatment or reoccurrence.DCIS in left breast in 2013. Lumpectomy. Treatment: 23 radiation treatments and taking Tamoxifen through September 2018. Other medical history: numerous surgeries including: tonsillectomy, appendectomy, hysterectomy, oophorectomy, salpingectomy, cholecystectomy, left and right knee arthroplasties, and left hip arthroplasty. Family history: mother lost an eye to cancer at age 41, but had no further occurrence of any cancer during her remaining 41 years; sister died at age 75 of myelodysplastic syndrome.

WL9215	1-Nov-2105	End of February 2015 - bad side and back pain started. After multiple trips to ER with CT scans showing calcified nodules (which we were told were nothing to worry about, mis-diagnosis), and Pulmonologist. June 9, 2015 - diagnostic surgery was done. Surgery consisted of wedge resection, removal of inflamed tissue, removal of a now live nodule. These samples were sent to University of Michigan hospital. June 23, 2015 - Diagnosed at age 23 by University of Michigan. July 4, 2015 - Met with Dr Schuetze at UofM hospital. Recommended and started Interferon around 7/15/15 with dosage of 5 ml and increased dose to 7.5 ml mid August. September 16, 2015 - CT scan showed stability in tumors and Dr Schuetze thought slight decrease in inflammation. For pain and inflammation taking Gabapentin (600 mg 3 times per day), Methadone (2.5 mg 2 times daily & 5 mg once per day) Tramadol (100 mg 4 times daily), Motrin (400 mg every 4 hours). October 15, 2015 - applied a tens unit which has provided the most pain relief. Pain seems to be somewhat controlled now with use of medications and tens unit. We stopped the Interferon, she started having issues with her liver and they felt it caused her autoimmune hepatitis. She is taking prednisone for the autoimmune hepatitis and inflammation. The only other anti inflammatory is motrin, none of the prescription ones seem to work for her.
WS0015	1-Nov-2015	EHE of Superior vena cava, surrounding tissue, and lymph nodes June 2014 - it was determined that I had Superior Vena Cava tumor. Aug 18, 2014 - two veins removed as a result of biopsy performed during surgery. Epithelioid Hemangioendothelioma with atypical/malignant features, involving the innominate vein wall and extending into surrounding tissue approx 0.8cm extending to cauterized margin, also involving inked and cauterized peripheral margin focally. 1.5 cm in greatest dimensions. EHE arising from the vein wall extending into surrounding soft tissue 2.5 cm with partial luminal occlusion with focal direct extention into one adjacent lymph node. 1/4 lymph nodes involved. 23 treatments of radiation to make sure the margins were clean. Early Jan 2015 - Ended radiation treatment. Nov 2015 - Four spots on lungs, 2 on each side, probably unrelated to EHE, on Xarelto for blood clots, stable.
WT0015	1-Oct-2015	suspected EHE in Liver August 2014 - Pain in Right Upper Quadrant. CT showed numerous tumors on both lobes of the liver, largest 3.1X2.3 cm. Biopsy is inconcusive. Doctors suspect EHE by the way tumors look on imaging. A 5 mm lesion in the pancreatic head. No treatment. January 2015 - MRI showed stable liver tumors. October 2015 - Seeking a second opinion in Stanford.
YB6614	1-Nov-2015	EHE in lungs. September 2014 - diagnosed with cancer. I then was 48 years old. At first they thought it was mesothelioom cancer, but when i went to the Antoni van Leeuwenhoekziekenhuis in Amsterdam, they did a thoroscocopie and discovered it was EHE. November and December 2014- before they knew it was EHE they tried chemotherapy. I got cisplatin. But unfortunately it was not the right chemo and it grew a little bit. November 2015 - Since January 2015, I am on a watch and see treatment. I only get a CT scan every 6 months. The EHE is located in both my lung tissues. There are many nodules but all under 2 centimeters. One nodule is about 1.8 centimeter. For the pain i have to take paracetamol, amytriptiline, and diclofenac on a daily basis and a plaster with 75 mg Morphine. My doctors name is Dr. Steeghs.

Deceased Patients

Patient ID	Misc	History
0A8600	Dx 5/2004aged 18 Update June 2008	JUST FOR INTEREST _______ and _______ are identical twins. May 2004: _______ was tested when _______ was diagnosed with EHE. Lungs/liver are clear but ribs are suspect; not yet confirmed as EHE. Now contacting other major cancer centers for consultation, including Memorial Sloan Kettering and M. D. Anderson July 2004 – Tests show that ______ does NOT have EHE, though she does have some CYSTS on the liver. Is on the same organic diet as her sister, and is being monitored. June 2005 – Does not have EHE. No need for continued reporting.
0A8604	Dx 5/2004 aged 18 Update Aug 2008	DECEASED EHE in liver and lungs _________ and _______ are identical twins. May 2004: patient's EHE was diagnosed with needle biopsy as result of routine college entry physical exam. Over 100 lesions on lung. Malignant sarcoma in liver. Now contacting other major cancer centers for consultation, including Memorial Sloan Kettering and M. D. Anderson. June 2005 - Things have been hectic and patient is off to college. She is using a trial version of a treatment as well as an all organic diet. Aug 2008 - After years of battling the disease, ________ passed away on August 5th. she suffered heart failure. She had been living in pain for most of the past two years. ______ had changed her diet to organic food, and living a healthy life, despite that her battle was lost. The last year she was in and out of the hospital more frequently as she continued to have problems breathing. The tumors in the lungs supposedly were not getting larger nor were they diminishing. She tried acupuncture and as well as other alternative methods to control the disease, but to no avail..
0A8905	Dx: 2005 Aged 16 Updated Oct 2005	DECEASED Hepatic EHE Sep 2005 - Diagnosis following a liver transplant for what was initially thought to be Budd chiari disease. There were further cells discovered in the portal veins to the new liver and now a suspicion that it may be invading lungs, spine and abdomen too, because of severe pain, difficulty breathing and her anorexia which despite a parental feed direct into the stomach, she is now only 5 stone (32kg). She was started on chemotherapy but developed sceptacaemia and was too ill to continue. Oct 19 2005 – Sadly Patient has passed away.
0B3905	Dx 3/2005 Aged 64 Updated Dec 05	DECEASED EHE in ankle, shin and hip bones. 2003 - Ankle pain for over 2 years following an accident at work. X-Rays showed significant bone and ligament damage. No therapy was relieving the pain. March 2005 - Diagnosed with EHE in bones of left ankle, tibia and hip. April 2005 - Had radiotherapy course. Using crutches full-time to alleviate any pressure on leg bones. Has changed diet, using organic food, using massage and shiatsu treatments and meditation. Nov 2005 - Fell and broke the femur 4 months ago and this seems to have set the EHE off on a rampage. Has had a second lot of radiation therapy after the site of the break was found to be cancerous but this had no effect. The EHE is spreading quite rapidly in his legs especially in the leg which suffered the break and is affecting his bone marrow's capacity to produce blood, so receiving blood transfusions but very low in energy. Dec 3 2005 - Sadly, patient died. A peaceful death, we had amazing and precious time with each other in the weeks before and he was lucid 'til the moment of his death. The EHE in his right hip and leg became uncharacteristically very aggressive very quickly, the treating physicians were taken aback at the change.
0C2304	Dx Aug2004 Updated Oct 2004	DECEASED EHE in multiple bone sites Sept 2004 - EHE confirmed by surgical biopsy (Dr. Eckhardt at UCLA) left leg lesions on femur, tibia, & fibula. Initial symptoms were low grade fever in the afternoons, and fatigue. Blood tests showed high sedimentation rate, high C-Reactive protein and low sodium. Was anaemic, and had very low sodium. Had several units of blood, stabilized her sodium, and started IV antibiotics in case the high sed rate was because of an infectious process. Two weeks later, suddenly her calcium levels spiked up, making her almost comatose. Her hypercalcemia was stabilized in ICU with fluids and pamidronate. A PET scan showed lesions in the spine and one on the pelvis. Doctors in SB now question the EHE diagnosis, partly because of the multiple lesions, and partly because of the hypercalcemia not being mentioned in the cases they found in the literature. Gorham-Stout syndrome was discussed, as was the possibility of a more agressive form of cancer. They honestly are "stumped", and referred us to a larger regional hospital. Patient has decided that they have done enough testing, and does not want to go to Los Angeles. We have decided to monitor her blood chemistry carefully, stabilize her calcium levels if possible, and hope all the lesions are EHE and slow moving. Oct 2004 – Sadly, my mother has passed away .

0C7604	Dx 3/2004 aged 28 Update Mar 2006	DECEASED EHE in above one breast, in a lung, in stomach, vertebrae and spine. March 2004 - After 4 years of severe back pain following an injury, and limited mobility, until about 10 weeks ago when I had a "sebaceous cyst" removed, only it turned out to be a tumour instead. Currently taking methadone for pain, plus gabapentin & celebrex. Dec 2004 - Methadone was way too strong. Taking Celebrex twice a day, as well as using Fentanyl pain patches. Found a new tumour on my head, so had it and larger one above my right breast removed. Had a collapsed right lung 2 days before the op, but ok now. Doctors found LOTS of new tumours and 'problem areas' in various bones showed up in lot of scans. April 2005 - Cracked pelvis!! May 2005 - Having a few weeks of radiation at the moment and got approved for Avastin trial. Having APD (pamidronate) infusions monthly. Up to the full fentanyl patch, plus taking Oxynorm for pain + anti-nausea stuff. Got ongoing pain above right knee, and in right hip and lower back. Still on crutches & making a slow recovery from fractured pelvis. Aug 2005 - The pain in my hip is excruciating. I developed an ulcer and have lost a lot of weight. Virtually bedridden these days Feb 2006 - started chemo using Carboplatin, Ifosfomide & Etoposide. Shortness of breath - Got oxygen at home for when needed. Mainly bed-ridden, but vastly improved pain levels. Taking Celebrex for inflammation, Dexmethasone for nausea, appetite, & energy, and Fentanyl patch. Got very sick leading up to Christmas, losing about 20kg in a few months. Currently trying to healthily gain weight and energy. Mar 2006 – Sadly patient passed away earlier this month.
0C8805	Dx 1/2005 Aged 17 Updated Jan 2005	DECEASED EHE - wrapped around an artery behind the lungs and spread to the lungs Jan 2005 - trialed chemo. Feb 2005 - Starting chemo regime of 5 days long so he will be spending 6 days in the hospital every 3rd week. Medications: Vincristine sulfate, Mesna, Cytoxan, and Adriamycine. He is also still on morphine and neurontin for pain (he is in a substantial amount of pain all the time), zofran for nausea, bactrim (an antibiotic) and protonics. It still amazes me that this illness wasn't caught earlier on, particularly given the amount of weight my nephew lost over the past year. He is now down another 20 pounds since going to the hospital for a total of 60 pounds lost! He is skin and bones! March 2005 - Tumors have spread very aggressively and there is nothing more the doctors can do. Patient wanted to be home so the doctors released him from the hospital on Friday with his oxygen tank and plenty of medication. Hospice is coming to the house to help care for him. May 05: Sadly, my nephew died on 4/26 after a brave battle against EHE. He was only 17. He lasted only 3 1/2 months from his initial diagnosis to his death.
0D0005	Dx: 2005 Aged Updated Sept 2005	DECEASED Hepatic hemangioendothelioma 2005 - One of my best friends is diagnosed with this rare disease originating from her liver. We are from South Africa and the Oncologist treating her is not even familiar with this type of cancer. September 2005 - Patient passed away.
0D6287	Diag 2007 Aged Updated Aug 2007	DECEASED EHE in lungs, neck and spine July 2007 - My sister in law was diagnosed 20 years ago and told she had an average of 5 years to live. She has had NO treatment whatsoever. She basically ignored it, lived her life, ran a marathon, worked hard, married, etc. Basically, felt great. She was doing fantastic until about 2 months ago. It's the pain that's the worst part for her. Doctors are trying to manage her pain. She literally wakes up screaming in pain and my mother in law is with her 24/7. A surgeon came into look at her and said possibly surgery was an option - to remove the tumor pressing on her spine or they will just manage her pain. Aug 2007 – sadly my sister has lost her fight against this cancer.
0D6607	Diag 2007 Aged 41 Updated Aug 2008	DECEASED EHE of the penis July 2007 – felt a lump in the penis. Tests indicate EHE. Awaiting surgery. Sep 2007 - Doing well. I only had to have a partial penectoy and am now at home recovering. I go back for another CT scan on the 19th to check and see if they will have to remove my lymph nodes ... this one will be a full upper body scan as they think there is something on my lungs as well. Nov 2007 - CT Scan results in - not good lymph nodes at the top of legs are coming out. Jan 2008 - They have taken a total of 20 nodes out but saw "something" in there so gettig another scan as soon as I've healed from this one. April 2008 - Saw plastic surgeon as next operation will leave a big hole inside so they are going to move some muscle around. June 2008 - Due for another operation on lymph nodes and a bit more from the top of my legs July 17 2008 - Patient was released from hospital on the 11th July but unexpectedly passed away 6 days later. It was not the EHE that killed him but a blood clot to his lung and as the coroner said, it was a recognised complication of surgery.

0G4303	Dx 2003 aged 60 CODE: 16IT02 Update Dec 2004	DECEASED HE in thyroid, spread to brain and lungs. Was originally diagnosed as thyroid cancer. Has had surgery on her neck and throat. Considering radiotherapy. Oct 2002 - Sudden trouble in breathing. Tumors in lungs are growing. Dec 2004 - My aunt is now in the hospital getting Chemo. Mar 2005 - Apparently, my aunt's cancer is a direct result from the radiation cloud that drifted down from Russian when Chernobyl melted down. She is now on a new drug that has slowed the progression of her cancer. I do not know what its name is, but I do know that it comes from Canada. Her spirits are Ok and she does venture out on her own to get fresh vegetables and flowers on a weekly basis, I am grateful that she is mobile and does venture out with her girlfriends. My aunt is at home resting. The doctors believe they have run out of options for her. 9 June 2005 - Sadly, patient passed away today.
0J0005	Dx: Mar 2005 Aged 10 Updated Feb 2006	DECEASED EHE in spine Nov 2005 - The oncologist recomends surgery to remove T4 & T5 and partial resection of the ribs attached as well as the soft tissue involvement. Patient is having considerable pain in his back and chest. He is now taking Celbre twice a day and using Percocet to help him at night to sleep. The orthopedic oncological spine surgeon that we saw the end of October told us that the cancer had spread from its original location in T4 and is now in T5 as well. Feb 2006 – Patient has been going to a pain management center but they have been unable to control his pain. He can't take any of the morphines they make him severely nauseated. He can only lie down for about two hours at a time, he cant sleep. Taking Lortab to try to ease pain. Follow up MRI showed tumor has spread to T5 as well and the lytic process in T4 is progressive. His only option is to agree to the surgery even though there is no way to ensure they will get all of the tumor. We are hoping that it helps the pain. They will be operating on March 6 Sadly Patient has passed away
0K9005	Dx 2/2005 Aged 15 Updated May 05	DECEASED Hepatic EHE Feb 2005 - l5 yr old daughter diagnosed with HEH confined to the liver. March 2005 - Liver resection (3/4 of liver removed entire right lobe and section of left). Vinblastine 3 mg weekly and Avastin twice monthly 9th May 2005 - Thank you for all your support, but my sweet l5 yr old baby lost her battle with this horrible disease yesterday afternoon after only being diagnosed on Feb 22, 2005
0L4807	Diag Mar 07 Aged 59 Updated May 2007	DECEASED EHE in lungs and liver March 2007 - coughing up blood. Scans, etc, sent to a Dr. Colby from the Mayo Clinic in Scottsdale, AZ to review. May 2007 - Sadly, patient passed away on Tuesday. She underwent 20 radiation treatments on the mass on her lung. The mass hadn't grown but the EHE had spread throughout her abdomen really fast - like in three months.

0M6706	Dx: 6/2006 Aged 38 CODE: 108UK06 Updated Mar 2007	DECEASED EHE in both lungs and also in the mediastinum close to the aorta and pulmonary artery. May 2006 – diagnosed, although under investigation since Jan 2006. The solid tumour in the mediastinum is not resectable and there is also a tumour in the third rib. Liposomal doxorubicin and Avastin have been recommended. Currently in work and not feeling too bad, but has to take regular ibuprofen and paracetamol for pain and night sweats. He has also been prescribed amytryptyline to help him sleep but this does not seem very effective. Aug 2006 – Having 40 mg/m2 liposomal doxorubicin (Caelyx/Doxil) and if he tolerates this will have 6x4 weekly cycles. The main side effect so far is heart tachycardia. Although patient had this beforehand it seems to have been potentiated by the chemotherapy, and he has now been switched from sotalol (beta blocker) to veramapil (calcium channel blocker) to control this. This is due to the position of patient's tumour in the mediastinum, it is irritating the sinoatrial node of the heart. Sept 2006 - A sample of patient's tumour has been sent for RNA. Results are ESR1 (Estrogen receptor alpha) - suggests tamoxifen therapy? KDR/flk-1 : one of the VEGF receptors,VEGF NM_003376: ligand for VEGF Receptor - Suggests Avastin therapy NM_002609 Homo sapiens platelet-derived growth factor receptor, beta polypeptide (PDGFRB), mRNA, PDGFRA NM_006206 ,KIT NM_000222 - All three are inhibited by Gleevec, the BCR-ABL inhibitor that also is active in GIS because it also inhibits KIT and PDGFR!! The sample has both KIT and PDGFR expression. PRKCB1 (M13975). - the target of an experimental Lilly drug that is used in clinical trials in Leukemia. Patient is now on tamoxifen (estrogen receptor blocker) and we are planning to add in Avastin as VEGF and the VEGF receptor are expressed, and if this combination is tolerated, Gleevec. Nov 2006 - Scan results after 3 months of liposomal doxorubicin, and a couple of doses of Avastin (these were the baseline scans for Avastin). The main tumour in his chest has shrunk a bit which is great news, but he has metastases in both kidneys, illiac bones, T6 vertebra, and 2 ribs. Some of these (vertebra and illiac) are new to us, although I think the consultants suspected these from the previous scan, and all have grown a bit. So strange results with the main tumour shrinking and the others growing. March 2007 - Patient died on the 13th March. It was very sudden. Unfortunately the location of the tumour wrapped around Patient's aorta and in his left lung lead to a major haemorrhage. He died very quickly. We had only just returned from visiting Dr Lederman at Radiosurgery New York, where another EHE patient was also treated, and were expecting him to get better. I would strongly recommend that anyone who has EHE around the aorta visits Dr Lederman early. If Patient had been treated earlier I think he would still have been here.
0R4704	Dx: 10/2004 Aged 60 Updated July 2007	DECEASED EHE in lung, artery, heart, ribs, backbone, hip Aug 2004 – told he had pneumonia. Oct 2004 – rediagnosed as 'some' cancer. Dec 2004 - very ill. Hospitalized due to horrible infection. At that time the tiny spot on his right lung was the size of a baseball and the cancer has just eaten away his lung leaving a hollowed spot in his lung that caused the infection. Lost about 50 lb in a month. Diagnosed as EHE. Jan 2005 - they tried to remove his lung. They were unable to because the cancer was growing around an artery that went to his heart. Tried chemo carbo taxol 2 rounds and taxitiere 3 or 4 rounds. Once every 4 weeks. We thought that it seemed to be working. He had to stay on antibiotics for the next year to keep infections down. Aug 2005 - Retired from the Navy and moved to NC to be closer to family. July 2006 - Doctors wanted to try and remove his lung again. This time it had spread to a chamber of his heart and was on several of his ribs. They thought about doing radiation but decided not to because it might kill him. Sept 2006 - started Chemo again this time with Doxil once again every 4 weeks. Oct 2006 - admitted to the hospital for back pain. They found that the cancer had spread to his backbone and in his right hip. Radiation treatment everyday for 2 weeks. The doctors have told us that all of these thing are for palliative purposes only. Dec 2006 - Latest CT scan looks worse than before. Doctor is calling Hospice to help us. Nothing is working and he feels that my husband needs to not continue with treatment as it makes him very sick. As of today he has lost over 40 lb in less than a month and he has spent the last 3 weeks in bed literally sleeping about 23 hours a day. Current medications are Augmenten, 2 different doses of Oxycodone, and today the doctor put him on Marinol which is the active ingredient of Pot. May 2007 - Patient has been on hospice since Feb. He has switched from oxycotin to morphine pills and liquid. His left arm began to swell in March and it was found that the cancer had spread to his shoulder and he also had severe blood clots in both shoulder areas. He was on Lovinox for a month which also included a brief hospital stay. He also had 2 weeks of radiation treatments to try and control the pain. He is not doing very well.. We are just taking it day by day. July 2007 – Sad to report that Patient has passed away
0R7505	Dx: 05/05 Aged 29 Updated Aug 2005	DECEASED HE in lining of both lungs Feb 2005 - Went to the Dr. for severe left chest pain and side pain - misdignosised with pleuralcy. He did 2 rounds of pridizone. May 2005 - Was taken to the ER with shortness of breath and severe pain. An xray showed a moderate left pleural effusion and a small right pleural effusion. After having a VAT's procedure (Visual Assist Thoracintisis - entered th left lung and drained 1 liter of fluid, did biopsies, and filled the pleural space with talc), patient was diagnosed with HE in lining of both lungs as well as the chest cavity. The doctor has said that it is acting very aggressive. It is in a stage 3 or 4. Patient is in constant pain and is now required to be on 4 litres of oxygen at all times. He is very short of breath when he walks, even on the oxygen. He takes morphine for the pain which does not always control the pain and he also vomits a lot. He has been on tarceva for 30 days and we are waiting for scan results. Our doctor has suggested that we go to MD Anderson for a second opinion but at the moment he thinks patient is too sick to travel Aug 2005 - Patient passed away on Aug 4. His disease had progressed to both lungs and so fast that there wasn't anything else to do. Our sympathies to his loved ones.

0Z0003	Dx: 12/2000 Aged Updated Jan 2008	DECEASED EHE in lung and bone October 2002: initial diagnosis of multiple pulmonary nodules. December 2002: diagnosis on broncoscopica biopsy of carninoma not to small cells. Confirmation moreover litiche lesions bony (between vertebre ridges). February - June 2003: chemotherapy with CDDP + GCB, + Zometa July 2003: VATS with biopsy of pulmonary nodule. Diagnosis by The National Institute Tumors of Milan (Dr. Casali): EHE. September 2003: Radiotherapy to reduce the pains in D1,D2 and L2-L5 (30 Gy totals) TAC thorax and abdomen. Small increment to some pulmonary sites, others stable.. August 2004 - December 2005: Cure of Dr. di Bella, with disease stability. December 2005: TAC thorax + RMN (magnetic resonance) rachide back-lumbar: Atelettasia pulmonary lobe inferior right. RX river basin: litica lesion to cargo of the left crest of ilium. February 2006: Thalidomide 300 mg to the day, for 3 months, then interrupted due to pulmonary progression. September 2006: treatment with PEGINTRON (INTERFERONE) 80 and 100, stopped in December for intolerance (myalgias) - reduction of disease to pulmonary level. June 2007: radiotherapy Sept 2007: My brother today has strong pains to the hip, right arm and the back. Using cortisone, toradol, and bentenal. No other treatment. My brother is mechanic, working when able. Dec 2007 – sadly passed away on 21/12/07 from Intestinal bleeding
BA4909	Dx 2009 Age, 60 Updated July 2009	DECEASED EHE in lungs Feb 2009 - started with a dry cough in February. I had an x-ray that showed spots on one lung. I then had a CT scan which was inconclusive. I had a bronchoscopy and they were able to biopsy tissue and make the diagnosis. Unfortunately a PET scan showed that it has spread considerably to lungs, adrenal glands and lymph nodes and my shoulder blade. June 2009 - I was just diagnosed this month so still have not seen an oncologist for any treatment (surgery is not an option). The "alternative" information I have been reading also encourages change to diet. I have pretty much stopped dairy and meat and sugar, although I find that I need to eat some animal protein sources for now as I'm losing weight. I'm doing all I can to help my body's immune system through yoga, meditation, etc. July 2009 – __________died.
BB0006	Dx: 04/2006 Aged Updated Feb 2008	DECEASED EHE in liver and lungs Sep 2006 - surgery to remove a mass of 2cm. I have a number of small nodes remaining in both lungs. I have 2-3 substantial tumors on my liver which we are watching to see what kind of activity they have. I do have some pain o and on with my right abdomen which is supposedly assoc. with the liver. Anxiety and Depression have affected me a bit. June 2007 - Thorocodomy about two months ago, found more cells but nothing shows up on a scan. Was doing okay after the surgery and then about a month ago started having more pain...on percaset, oxycodone, and now on methadone for pain and nothing is touching it. Has never had a bone scan or an MRI. He is not doing well at all. In a terrible amount of pain and the doctors don't know what is causing the pain...very frustrating and scary. Oct 2007 – My brother has had CT scan, x-rays, MRI, and Pet Scan, and nothing really shows up, yet he is still in a lot of pain. My brother has no appetite and has lost 30 pounds at least. He cannot function...he sleeps and goes for walks if he can. He had his surgery the end of April, so it has been almost six months, and he keeps losing weight, is in pain, and is non-functional. They will not treat him at Rochester, MN at the Mayo Clinic because the scans aren't showing any growth. But they know there is cancer in there that is not showing up. Feb 2008 - It saddens me to write that my brother passed away on January 5, 2008. After many tests every three weeks or so, because my brother was in so much pain, a massive tumor that appeared as a sheet...just like the doctor said in Eau Claire, was covering his left lung and had totally taken it over. That was at the end of November. Then he came home for a couple weeks and left us on January 5, 2008.
BM4105	Dx 3/2005 aged 63 Updated April 05	DECEASED EHE in liver. March 2005: - Epithelioid Hemangiodenthelioma in liver confirmed by needle biopsy. Four small lesions on the liver. April 2005: - My mom passed away on 6 April and I am very sad but am managing a way to move on because she would have wanted me to move on as best I can and she always instilled lots of wisdom in me through the years, which I think will help me in this sad time. What I don't understand is how she went so fast, she was diagnosed on March 28th and then 9 days later she passed away. At least she is now in peace.

BR5014	6/1/2015	DECEASED EHE in lungs, scapula and lumbar IV 2014: Shortness of breath and coughing. Eventually coughed up blood. A CT scan showed "lesions" on my right and left lungs and on right scapula. Results of lung biopsy were inconclusive. Bone scan revealed extent of lesion on scapula. Biopsy of lesion led to diagnosis of EHE; present in lungs (full of nodules), scapula and lumbar IV. June 2014: I had a second opinion at Dana-Farber Cancer Institute with a Dr. Butrinsky. Doxil was prescribed. Doxil caused extreme side effects. Scans showed Doxil was ineffective. June 2015: Our new Dr. Is Dr. Suzane George. We continue under her care, with treatments being done lately in Peabody, Mass for convenience under the supervision of Dr. Paola Rode. The second chemo we opted for was Taxol on a once a week for 3 weeks, then an off week, schedule. This was apparently keeping the lesions stable but my breathing continued to flag. Finally, at my last appointment Dr. George suggested we drop the Taxol and go with gemcitibine on a 3 week on 1 off schedule. I have just had my second dose of this (800mg) and while there have been no scans done I do feel marginally better. Due to the past incidents my lungs are fairly well compromised, so I am on oxygen 24 X 7 now. November 2015: Worsening of shortness of breath, developed Afib, admitted to ICU and just kept comfortable, prior to saddly passing away.
CA7207	Dx: 05/2007 Aged 35 Updated June 2007	DECEASED Multiple EHE tumors Apr 2007 - CT scan shows suspected lymphoma. A PET scan confirmed four locations: lower abdomen, liver, right lung, and center of her chest. A needle biopsy confirmed EHE. May 2007 - began treatment for EHE last Monday, May 21st. She was scheduled to take 3 days of Adriamycin and Ifosfamide, but was only able to take 2 due to excessive fluid in her lungs. June 2007 - My wife died last week (June 26th) of EHE. She had completed her second cycle of adriamycin and ifosfamide, and thought that she would be going home, when things started down hill. Essentially, the extensive cancer in her lungs prevented her from properly oxygenating thus death shortly thereafter.
CC5891	Dx 1991 Aged 32 Updated June 2005	DECEASED Multiple EHE in liver, lungs and skin 1991 – initial diagnosis. – no treatment. Over time, lesions in liver and lungs changed, some calcified and new ones would also appear. Lesions on skin healed spontaneously over a period of months. Have annual CT scans. Doct uses my case as a classic example of "no treatment is the best treatment at this time" if a normal daily life can be maintained. (individual cases must be judged by the doctor for each person) Dec 2004 – CAT scan showed increase in size in some tumors and there are some new ones in the spleen. Nov 2005 - EHE in the liver, lungs, spleen, abdomen and thyroid. Last November, started getting worse and by March had ascites that required draining, was losing weight and had painful rashes over entire body. Heavy diarrhea, about 20 times per day. Required several blood transfusions due to internal bleeding. Intense pain. Also, the ascites caused an abdomen hernia which at this time is inoperable until the ascites get under control. With every test the overall condition got worse. Was put on this “serafenib” experimental drug program that Sloan Kettering is running which has been very promising, but it had adverse effects and was causing high levels of bilirubin. So it was stopped. Doctors are pessimistic. _________ decided to follow the natural, herbal path. June 2006 – Sadly Patient lost her fight with this disease.

CD0011	Dx: 09/2011	DECEASED Hepatic EHE. May 2011 – Went to drs. for a wellness physical and blood work was done. General practitioner called to advise my liver enzymes were elevated (ALT, AST and ALK-Phos). Immediately had add'l blood work done and recommended ultrasound. Ultrasound reported 5 lesions were found and recommended a CT Scan. CT Scan confirmed lesions however radiologist's report said 'not believed to be metastic' however recommend and MRI. She then referred me to Dr. John Polio at St. Francis for further evaluation. June 2011- Shared CT results with Dr. Polio. He stated that liver was enlarged, otherwise I was healthy and he would share this with his radiologist. A few days later he called to say that they believed it to be 'polycystic liver disease' and an MRI was needed. Had an MRI and 5 days later Dr. Polio called to say he had consulted with Yale transplant team and they all agreed I had a dramatic presentation and they looked like vascular tumours. Yale recommended that St. Francis do a transjugular biopsy. July 2011- I was scheduled to have biopsy and 3 days prior started experiencing severe abdominal pain in right upper quadrant under rib cage. 7/07/11 - St. Francis prepped me for the biopsy and just prior ran a CT with contrast so the radiologist could see the contrast. After the scan, the radiologist came out and stated "I am not performing this biopsy because it's very risky for bleeding and I am 90% sure it is 'Peliosis Hepatis' however I don't understand why you would have this." Dr. Polio ran tests for diseases associated with Peliosis Hepatis – HIV, Syphyllis; TB – all came back negative. He performed endoscopy & biopsied. Confirmed that I did not have celiac sprue (associated with Peliosis hepatis). All biopsies came back normal. I did not believe it was peliosis based on the medical articles I read and all test coming back negative, however, Dr. Polio still believed this to be the case. I had also set up 2nd opinion with Dr. Colin Swales of Hartford. August 2011 – Met with Dr. Colin Swales & shared details with him. He did not believe I had peliosis and requested my MRI on disk so that he could research. Dr. Swales took MRI results to Lahey Clinic outside of Boston and called to say 'it looks like a rare disease called EHE' and said only a biopsy could confirm. September 2011 - Went to emergency room with severe abdominal pain and was admitted to Hartford Hospital. While there, Dr. Swales performed a needle biopsy, however it was undiagnostic. In the meantime Dr. Polio referred me to Yale. Went to Yale for a biopsy with Dr. Rodriguez, he too believed it to be peliosis. Biopsy determined this to be EHE and found my liver adhered to my abdominal wall which he had to cut free. I met with the chief of transplant, Dr. Emre. There are numerous tumours all over my liver, the largest being 9.3 cm., so resection not an option, told I needed a transplant. Officially on the liver transplant list. MELD score is quite low. This score looks at specific liver enzymes and functions - EHE does not raise the typical enzyme that liver cancer does and typically results with tumour markers showing as negative. Diagnosed with HEH. I was added to the UNOS registry and my sister was tested to see if she could be a live donor. November 11 2011 - we got the call that my sister was a good match. December 6, 2011- I had my transplant. Liver and gallbladder removed at Yale by Dr. Sukru Emre and Dr. Maual Rodriguez-Davalos. I remained in the hospital for 2-1/2 wks, due to a large ascites pouring from my incision. At the end of my stay the doctors had informed me that EHE cells had moved from my livers large vessels to the small vessels. Also showed that the lymph node removed showed EHE in it as well. Doctors advised that I would need chemotherapy as well. I was started on Prograf anti-rejection initially and now I am on Rapamune. I believe they will eventually reduce my Prograf dose and I will remain on Rapamune. January 2012- I met with oncologist last week. He first suggested a wait and see. I am not comfortable as within a 4 month period doctors could see from one scan to another that my tumors had grown. EHE is not predictable it can be slow-growing to aggressive. My liver transplant team seemed confident that I would need chemotherapy. Based on a similar case and that patient's success, my oncologist is planning to use Nexavar and Doxyrubicin. I am supposed to start 6-8 rounds of chemo in February 2012. I've tried to contact authors of articles about HEH to find out if they have any updates on successful chemotherapies, however, no response yet. Feb 2012 - Started that chemo July 2012 - Was scheduled for 8th and last round of chemo in July 2012 when lesions discovered on new liver and spleen. Doctors canceled last round of adriamycin and started daily treatments of Nexavar. Working with Yale oncology. Tomorrow i will see Dana Farber for second opnion on treatment. On Aug 20 will see Dr. Robert Maki at Mt. Sinai in NYC for another opinion. 2014 - Patient Passed away

CE0011	12/1/2012	DECEASED EHE in Lungs, Liver, Spleen and Bowels May 2011 – Symptoms began with an uncomfortable full feeling, followed by vomiting the next morning, and another night of discomfort followed by more vomiting. I went to see my PCP who sent me to Skye Ridge Medical Center ER (Lonetree, CO). A CT scan was done which showed a small bowel obstruction, nodules on the lungs, liver, spleen and studding of the peritoneum and a bone lesion. May 6, 2011 – Surgery was scheduled and the surgeon Dr. Steven Kim did a resection of the small bowel to remove the obstruction; he also did a biopsy of my liver, small bowel, and lateral peritoneal wall. The surgeon stated tha had metastatic cancer. Diagnosis of EHE was confirmed by Dr. Christopher Fletcher of Harvard. The oncologist that I met with, Dr. Michelle Bashe of Rocky Mountain Cancer Center, also indicated that I have “peritoneal carcinomatosis”. Chemotherapy is scheduled for June 10, 2011. IV Taxol and Doxil the first week, Taxol the second and third weeks, one week off, then repeat the cycle. Repeat CT scan to check responses. I am on a mostly liquid diet plus soft foods, very limited fiber/bulk to avoid bowel blockage. November 2011 – An additional tumour was found in my right eye orbit following an MRI for vertigo and vomiting. My vision is normal and I have no visual symptoms. The vertigo has not recurred. April 2012 – I had an online consult with Dr. D’Adamo at Dana-Farber in Boston, who recommended discontinuing my chemotherapy since my tumors were stable after 7 months. I have been off chemo since mid-December and have been followed with CT scans and MRIs. Results have continued to be stable. My lower left leg pain had improved with chemotherapy and I have had some worsening of this pain since being off chemo, but it is manageable with OTC meds. I will be going to MD Anderson the second week of April 2012 for another consultation. August 2012 - I have been to MD Anderson twice now, in April & July, seeing Dr. Vinod Ravi. My CT scans of the chest, abdomen & pelvis are stable; the MRI of the tumor near my right eye is also stable. My next scans will be in months. Dr. Michele Basche continues to be my Colorado oncologist. I have continued to have left leg pain, my only significant symptom. This is treated with naproxen sodium and ibuprofen; these give better pain relief than narcotics for me. My disease was stable for most of 2012, but I continued to have pain in my left calf. Imaging and a biopsy were not able to confirm that this was related to EHE until I had my first PET scan 8/2012. I then had 13 radiation treatments to the small tumor in my calf in September & October. This treatment was managed by Dr. Dennis Carter with Rocky Mountain Cancer Center in Aurora, Colorado. The radiation was successful in relieving my pain which it is believed was caused by the tumor pressing on a nerve since my pain was out of proportion to the size of the tumor, just 1.25 cms diam. October 2012 – I began to have some new symptoms, a feeling of uncomfortable abdominal fullness after eating. This is mostly controlled by eating small portions, choosing soft foods, smoothies, and chewing food well. November 2012 - CT scans at MD Anderson showed stable tumors, but a nuclear medicine study ordered by my local Colorado oncologist showed significant slowing in gastric emptying. December 2012 - CT scans showed slight growth in my liver tumors. I had developed additional symptoms of pain in my rib cage and abdomen with deep breathing & coughing, plus some shortness of breath with exertion. Dr. Basche in Colorado consulted with Dr. Ravi at MD Anderson, and the decision was made to start me on oral chemotherapy. I am now on a 12-week course of cyclophosphamide 100 mg bid and prednisone 20 mg daily, one week on, and one week off, x 6 cycles. So far, no side effects from the drugs. I am scheduled to have follow-up CT and MRI scans in March. I am told that changes in my symptoms will be very important in guiding my treatment because imaging does not show all the tumors, including the peritoneal carcinomatosis. ________ passed away August 2014
CJ8080	Dx 1980 Aged 6 months then recurred at age 21 Updated Mar 2005	DECEASED HE in new liver, lung, bones, pelvis and spinal cord. 1980: diagnosed with infantile hemangioendothelioma in liver @ 6months of age. Shrunk with massive doses of Prednisone. Disappeared. 2001: Rediagnosed with HE once tumors were found in liver. Living donor liver transplant in June. Liver donated by mom. Operated at UPenn by Shaked, Olthoff, and Markman team. 12lbs tumorous liver removed! Placed on Prograf for liver anti-rejection. Sept 2002: Pain while sitting. Ignored until Nov. Admitted to HUP. Tumors have spread to lungs and spinal cord esp coxyxx and sacral regions...also found in new liver. Radiation therapy done (10 sessions or so) - no improvement...Interfernon started. Taken off Prograf because it was found that it causes angiogenesis. Placed on Rapamune. March 2003: Major major internal upper gi bleed. Almost died. Taken off Rapamune because in one case it was associated to G.I. bleeds..put back on Prograf. May 2003: Tumors were increasing. Dec 2003: Back in school and on Interferon. May 2004: Took myself off interferon cause I hated it and deep down knew it wasn't working. Fractured left femur playing golf, needed surgery for placement of a titanium rod in femur and from femur to hip. Right hip also deteroriating. Sept 2004: Tumors slightly increasing...put on avastin only. Oct 2004: Tumors still increasing, Oxaliplatin and Xeloda added. Jan 2005: Tumors have decreased in my lungs! and other tumorous areas are "stable." Current medications are Rapamune (liver transplant) 3mg, Celebrex 200mg, Synthroid 075 mg, Morphine Sulfate-ER 15mg, Ambien 5mg...then every fortnight during the 4 hr infusion: Oxaliplatin (chemo), Avastin, Benadryl, and Ativan. Follow up chemo for a week: Xeloda 500mg bid, and every month during chemo infusion: Zomeda for bones. Sept 2006 – Advised that Patient had passed away.
CN0005	Dx 2005 Aged 69 Updated May 07	DECEASED EHE Mar 2005: Dx EHE with rt. anterior medial steinum mass, 2 cm. in diameter and described as slow growing. Needle biopsy at Christ Hospital under Dr.Leider. CAT scan shows no other evidence of cancer. May 2005: Mass surgically removed by Dr. Wolf at University Hospital, Cincinnati OH. Unable to get clean margins due to closeness to heart. June 2005: Radiation treatment for 6 weeks to medial steinum area. Mar 2006: CAT scan shows multiple small lesions on liver. Biopsy unable to get significant tissue sample to test. May 2006: Meeting with Dr. Baker of University Michigan who recommends clinical trial with sorafenib. He also recommends another biopsy to confirm dx. of EHE. May 2007 – Sadly Mom passed away about 4 weeks ago. She had not been doing well and we had just been told she had 2-6 months. And she went sooner than we wanted. Thanks for your concern and help. The clinical trial of soranifib at Univ. of Michigan didn't help. She had been on a low dose of interferon for the past 3-4 months but that didn't help either.

CP6304	Dx Aug 2004 Updated Nov 2004	DECEASED HE of the bones 2002: pain in jaw 2003: pain in breast near the heart. Diagnosed as stress. Early 2004: Taking Ibrufen for constant pain in jaw, chest and elbows. Suddenly, massive increase in pain. Put on morphine, but not very effective. Still diagnosed as stress. August 2004: Could hardly walk. Vomiting. Admitted to Intensive Care where 2 litres of liquid was extracted from the heart. Lost 26 kilo in weight. On 600mg morphine plus others. Finally diagnosed as malignant multi-centric HE of the bones. Put on Methadone for pain. Doctor is considering Avastin Nov 22 2004 – Regretably, __________passed away today. He was in great pain. He is now at peace.
DD5304	Dx Mar 04 Aged 51 Updated Jun 2006	DECEASED EHE in liver August 2001 - Hepatitis. Doctors felt it was NASH. I was not satisfied with this diagnosis. March of 2004 - Diagnosed with EHE by liver biopsy at U. of M.. Has metastasized to lung, clavicular lymph node, and skull. January 2005 - Lung cat scan - no change; MRI - slight but measurable decrease in liver tumors. Doctor stopped Interferon due to uncertainty if it is causing vasculitis. Seeing Rheumatologist re inflamation. Feeling fairly good and continuing to teach parttime. February 2005 - Saw Rheumatologist and Oncologist. Vasculitis is continuing, although symptoms seem a bit better. Prescribed Sinequan to help with vasculitis. Oncologist feels that it is best to stay off the interferon. Suggests getting another MRI of abdomen in late March and starting a course of chemotherapy (Doxil) on April 8th. Aug 2005 - I have changed doctors and treatment centers. Doctor Eisenberg has had additional tests run on my biopsies. He is discussing regarding possible treatment with Gleevac. Nov 2005 – About to start Gleevec. But I was having some headaches. A Brain MRI showed there was no cancer on my brain, but a lesion on the lining of the brain. They are currently evaluating the situation and figuring out whether surgery and/or radiation to stop it from going to my brain. Dec 2005 - Started radiation therapy to treat the EHE on my skull which has spread to the lining of my brain. I will be treated 5 days a week for 6 weeks. A small 'lump' had developed on my scalp that appears like a keloid - smooth, slightly raised with no hair follicles, and pinkish, redish in color. I have other keloids on my arm, back, and leg previous to diagnosis. I don't believe those are related to the EHE. Dr. Hart wasn't sure what it is without a biopsy. Jun 2006 - Completed radiation therapy for HEHE on skull and brain lining in mid-January, and started on thalidomide. Side effects - felt sluggish, put on weight, some swelling in my legs. In late April, I had a bout of diverticulitis and was hospitalized, and my oncologist stopped the thalidomide. Also, scans on scalp revealed EHE, though scans showed no change at all in the skull/brain lining area. Having radiotherapy on scalp. Its a different type of ray and the treatment lasts less than a minute. This spot is more painful than the one in my skull, apparently because there are more blood vessels in your scalp, than in the bone. July 2007 – sadly _______ passed away
ET0007	Dx 04/2007 Age, 48 Updated Feb 2010	DECEASED EHE in left arm. April 2007 - Felt a growth on the top of wrist. Left hand and forearm have always looked swollen - born with abnormal amounts of fluid in the arm, but it was never problematic. The doctors say this most likely didn't cause the sarcoma, it was just a place for it to start with lots of fluids to help it grow. May 2008 - Diagnosed as cancerous. Aug 2008 - had surgery to remove the tumors and started radiation. Spent a month in hospital, they did multiple skin grafts and reconstructive surgeries. A few weeks later, felt bumps in his upper arm, the EHE was travelling along the vein in the inner arm. Doctors removed this, and a few weeks later more tumors appeared. Sept 2008 – Started a 6 week trial of a new chemo drug, when that didn't work we tried Paclitaxel. New tumors are now visible again inside his elbow and on his wrist. Doctors would like to keep him on chemo for another six months to slow it down but have advised us to look into natural remedies because as of right now there's not much else they can do. June 2009 – __________ passed away.

FA5501	Dx 5/02 aged 46 Updated Sep 2006	DECEASED EHE in R lung and ribs, spine, Superior vena cava (SVC) Summer, 1987: Misdiagnosed with right shoulder impingement. Chronic pain in neck, back, right shoulder/arm ever since. (Attended “Pain clinic” summer, 1994 and began exercise/relaxation program which helped to manage symptoms.) April 2001 - May 2002: Dry cough, voice loss, fatigue, shortness of breath, SVC syndrome, collaterals prominent in right arm and chest. Initial Xray – possible AVM. Four 1.5 cm nodules in right middle lobe and a 3 cm. mass under the right clavicle were identified and biopsied. CT-guided needle biopsy of right lung confirmed EHE (Mayo Clinic). June, 2002: A stent was placed in right superior vena cava at Stanford, and a biopsy confirmed EHE in the SVC. Began Coumadin daily. August 2002: Attempted resection at MD Anderson. Thoracotomy revealed “studding” on some linings. Surgical biopsies confirmed EHE. September 2002 - March, 2003: Taxol 100mg – Stable. March 2003: Cytoxan/Celebrex (400 mg.) for 6 wks. Switched due to nausea/nail fungus side effects on Taxol. Result: progression of “paraspinous mass”, 8mm.-12mm; reclassified as a T12 lesion. Began Lovenox injections (60 mg.) twice daily due to thrombosis complication. May, 2003 - February 2004: Taxol 80 mg. Stable. February 2004 - October 2004: Gemcitabine 900 mg. – 2 wks on/1wk off. Switched due to development of bone lesion on 7th posterior rib. Horner’s syndrome also identified. Side effects: vascular swelling in chest and right hip pain; relieved with increase in Nortryptiline dosage from 10-30 mg. daily. Complementary modes: Jin Shin Jyutsu, EMDR, organic food, daily meditation/walking. ___________ is developing a fundraising website for restricted research for EHE. November, 2004: R lung pleural effusion; resume Zometa January - March 2005: Chemo break. February, 2005: Thoracentesis, no cancer cells; nerve block R ribs, add 1/2 Darvocet pm, Nortriptyline 60mg. March, 2005: Repeat. thoracentesis causes lung collapse. Recover with chest tube, no cancer cells; stable evaluation. April 2005: MDA recommends Avastin. Home doctor declines due to bleeding issues. Start Interferon 3 mu daily, pre med-Ibuprofen 500mg; switch to Aredia for bones. May 2005: Evaluation stable. Sept 2006: Daily Interferon injections for 7 months, then had a 10 month break with only monthly Aredia infusions. About to start Avastin infusions twice a month April 2008: Sadly deceased
FA8108	4/28/2014	DECEASED EHE of the liver and lung December 2008 - Diagnosed with EHE in liver with 4 large tumours taking up the entire liver and also one or two in lung. MD Anderson confirmed diagnosis of EHE and they stated best treatment was to wait and watch. They scanned her every 3 months in Houston until she lost her medical insurance. She now sees her local oncologist. Patient’s main complaint is pain control. She was initially put on Fentanyl patch 25 mcg for pain. Since then she is also on MSIR 30 mg 3x a day. She has had episodes of severe pain not controlled and has been admitted to the hospital. The last time she went to the hospital was a year ago. I went with _______ to her oncologist to talk about the pain flare ups and he stated that the liver gets inflamed because of the tumours pressing against the liver capsule. The doctor recommended she try a Medrol dosepack and put on an extra 25 mcg pain patch. This medication did shorten the period of inflammation but her last flare up lasted for approx. 3 weeks. We tried heating pad and used an extra pain patch and additional MSIR and rest. May 2011 – ________ went to the doctors and had her scans. The doctor told her that there was no change to her cancer and thought that the scans could be moved to every 8 months. She is due in December for another scan. The flare ups and pain fully exhaust her and she wants to give up. She also gets withdrawals really bad if the patches aren’t working properly. September 2011 - She did try acupuncture and will hopefully go 2 x weeks if it helps. Update from partner in 2014 - My best friend and partner died of EHE two years ago. She had EHE of the liver which spread to the lungs. She was only 33. Her doctor did not treat her and let it get so bad I took her to another oncologist to try chemo but it was too far gone.
FB1415	11/1/2015	DECEASED EHE in both lungs, pleura and diaphragm Patient started with coughing and shortness of breath, but with him having asthma that wasn't unusual for him and he kept putting off going to the doctor until some time had gone by without any relief. At that time he also was complaining of pain in the upper part of his right lung, which ended up being a large cavity forming. But when we think about Brian and the things he complained about physically a couple of years before he died, somethings add up to those things possibly being symptoms of EHE, PEH. Things like; back aches, knee aches, rashes, digestive pains (or what he thought was digestive pain) bad enough that he had to go to the emergency room and was told that was a bad case of indigestion. He had multiple CT scans which revealed a big mass in the lungs but multiple biopsies didn't identify the eitology. August 2014 - he developed acute lung hemmorage which caused respiratory and cardiac arrest. He was resuscitated and intubated but died on Septemeber 2nd. Autopsy revealed multiple nodules in both lungs and pleura and t diaphragm, in addition to a large mass. Autopsy identified those lesions as EHE. There was also a lot of infection present in the lungs. EHE infiltrated many vessels and airways. It was clear that he had EHE for a long time.

FS2804	Dx Oct 04 aged 76 Updated Aug 2005	DECEASED Hepatic EHE April 2004: First suspected of having a liver issue when during a routine physical, his physician noted hepatomegaly. Then referred to a specialist for biopsy, then PET scan, then a bone marrow biopsy which also proved negative. August 2004: a 2nd biopsy was conducted at St. Vincent's Medical Center in Bridgeport, CT. Oct 2004: Columbia Presbyterian in New York. Diagnosed “sclerosing neoplasm with epithelioid hemangioendothelioma of the liver". A concomitant test involving Immunoperoxidase showed "positive" antibody reaction with hepatocellular carincoma, hepatoid carcinoma, germ cell tumor, and a "focally positive" reaction with adenocarcinoma. Maybe these positive reactions hint at some cross sensitivity between the test antibodies, the cancers mentioned, and EHE. No major symptoms except fatigue. Nov 2004: Beginning a course of Doxil as per the recommendations of a consult between physician in Bridgeport, CT, and Sloan Kettering with a Dr. Maki. March 2005: Scan after completing the 4 rounds of doxil shows some enlargement of the liver tumors. Apparently not responding to chemo. Aug 2005: 2nd course of treatment with Taxol. He also is very intent on natural methods of treatment including a strict diet, low sodium, vitamins and Essiac tea and a broth that includes angelica root. Cat scan last week shows that the liver tumors are smaller! Oct 2005: Latest CAT showed very minor regression of liver tumors, but he is not doing well. Extreme fatigue, weakness and general loss of amibition which he insists is not depression. Prescribed hydrodocone for severe pain in liver region. Doctors are considering some type of intervention which my uncle describes as "cauterizing" the blood flow to the tumors (I'm assuming chemoembolization). April 4, 2006: sadly my uncle passed away today, from complications of HE. He had been deteriorating very rapidly, but toward the last day, he had been made very comfortable and passed peacefully.
GA5407	Dx: 03/2007 Aged 53 Updated Jan 2009	DECEASED Pulmonary EHE - rediagnosed as Angiosarcoma Dec 2006 - flu like symptoms. MD questioning Pneumonia. Chest xray showed Left Pleural Effusion, CT chest Confirmed Left pleural effusion. Thoracentesis performed (800mls) blood obtained. Treated with antibiotics but the effusion reaccumulted. Diagnoses with left narcotizing pneumonia. Thoracotomy and a left lower lung wedge resection was performed. Tissue for path specimen was sent to three different labs for study because there were unable to make a diagnosis. Feb 2007 - Started with hemoptosis. Bronchoscopy was performed with clot noted at op site but no active bleeding noted. The path finally came back making the diagnosis of Pulmonary Epithelioid Hemangioendothelioma. Still with hemoptosis. March 2007 - Chest CT showed clot left lower lobe and question of 2 small areas of calcifications in right lung. May 2007 – Re-diagnosed - Angio Sarcoma. He is receiving Abraxane which is a new form of Taxol. He is doing better. He is no longer coughing up blood (that stopped after his 2nd treatment). Prior to starting the chemo he had received 7 units of blood because he was coughing up so much blood. He is getting stronger. He still has the pain on the left chest area but it is more tolerable. On 300mg Neurontin for pain. July 2007 - things are going well. Feeling better and doing more each day. He just finished his second cycle of Abraxane three weeks on one week off. Aug 2007 - latest scan showed a mass on the right lung. Dr Morgan changed chemo to doxil, which makes him really tired for about a week, but he is still really active. Oct 2007 - Sept scans were worse. The lesion in the left lung is stable but the lesion in the right lung is bigger and he now has an area in the left side that is just above the spleen. I guess that is why he has been having all that pain on the left side. He also has another area in his right femur. The oncologist started him on Avastin and Navelbine. So far the pain has not changed much. This is the third change in chemo since we started. June 2008 - _______ is doing well, he is still receiving chemo. Since I emailed you last, he has had radiation to his right hip because he had mets to the hip. The other option was a total hip replacement but he would have had to be off the chemo for too long. While he was receiving Avastin and navalbine the right lung tumor increased in size and a new lesion had developed in the left lung. The oncologist started him on Sutent an oral medication used in the treatment of G.I.S.T. But after taking the medication for only 3 weeks he started with hemoptosis and they had to stop it. Well we have been through all the medications that were known to help patients with Angiosarcoma. ______ is now back on Abraxane (because he had a good response with it the first time) along with Gemzar. He has completed one cycle and his repeat scans showed marked improvement in the tumor sizes in both lungs. He has the Abraxane and Gemzar on 2 weeks off one week. Oct 2008 - ________ is doing about the same. He is still receiving the Abraxane and Gemzar. He had a lesion at L2 and was radiated to that area. He has good pain control and is still active. But the chemo makes him tired and it seems that it takes him a little longer to bounce back after the chemo. He has been getting chemo now for almost 2 years. He has a good outlook and he takes what ever comes his way and keeps plugging along. I admire him, because I do not think that I would be able to do what he has done. It is always in the back of my mind, when will the hammer drop. We have our faith and some days that is the only thing that gets me through. I used to pray for a miracle, but now I just pray to keep him comfortable and the tumors in check. Jan 2009 – sadly, passed away on 22 Jan after a 2 year battle.
GJ5409		DECEASED On April 11th, 2009, my dear sister, age 55, died of pleural epithelioid hemangioendothelioma. We also lost a brother in 1979 to what was then diagnosed as sanovial (sp?) carcinoma; a tumor that started on his jaw bone at the age of 23 then metastasized to his lungs. He died shortly after his 27th birthday. Neither of them were smokers. I believe these cancers were the same only given different names due to the time span between the two cases. I have read online that PEH is sometimes misdiagnosed as carcinoma. They called it a 'soft tissue tumor'....

GJ9107	Diag 3/2007 Aged 15 Updated Sept 2008	DECEASED Pleural effusion of the left lung cavity, vertebral lesions affecting over 50% of the vertebrae with lesions in various other skeletal areas, some nodules in both lungs Feb. 2007 - Diagnosed with an undifferentiated sarcoma stage 4, metastatic. Mar. 2007 - Sarcoma determined to be non Rhabdomyosarcoma - Epithelioid Hemagioendothelioma by Dr. Stephen Qualman of the COG Soft Tissue Sarcoma Biopathology Center - Columbus Children's Hospital, Ohio, along with assistance from immunoprofile provided by Drs. Chou and Edgar of MSKCC, NYC. Began chemo treatment of Doxirubicin and Paclitaxol. Aug. 2007 – disease stable, no significant improvement. 6th cycle and last treatment of Doxirubicin. Taxol continued. Nov. 2007 - Avastin introduced, then restaged at Sloan. Cease Taxol and switch to Irinotecan. 2 weeks later begin Irinotecan chemotherapy with continuation of Avastin. Severe side effects from Irinotecan. Back to Sloan. Interruption of chemo schedule. Note to editor – new drug “Irinotecan” – first time mentioned Dec. 21 2007 – PET and CT – relatively stable with slight increase in metabolic activity across the board at lesion sites. Sept. 8 2008 - My daughter went Home to be with her Lord and Savior. God gave her an assignment whereby she was able to do more to promote His Kingdom in her 17 years than most people who believe in Him do in a lifetime.
GM0011	1-Apr-2016	EHE in lungs, liver, spine & pelvis December 2009 - symptoms started. He had an inguinal hernia repair and was experiencing post-operative pain in his ribs for several days. His doctor thought it was a pulled muscle. He continued to have pain for the next few months that was attributed to muscle or a disc problem in his back. When he started to experience shortness of breath in addition to the pain he was referred to a pulmonary specialist, Joseph Ojile, M.D. A chest x-ray showed nodules in his lungs. June/July 2010 - he was again experiencing difficulty breathing and back pain. April 2011 - he had a microdiscectomy at L4 and L5. After surgery his pain increased and the neurosurgeon told him that it was unrelated to the back surgery. Pultmonologist ordered a CT and was leaning toward sarcodoisis. Broncoscopy was negative. July 16, 2011 - once again ended up in the emergency room at midnight. A CT w/contrast was performed. Pulmonologist suggested that a thoracoscopy pluriscopy (open lung biopsy) be performed. He stated that “something” had progressed since the April CT. A “nodular appearing process gathering steam." July 21 2011 - The open lung biopsy was performed with a diagnosis of Epithelioid Hemangioendothelioma (EHE). August 2011 - CT scans were performed and it was determined the tumors were in the lungs and liver. November 2011 - PET scan revealed the cancer had spread to the spine and pelvic region and the tumors in the lungs had multiplied. December 14 2011 - transported to St. Anthony’s Medical Center with severe shortness of breath. It was determined patient had a pleural effusion. It was drained and patient was transferred to Siteman. Once at Siteman a PleurX catheter was placed. December 24 - Two of the tumors in the spine and two in the pelvic region were removed. December 29 - Chemotherapy was started. January 7 - In an attempt to better handle the pain, a pain pump was inserted in the abdomen. Patient experienced respiratory distress and it was determined he had pneumonia and an underlying infection. The decision was made to put patient on a ventilator. January 18 - the family made a decision to take patient off the ventilator.
GM911	DX2011 Aged 20	DECEASED EHE in both lungs, pelvis bone and rib My 20 year old sister started off with a dry cough and shortness of breath and then stabbing shoulder pains and chest burning. She was misdiagnosed with anxiety, TB, walking pneumonia. The doctors scraped her lungs and the tests came back negative. Then diagnosed with some kind of allergy. Nothing was helping and she started coughing blood and getting very weak. She was referred to the University of Chicago to have a biopsy on her lung. April 2011 – Biopsy came back and she was diagnosed with EHE in both lungs, a spot on her pelvis bone and her rib. We received a second opinion and confirmation of EHE from the Mayo Clinic. The oncologist at UIC recommended chemotherapy to shrink the tumours and that a lung transplant was not possible due to both lungs having tumours. My sister did the chemotherapy and is now on her third round of Taxol with very little complications. She goes back to the oncologist after the sixth round of chemo. Aug 2012 - Received notification from the family that patient has passed away.
HJ8711	11/1/2015	DECEASED EHE in Lungs, rib and liver Fall of 2011 - He was dx when he was at Fort Campbell, he was 24. His doctor told him, "at least it wasn't cancer" and the biopsy came back from Vanderbilt - EHE. At the time there were tumors in his lungs (rt lung full of them) and on the rt side of his ribs. Prior to November 2015, he had been on Votrient for a year (it kept EHE stable), followed by Avastin for a few months. Everolimus 10 mg po q day w/ 120cc's of grapefruit juice, which he took for a month, and approx 1 month later was spent in hospital at UT Southwestern b/c he has a chylothorax. They put 2 chest tubes on his rt side and drained a lot of thick pus, then put in a pericardial tube and drained a liter and a half of clear serous fluid. He has scoliosis now as a result of long term chest wall pain. Nov 2015 - scan showed two new spots in the liver. February 2016 - Sadly Patient passsed away

HM6302	Dx: 2002 Aged 39 Updated May 2008	DECEASED Hepatic hemangioendothelioma 2002 - Diagnosed with hepatic HE after being misdiagnosed for over 2 years (they thought I had a benign hemangioma). Finally had a liver biopsy since I kept complaining of chronic spasmodic pain in the back right side of my liver. I was placed at the top of the transplant list (after letters of appeal by my doctors to UNOS) and received a transplant just a couple of months later. Sept 2005 - Just celebrated 3 years as a transplant recipient. I feel great and am completely active. UNTIL 2 days ago, after yearly scans, transplant doctor informed that a number of EHE lesions had appeared in the liver, and that, in fact, the EHE had shown up in CT scans dated as far back as August 2004 (and possibly earlier). As a result, immunosuppressant drug (taken in connection with her liver transplant) was changed from Prograf to Rapamune, as Prograf is believed to exacerbate the growth of tumors whereas Rapamune can stabilize them. We also consulted with a number of oncologists, including Dr. Robert Maki at Sloan Kettering. February 2006 - cat scan revealed that the EHE was continuing to grow, albeit slowly. March 2006 - At Dr. Maki's recommendation, commenced Nexavar (sorafenib), which was recently approved by the FDA for treating kidney cancer. May 2006 - CT scan appeared to show that some of the lesions had been killed. Side effects (none of which are considered "typical" for Nexavar) have included low-grade fever, sharp pains in various parts of the body (thigh, shoulder, etc. - the pains move around from week to week), and, most recently, a short case of walking pneumonia. Aug 2006 - ___________ started Sorafenib in March. Her symptoms were moderately bad -- sharp pain in the leg, then in the shoulder, then in the arm. Also neuropathy in the right arm. Dr Maki lowered the dosage and the symptoms largely went away. The first CT seemed positive -- Maki claimed that some of the tumors had actually been "killed", though some of those killed seemed to have expanded somewhat. The second CT, however, revealed that the tumors had actually grown 10-15%. Sloan-Kettering is now putting ________ on Sutent (sutinitib). If the Sutent doesn't work, we'll try Doxil. Jan 2007 – About to try Doxil. It's not that Sutent didn't work at all, its just that a few of the small tumors did grow and Dr. Maki felt we should try a more traditional drug instead. May 2007 – Being assessed for chemoembolization. Currently not on any drugs. Feeling fine. Jan 2008 - had a tips procedure end of December. Felt lousy after it for a few weeks, starting to feel better. Acites swelling has improved. I am still taking a diuretic. Getting stronger, but still not myself. Fatigue is the main issue and I'm still watching my belly. Took a leave of absence from work, hopefully it will be short. As of December 1st the tumors still appear dead. The chemoembolization was done back in June. Hopefully it can be done again, if need be. Going for an MRI in a couple of weeks. May 2008 – Sadly patient has passed away
HT9015	12/1/2015	DECEASED EHE in lymph nodes and lungs. September 9th 2015 - diagnosed with EHE at 25 years old. The EHE tumours are in my lymph nodes (the biggest in left axilla [extending into subpectoral region] and 3 smaller ones just above my collar bones which appeared after initial diagnosis) and in my lungs. September 22, 2015 - At last check (from PET CT scan) the size of the tumours were: 3.5 x 2.1 cm (largest, in left axilla), 8mm, 10mm, 6mm, 9mm, and two 7mm ones (which I think are the ones just above my collarbones). That's just from me trying to decipher the CT scan results. I don't know how many tumours are in my lungs, I have just been told there is a widespresd pattern in both my lungs of lymphangitis. The first tumour I noticed (in left axill had been present for 3 months before it was diagnosed as EHE and it seems relatively stable (from observation). I'm still waiting on a second CT scan, so I'm sorry I cannot be more definitive. The ones in my lungs seem to be aggressive because I've had 3 pleural taps in the last 3 weeks as my right lung keeps filling up with quite blood-stained fluid. I am being referred for Pleurodesis to help that lung stop filling up. November 24th 2015 - I began chemotherapy (weekly Paclitaxel) not sure of the exact dose, result uncertain as of yet as I've only had it 2 times. Tolerating it well for now. December 2015 - Worsening of pleural effusion, they attempted to remove it but it is coming back, a lot of blood in the liquid. Sadly -----lost her battle with EHE.

PJ7407	11/1/2014	DECEASED EHE in liver and lungs August 2007 - I was 33. Chest pain, required xrays, which showed infiltrates in my lungs. Subsequent CT scan reported “multiple bilateral pulmonary nodules…highly concerning for hematogenous metastatic lesions”. They ranged in size from a few millimeters to as large as 1.3cm. I had no plural effusion. PET CT scan found focal uptake in a left anterior rib, mild hypermetabolic uptake at multiple nodules in my lungs, and focus of increased activity in my left hepatic lobe. Sept 2007 - open lung biopsy via Video Assisted Thoracoscopy. Sent the biopsy results to the Mayo Clinic in Scottsdale, Arizona who confirmed the diagnosis of EHE. Oct 2007 - Group consultation - they suspected that the liver and rib lesions were involved and questioned if the liver biopsy actually got into the mass or missed it to reflect normal liver tissue. November 2007 - Consultation from Dr. Andrew Wagner at Dana-Farber Cancer Institute. He recommended to "watch and wait", since there was no evidence of my tumors growing. Dec 2007 and April 2008 - My CT scans have shown no growth in tumor size or number (in my lungs and liver). I am only monitoring - no treatment. June 2008 - I am sending my scans to Dr. Wagner to review, but am being followed by Dr. Lei Chen at Huntsman Cancer Institute locally (Salt Lake City) and she is also not recommending treatment. I am getting scans every 3-4 months for now. Dec 2011 - I had been on every three month scans with no treatment, when they found another tumor in my liver June 2011. I underwent 6 months of Doxil and things are (thankfully) stable again. Aug 2012 - Dr. Andrew Wagner at Dana-Farber was who I went to and he is fantastic (as is everyone at DFCI). I also have a sarcoma medical oncologist at Huntsman Cancer Institute in Salt Lake City, Utah where I live. Both oncologists are following my case and I travel to Boston once a year. I am back to every 3 month CT/MRI. June 2013 - Lung tumors have stable since dx. Liver tumors stable after 6 months of Doxil until now. Had TACE procedure. Nov. 2014 - Liver stable until Sept 2014, growth of 2 tumors. Underwent Y90 ablation. Post treatment scan is stable but mild pleural effusion in the lung causing back pain. January 2015 - Very bad pleural effusion, drained but keeps coming back. Pleurodesis performed, went well. April 2015 - I'm feeling more normal lately. I am on Doxil. My pain is being managed by the pain pump (Morphine and bupivicaine) and Celebrex. Celebrex has made a world of difference so I'm just so convinced of the inflammato nature of EHE. May 2015 - last scan showed slight progression of both liver and lung tumors after 5 rounds of Doxil. I'm going to get another scan end of June and then possibly switch to a Vegf inhibitor or another chemo agent. They are also considering cryotherapy on some of the tumors they can reach. July 2015 - Doing well. I was able to take two mini vacations with my family and I get a break from treatment until Sept scan. Pain is managed most of the time but there are some times when it's really bad. Thankful for the good times! February 2016 - sadly patient passed away.
KL6607	Dx 11/2007 Age, 41 Updated Mar 2011	DECEASED EHE of the pleura November 2007 - diagnosed. Previously misdiagnosed 2 months ago with mesothelioma. Patient has been having pain for about 2 years now - started out pretty mild - progressively got worse. Prior to being diagnosed Patient was in incredible shape. He was running 5 miles a day. He is a skier, snowboarder, windsurfer, etc, etc. Jan 2008 - Had his first chemo infusion last friday, at Sloan. Patient was first put on Doxorubicin for 2 treatments (each 1 month apart), that seemed to be ineffective. April 2008 - started on a combination of Gemcitabine & Docetaxel - 2 weeks on (1 x per week), 1 week off - about 8 weeks. The doctors (Sloan Kettering) feel that this has regressed the fluid caused by the tumors, enough that they feel that there is a window of opportunity to operate - possibly removing the pleura (lining of the lung), but more likely removing patient's lung (EPP). He is on painkiller meds 24/7. He, most of the time, feels pretty bad. I should mention that he is also being treated by an integrative medicine doctor & is taking 16 daily supplements. July 2008 – still deciding whether to operate to remove the lung, or continue treating. Nov 2008 - After Patient had the VATS biopsy which changed his diagnosis from mesothelioma to EHE, he was put on doxyrubicin. He had 2 rounds, each one month apart. Dr. D'Adamo determined that Patient's tumors had not regressed, and he was switched to a combo of Gemcitibine & Docetaxol - 2 weeks on, 1 off. After 4 rounds (8 infusions) Dr. D'Adamo told us that he felt that there was some response & told us to make an appt. with the surgeon, Dr. Valerie Rusch. Rusch informed us that she thought that operating on patient, at this point in time, would be his best shot at the possibility of eliminating the tumors (by removing his lung & surrounding tissue). Patinet went to the operating room on August 26th. After only one & one half hours, we were called in to speak with Dr. Rusch. She said that because the tumors had grown into his chest wall, she was unable to remove his lung, & that she had only removed a small portion of his pleura. We all were devastated that Patient underwent this intensely painful surgery (the cut is about 14 inches & a portion of his rib was removed) only to realize that the most hopeful option was voided. Patient had been in a great deal of pain prior to the operation. It is now 6 weeks since he was operated on & he is on a lot more pain medication than pre-op (150 micrograms of fentayl patch, 15 mg oxycodon - 6 per day, motrin - 1-2 every 6 hrs, tylenol 1-2 every 4 hrs, lyrica - 2 per day), and he still is suffering with much more pain than before the surgery. He is scheduled to start radiation therapy next week. Dr. Rosenzweig, at Sloan, will be doing IMRT, & employing a cutting edge technique that is being used only @ Sloan. It was developed to treat Mesothelioma patients. Patient will be going for treatment 5 days a week, for 5 and a half weeks. Aside from the usual radiation side effects, radiating the pleura, chest wall area & diaphragm is definitely going to kill a portion of the healthy lung tissue. Patient will no doubt have reduced breathing capacity, but if it also kills the tumors, we will happily take that. Since EHE, especially in the pleura, is so incredibly rare, the docs are treating this like meso. Aside from the team at Sloan Kettering, we consulted with a number of doctors including Dr. Suzanne George, Dana Farber, Boston, MA, Dr. Altorki, Weil/Cornell, NY,NY. Patient's oncologist, at our request, spoke with Dr Robert Benjamin @MD Anderson in TX. Patient was also seeing an integrative medicine oncologist in NY - Dr. Mitchell Gaynor, & prior to surgery was on about 15 different supplements daily. Mar 2009 - Patient went through a few months, after the radiation ended of extreme fatigue, & began having severe depression & anxiety. He is still having pain (generally under control), but his last CAT scan showed NED!!! We were warned, though, that this is not unusual for the 1st or 2nd scan, & not to get the notion that Patient is "out of the woods." He is currently on some supplements, as per Dr. Mitchell Gaynor - integrative medicine onc. March 2, 2011- Patient passed away after being in a coma for 4 weeks. In January he passed out at home and was admitted to hospital were he had ventricular fibrillation, was intubated and never regained conciousness. Unfortunately the doctors never diagnosed Patient with metastatic cancer, which after an autopsy, turns out to be what it was.

KM6607	Diag 11/2007 Aged 41 Updated Sept 2008	DECEASED EHE in diaphragm and lungs Nov 2007 - History of asthma and allergies but I am otherwise quite healthy. I have had bouts of pneumonia in the past though the diagnosis was usually listed as "probable" since it was never the typical look of pneumonia on X-ray. Just had one of these presumed "pneumonias" but this time I also had hemoptysis which was new, and my breathing worsened. Had to go to the ER there to rule out a pulmonary embolism. CT revealed multiple pulmonary nodules. Lung biopsy revealed EHE on my diaphragm and in lungs. After my biopsy I got a respiratory virus (not what I needed!!) and due to the intensity of my coughing I just found out yesterday that I broke and displaced my 9th rib (ouch). All of my blood work looks normal otherwise. I have not had a PET scan of other body parts and do not have plans to do that at this time Sept 2008 - I 'm sorry to say that patient passed away yesterday from complications of EHE. She was treated for about 4 months with Avastin last Spring/Summer, but in July there was evidence of tumor progression and she was having problems with bleeding from tumors in her stomach wall. From there she elected to not have further chemotherapy treatment, and we mostly worked on keeping her as pain free as possible. She did her best to keep working, very important to her, and only stopped about 3 weeks ago.
KT8704	Dx Sep 04 Aged 16 Updated May 2006	DECEASED EHE in liver and lungs Jan 2003 – experienced pain, but dismissed by doctors. March 2004 - Diagnosed with ultrasound as having 3 (13-16mm) "hypoechoic lesions" in the liver and told nothing to worry about. Sept 2004 - Increasingly severe pain and a needle biopsy was performed but not enough cells were taken and results were unclear. From the needle biopsy they diagnosed me with a childhood cancer PNET. Though after a surgical biopsy I was re diagnosed with EHE. January 2005 – Completed 3 months of Bevacizumb (Avastin) – stopped due to lack of funding (6 needle - 12 week trial & after having no results the drug company stopped supplying it.) While I was on Avastin I was 100% pain free 90% of the time and my 17yr old energy levels were almost back to normal. May 2005: - Medication has since stopped and the pain returned. Not at school any more and need as much rest possible due to tiredness and pain. (Note – my doctor managed to locate one needle of Avastin left over from a patient and I received it on the 22nd of March. We were all amazed at the amount of pain relief one needle gave me. After about 6 weeks the pain started to return, so we knew the Avastin was wearing out). The transplant team at Royal Prince Albert Hospital (Sydney) accepted me for a liver transplant - even though there are lung tumours, but I removed my name because I was in too much pain, and my parents decided to pay for the Avastin themselves. (We bought 3 needles). After the third needle there has to be a 4 week period before I can reapply to be on the transplant list. June & July 05 2005 - Was overseas in Lebanon. Had a fantastic time. Pain occassionally and took Endone to help stop it. August 2005 - CT scan. The 50(approx) tumours on the lungs have not changed - largest one being 8mm. Evidence of growth on the extensive tumours on my liver. Am back on the liver transplant list though things will change if tumours on lungs grow. September 2005 - Pain has increased. Energy levels are very low and I'm home each day - not really doing much at all. Discussions with oncologist Dr. Gurney and we have decided that if I don't have the transplant within one month, to try Thalidomide because of nausea and increased chest pain. Jan 2006 - Stopped the Interferon due to depression. As soon as I stopped Interferon the pain came back- severe pain. I had my stomach drained from ascites on the 22 December - though 4 days later it refilled and this time alot bigger then before. It is very uncomfortable and now I am getting back pain. It is even difficult for me to walk. May 2006 - was on the anit-depression tablet Nortriptyline but last week changed to Citalopram because of the dry mouth side-effect. I have lost a lot of weight and now my ascites condition is very bad. I have to get drained every week. The most they take out is 6L. I was on Interferon from 31/10/05 till -21/12/05 and stopped because of depression. Now I am currently on Thalidomide since 12/2/06. I'm trying hard to stay positive and to put on weight. August 2006 – Sadly patient lost her battle with this disease
LC5010	Dx 2010 Age 60 Updated Mar 2010	DECEASED EHE in pleura March 2010 - diagnosed EHE of the pleura some months ago and am in the middle of an intensive course of chemotherapy. To date, I have had various scans, i.e. CT, MRI & PET and a "fine needle biopsy" under guidance of the CT scanner, and a more detailed procedure to take a larger biopsy and to strip-out as much soft tumour tissue as possible (dependent on volume of bleeding caused during the process). Although I recognise that chemotherapy is not always prescribed, in my case it has provided a deal of pain relief, to the extent that I can sleep (lying down) sometimes 7-8 hours at a time! August 2010 – Patient died recently.

LH0012	11/21/2014	DECEASED EHE in lungs and liver, possibly kidney (?) 2002 – Pain in/under ribs and rectal bleeding. Sent to gastroenterologist thinking it is intestinal. Colonoscopy negative, sent for CT scan. CT scan showed mass in left kidney. Dx rib pain: costochondritis - Dx bleeding: Fissures 2003 – Follow up with U of M Urological Oncology. Partial nephrectomy left kidney. Pathology positive it was cancerous. Dx mass: Renal Cell Carcinoma. 2004 – Follow up CT scan post nephrectomy found a few nodules in lungs. Sent to pulmonologist who believes it could be scarring. We decide to “watch and see”. CT scan also shows possible hemangioma in liver. Blood work shows elevated AST and SLT liver numbers. Doctors not concerned, so I thought nothing of it. Also huge protein spillage in urine is found and attributed to the nephrectomy. Spillage continues to this day (3/2012) 2007/098 – Hemoptysis begins. Tests rule out TB. Bronchoscopy inconclusive. Dr. says not to worry. Hemoptysis stops. Figured it was related to smoking. Start trying to quit. 2009 – Hemoptysis continues intermittent. Still smoking. 2010 – Follow up with another pulmonologist. Bronchoscopy inconclusive again. This pulmonologist gives me a dx of Idiopathic Pulmonary Hemosiderosis and tells me to contact him if it gets worse. I finally quit smoking but bleeding didn’t stop. 2011 – Hemoptysis continues off and on and sometime b/w June & Sept becomes quite consistent. By December I could produce “blood on command” This episode/attack does not subside and continues into beginning of 2012. Dyspnea follows. Generally fatigues, achy and tired of coughing up blood. 2012 – Hemoptysis lessens and finally stops between Jan & Feb and as of March 2012 has not returned. Went to a new pulmonologist late January. New CT scan shows multiple “ground glass opacities” and “several” nodules bilaterally as well as a 2x2x2 cm nodule in liver. New doctor orders a lung biopsy. Pathology on biopsy comes back Dx EH. PET scan shows no uptake in liver or lungs. March 2012 – Planned trip to Dana Farber Institute in Boston. I have a bone scan 3/2/12 to see if there is any involvement there. November 21, 2014 - Patient sadly passed
LM5108	Dx 08/2008 Age, 57 Updated Jan 2010	DECEASED EHE in spine May 2008 – severe backpain and headache – admitted to hospital, numerous tests. Pain got worse, and spread to lower limbs. Aug 2008 – diagnosed as EHE, and received radiotherapy. Oct 2008 – severe pain, and is paraplegic. Has also developed pneumonia. Dec 2008 - Patient's last MRI has shown that the tumour is contained and not spreading but the area is very crammed hence crushing down on the nerve roots and of consequence the pain. He is now on LYRICA which seems to be helping a bit with the neuropathic pain, but still gets bad moments. February 2009 - Patient passed away. It was not the cancer that killed him but the stay in hospital. He actually died of septicemia.
MB6614	1/1/2016	DECEASED EHE in liver and lungs March 2014 - Incidental finding in a radiograph: unclear nodules in both lungs. Transfer in the University Hospital of Mainz with a suspected autoimmune disease. It was followed by a CT guided puncture in the lungs with unclear histology. In the liver a lesion is found, probably a hemangioma that behaves size constant to this day. April 2014 - Surgery (VATS atypical upper lobectomy right) diagnosed with epithelioid hemangioendothelioma multifocal growing with partly necrotic, partly hyalinised areas. June 2014 - After a follow-up, chemotherapy for sarcomas has been proposed. July 2014 - Asking for a second opinion in the University Hospital of Heidelberg / National Center for Tumor Diseases. Recommended treatment: Temozolomide (tablets) and Bevazizumab / Avastin (infusion). I opted for this therapy, I was able to let close to home perform in an oncology clinic. August 2014 - CT check-up before starting treatment. Result: In approximately constant size until minimal progressive lung lesions. December 2014 - after 2.5 cycles of temozolomide and Bevazizumab CT Kontrollungersuchung. Result: Progressive pulmonary branch operations and new ovens. Discontinuation of therapy with temozolomide and Bevazizumab. January 2015 - Renewed presentation at the National Center for Tumor Diseases in Heidelberg. February 2015 - Attending a Master's Degree in which through extensive genetic analysis of tumor therapy - relevant molecular changes to be identified. At the same time I started a therapy with lenalidomide (Revlimid). April 2015 - CT check-up after 2 cycles with Revlimid. Result: Größenprogredienz of lung metastases. May 2015 - new treatment with pazopanib (Votrient). End July 2015 - CT- control examination of the lungs. Tumors in the lungs stable teiweise slight decrease in tumors. August 2015 - MRI checkup liver. Occurrence of liver metastases. According to the radiologist unmasking of liver metastases in terms of a response to pazopanib. January 2016 - Sadly, patient passed away.

MG4705	Dx: 02/05Aged 57 Updated July 2006	DECEASED EHE in lung and liver Dec 2004 - A chest x-ray check for pneumonia, showed tumor in left lung. Jan 2005 - Needle biopsy misdiagnosed non-small cell lung cancer, CT scan showed lesions in right lung and liver. Referred to UAB for second opinion where Dr. Robert-Vizcarrondo ordered a surgial biopsy and I was diagnosed with EHE. Confirmed at M.D. Anderson. Saw Dr. Burgess at MDA who told me he was "following" a few cases and that this could be done locally or at UAB if I preferred. I returned to Dr. Robert at UAB. May 2005 - CT Scan at UAB showed "some" growth and I am looking at Phase I Clinical trials to include Taxotere and an oral medical SU011248. I am currently juicing, adhering to strict vegatarian diet (as much raw as possible) and seeing a chiroprator who helps me with supplements. Jan 2 2006 - Patient passed away. She developed pneumonia in her right lung. The infection was trapped by two tumors, antibiotics were not effective at this point. Thoughts and prayers are with you all ... keep fighting!! Sincerely, _(daughter of patient)_____________.
MR0012	2013	DECEASED EHE in lungs Jan 30, 2012 - Admitted to hospital and diagnosed with collapsed left lung. Feb 21, 2012 - Underwent keyhole surgery and had a pleurectomy to try and fix left lung and discover cause. Blood and tissue samples taken to look for a diagnosis. Mar 15, 2012 - Keyhole surgery was unsuccessful at reinflating left lung. Underwent open chest surgery and had a decortication. More blood and tissue samples taken to look for a diagnosis. Mar 21, 2012 - Histology and imaging reviewed and decided consistent with EHE - patient diagnosed. Mar 27, 2012 - Began cycle 1 of chemotherapy on Carboplatin and Paclitaxel at Guy's Hospital London. April 3, 2012 - Began cycle 2 of Carboplatin and Paclitaxel at Guy's Hospital London. April 10, 2012 - Began cycle 3 of Carboplatin and Pacliataxel at Guy's Hospital London, followed by a weeks rest. Transferred from Guy's Hospital to continue all treatment at The Royal Marsden in London, a specialist cancer hospital. The Royal Marsden plan to stop the Carboplatin treatment started at Guy's Hospital and treat with Paclitaxel once weekly instead, as Paclitaxel has been found to be more successful in targeting blood vessels in previous patients. April 25, 2012 - Began cycle 4 of Paclitaxel at The Royal Marsden. November 2012 - After discussing the pros and cons of Pazopanib and Thalidomide with my doctor we have decided to progress with Thalidomide as maintenance therapy, purely as there are more examples of EHE patients beir treated with Thalidomide successfully. If it doesn't work I will start on Pazopanib. I have taken Thalidomide for two months now- the recommended dose for EHE patients is 400mg a day and they plan to bring my dose up monthly Currently I am on 200mg a day. Few side effects but some fatigue, very occasional nausea. Quite often I get dizzy spells where I feel very weak and lightheaded and I have to sit down - this isn't a common side effect apparently so they are going to look into it. My last 3 CT scans since finishing chemotherapy have all been stable so they are going to make my scans once every three months. I had an indwelling catheter to remove fluid building around my lung but the fluid has stopped so last week I got it removed. Chemotherapy has definitely improved my symptoms. 2013 - patient passed away.
MS2982	Dx 2/1982& 10/2002 Update July 2005	DECEASED EHE in lung, left femur, liver and spine Early 1982: chest xray reveals many nodules on lung. February 1982: lung biopsy results inconclusive. Slides sent to National Institute of Health in Washington, DC which determines pre-cancerous condition, possibly EHE. No change in chest xrays for the next 14 years. Discontinues yearly xrays and doctor visits. October 2002: pain in left hip, visits orthopedic specialist. MRI shows tumor in left femur, tumors in lung, liver and spine. This tumor biopsy compared to slides from 1982 biopsy reveal the same condition, EHE. November 2002: left femur removed, replaced with titanium rod. Fall 2003: begins monthly Zometa treatment. Tumors growing at a very slow rate. 2004: 10 day course of low dose radiation to decrease tumor on spine at L5 – unsuccessful. June 2004: gold seeds planted in spine to aid in pinpointing tumors in spine at T2, T8-9 for 30 day course of radiation at MSK, New York City. Feb 2005: Patient finished some intense radiation this past summer. She just had scans and to our relief, no change! I never thought that a report of no change would be good, but it thrills me. Maybe the radiation can be considered successful? July 2005: A front tooth had an abscess, then it was noted that a piece of jawbone had crumbled. Apparently this is a reported side effect from Zometa, and Dr. Casper immediately stopped the monthly Zometa treatments. In the meantime, she is anaemic. Tried procrit, but it caused flu like symptoms, so stopped it. Oct 2005: surgery Wednesday to correct some of the problems caused by the Zometa. Her jaw bone became necrotic (it died) and the skin pulled away from the dead bone revealing it. The surgery was done in the oral surgeon's office with local anesthesia. Nov 2005: Sadly my mother passed away on 12 November.

MW5608	Dx 07/2008 Age, 52 Updated Mar 2010	DECEASED EHE in bones, lung Nov 1988 - Tumor removed from iliac vein in right leg and a vein graft from external juggler vein. Lymph nodes removed from hip area. Intense radiation to right hip area. Stint placed in collapsed iliac vein. Restricted flow in vein to present time. Chronic cellulites in right leg. June 2005 - Developed pain in left rib area. Several procedures done to control pain; nerve blocks, injections, and manipulation. Nothing helped with the pain and continues to present. April 2008 - Chest X-ray shows fluid in left lung. May 2008 - CT scan show large tumor in left lung. Right lung is said to be clear. July 2008 - Dr. Bascom @ sacred heart hospital. MRI shows tumor has grown up the lining of left lung. Biopsy confirms it is as EHE. Less than 25% capacity in left lung. August 2008 - Dr. Wood @ University Washington Medical Center. Biopsy on right lung 3 small spots but the surgeon said thousands of nodules not yet detected on the CT scan. September 2008 - We have been told to contact doctors in Boston @ Dana Fraber and MD Anderson in Texas. The doctors we have seen have no other options for patient. Dec 2008 - Patient is losing a little weight and is feeling very tired. He is not sure what he wants to do about seeing any new doctors. He did tell me that he is not going to do any treatment. He said he is in too much pain and would not be able to handle feeling like crap also. The doctors have said it is slow growing so we are hopeful we have some more time together. Apr 2009 - Patient is still in a lot of pain, and he does see a pain specialist. He has continued to lose weight and is weak. Just getting over pneumonia. Feb 2010 - Patient has been getting worse since he was diagnosed with lung cancer almost 2 years ago. He has been on Hospice since July 2009 to help him through the dying process. He has lost a lot of weight, is very weak ar has a tremendous amount of pain. Mar 2010 - Patient passed away on March 7th. He fought a courageous battle but there was nothing they could do for him in the end. He did change his diet and went much more natural whole foods. He did meet several times with a Natural-path but we really did not see a change. He could not get past the pain.
OA0002	8/1/2012	DECEASED EHE in lungs and liver. Aug 2006 - No change since original diagnosis. Sees doctor 6 monthly. Not on any treatment. I remain symptom free, but I will go for my next round of tests in a couple of weeks. It's now 4 years this month since the EHE was accidentally discovered, and I have had no treatments and absolutely no change in status. My docs think I may have had it for years before they found it. May 2007 - I am fine, no changes, no symptoms, no nothing. Sept 2007 - Some very small growth in a few of my liver tumors...plus one new one. Oddly, they tell me that some of these changes actually occurred before my last series of CT scans in January, but were not caught then. There's a new radiologist and new CT equipment now. Most of the changes are so small (1 or 2 mm) that there is a question as to if they are real or related to positioning. No other changes, no treatment, no side-effects. July 2008 - I'm doing ok. Last fall's CT scans revealed that I have some small changes, and prompted a review of all the previous scans. Turns out that, utilizing new software, they were now able to see that there have actually been minute changes all along. This was something of a shock as I had previously been told there were NO changes from the time I was diagnosed in 2002. Big difference! In any case, some of the changes are positive - there's some calcification of tumors in my lungs. Some negative changes as well - slight growth in a couple of tumors and a couple of tiny new tumors in my liver. Still no change in my health and nobody sees any need to do anything in terms of treatment. Oct 2009 - In August, my daughter and I both I got ill with what my doc thought was H1N1, although my flu swab was negative and I never had a fever. My daughter had a fever, did test positive for flu, and she was sick for a week. She's fine now. I've been sick ever since with shortness of breath, difficulty speaking/raspy voice and fatigue (probably b/c it's hard to breathe). Some days are better than others and I'm better than I was 2 months ago, but I'm still pretty sick. My O2 saturation goes down to 94 and my pulse goes up to 130 - 140 with minimal exertion. Not bad enough to qualify for an oxygen tank, but not normal for me. I'm (usually) in pretty good shape! A CT scan in September showed significant growth in some existing tumors for the first time since I was diagnosed in 2002, but my doc feels it's more inflammation related to H1N1 than real EHE growth. He suggests a repeat CT in December or January. My doctor thinks my continuing symptoms are some sort of post viral symptom, complicated by the underlying EHE. At this point, after 3 months, I don't know what to think. We've tried steroids, breathing treatments, inhalers, Claritin, etc., with no effect and I'm pretty much housebound. Aug 2012 - My EHE remains stable, no significant changes since I was diagnosed 10 years ago, still no treatment and I remain functionally asymptomatic. Have had one other health change. My routine CT scan in Feb. revealed pulmonary lymph tissue enlargement. I went to see my specialist (Dr. Robert Maki, formerly at Sloan Kettering, now at Mt. Sinai in NYC) and he did not think it was connected to the EHE but suggested a biopsy. However, the location of the affected tissue coupled with the presence of innumerable EHE tumors in my lungs made biopsy too high risk, so instead we did a repeat CT in May. The CT revealed no changes, so a PET scan (to look for maligna tissue) was done to help us figure out what was going on. PET scans associate a numeric value with areas of malignancy, with anything registering over 2.5 being of possible concern. The values can climb into the 20s. My scan revealed a small area of the lymph tissue that registered a 2.8, which my docs feel may not be related to infection and not necessarily indicative of a malignancy at all, so once again we have decided to wait and see. Repeat CT in 6 months, repeat PET if indicated after that. The really interesting part is this...only one tumor (in my lung) of the hundreds of EHE tumors I have in my lungs & liver registered above 2.5...and it only registered at a 3. Sadly patient passed away February 2015.
OC5508	Dx 8/2008 Aged 53 updated Apr 2009	DECEASED EHE in lung Feb 2009 - Diagnosis took over 6 months - It is affecting only her right lung at present and she has had to have 6 chest drains due to fluid build-up in her lung. She developed a very bad cough after her last drain, where she coughs for up to 30-40 mins at a time and ends up being sick or bringing up fluid. It was after this development her oncologist suggested she started chemo. This started in January. March 2009 - has been admitted to hospital. She went along for another Chemo (Doxorubicin) and they decided not to give it to her but kept her in to drain the ever filling lung. She has been suffering very badly from the chemo and has gone downhill quite quickly. Apri 2009 - Patient passed away at home in the early hours of Thursday 9th April

OO0007	Diag March 07 Aged Updated May 2007	DECEASED EHE in lungs, spine and possibly liver Started on Nexavar. It’s got some significant side effects - a terrible rash, nausea and fatigue - but we’re hopeful that it will work for her. The nodules in her left lung have multiplied and her doctor says she’s not even using that lung at all (there are no nodules in her right lung). One of the spots on her spine has grown as well. And now, there is a “spot” on her liver, but they aren’t sure what it is. All of this amounts to more pain for her. However, it seems to be somewhat well-controlled with meds. May 2007 - Sadly has passed away
OO3408	Dx 10/2008 updated Dec 2008	DECEASED EHE of the thyroid - rediagnosed as anaplastic carcinoma of the thyroid Oct 2008 – just diagnosed, and the consultant is unable to give us a treatment. Nov 2008 - Admitted to hospital and is not doing too well. It seems the tumour is very aggressive and has doubled in size in the last week. There seems to be little they can do which will affect the outcome. Dec 2008 – home from the hospital. Not really well enough, but it was all she wanted. It's been a massive learning curve in how to use all the oxygen, nebulisers and medications. The doctors now think that the diagnosis of the biopsy was wrong as the cancer is behaving in the way of the more aggressive type and they think there was a lot of dead tissue in the biopsy which may have made the results incorrect 10 Dec 2008 - Mum died on Monday at 4.40 am. she was at home surrounded by her family.
OO3505	Dx: 9/2005 Aged 70 Updated Nov 2005	DECEASED HE in both lungs Oct 2005 - Currently she is in Italy doing some last explorations to determine the complete illness scenario. Italian doctor has given 6,12,18 months of life to my mom. She will fly back to Venezuela (where she lives) next Monday. Nov 2005 – On Interferon and she is receiving the treatment in Venezuela. So far she has lost some weight (was vomitting from Interferon, now under better control), but her blood analysis results are better that before. Dec 23 2005 - Sadly, my mom past away. She rests in peace now.
OO7402	Dx: 2002 Updated June 2006	DECEASED Initial diagnosis EHE, revised to Epithelioid Sarcoma. 2002 – Our son had a sore on his thumb that would not heal, and the doctors decided that 1/2 of his thumb needed to be removed. Early 2005 - one of the regular scans showed he had several lesions in his lungs. The doctors decided not to start any kind of treatment but to monitor closely. December 2005 - Severe headaches - it was discovered that he had 3 lesions on his brain, the ones in his lungs and possibly one in a lymph node in his stomach. One of the lesions on the back of his head had ruptured and was causing all the pain. Had surgery to remove that lesion. Started on Interferon. Two weeks after starting the treatments he started having severe pain in his neck. After an MRI the doctors discovered that the lesions that were left in his brain were growing and he also had several in his spine and one in his spinal cord. The doctors decided to start radiation treatment immediately. He had 10 treatments of radiation and is now home with his family. My son is 28 years old and is married with two small children. We are now in the process of getting an appointment at MD Anderson in TX. March 2006 - Consultation at MD Anderson and they have changed the diagnosis from Hemangioendothelioma to Epithelioid Sarcoma. Will be starting Chemo treatments immediately. June 2006 – Sadly, our son passed away recently
OO7801	Dx: 2/2001 Aged 23	DECEASED EHE in liver and lungs He had been coughing up blood. After being told over and over again that it was just from previous lung infections, they finally did a x-ray months later. They had found the nodules and started exploring. It was discovered there was a nodule on his liver and did a biopsy on his lungs and liver then was diagnosed with epithelioid hemangioendothelioma. He started chemo right away. The chemo shrunk the liver cancer to almost nothing but it kept spreading thru his lungs. They tried 2 other chemo's but with no luck. April 2004 - Passed away, aged 26

OR4704	Dx: 12/2004 Aged 60 Updated Oct 2008	DECEASED EH in liver, spleen and possibly hip Dec 2006 - Looking at resection or ablation. Feeling tired, has pain in his stomach and shoulder and is nausated a good deal of the time. The bone biopsy found only normal bone, no bone lesions. Surgery planned around Jan 4 to remove the two large tumors on the liver. They are really making ________ uncomfortable. We will then start on Thalidamide. We also had the lab results double checked and the answer was the same "EHE." April 2007 - CT scan showed tumors on the liver to be growing as well as an enlarged lymph node, not quit 10 cm. Increased Thalidamide from 50 ml to 200 ml. and we just completed another CT. Results will be next week to see the effect. We are talking about going to Taxol if this doesn’t seem to have stopped the growth. July 2007 – CT showed some shrinkage and no new growth Oct 2007 – CT shows increased size from 4.8 centimeters for the largest tumor on the liver and an increase in the lymph node. We are considering MD Anderson at this time. In a great deal of pain most of the time but pain meds help. May 2008 - Patient has been in the hospital twice, once with pneumonia and the second time with fluid in the plureal lining. The pain is extreme at this point and we are finally going to a pain specialist. His oncologist here has him 90 mgs of morphine, darvacet -n 100 - 625 and advil 400mg. He is managing but is absolutely out of it. He is starting to have hallucinations. We actually backed down the morphine ourselves. We saw Dr. Patel at MD Anderson. Patient has started a regimine of Avastin. The revlimed had not impact and Dr. Patel seemed to think it was unconventional therapy. We did a whole series of MRI's and CTs there and the EHE is moving up the spine. Patient did a 13 day regime of radiation to help with that pain, but with the fluid in the pleural lining of the lungs, the pain from that got in the way of knowing if there has been any impact. June 2008 - Patient's tumors continue to grow. He is now on oxygen which is helping tremendously. He has had radiation therapy for parts of his back to control the pain and is on Methodone which is a much better pain releaver than morphine. In terms of treatment - he has had three Avastin treatments. We don't know if the tumors are continuining to grow but his progress was so poor we have now added Taxotere. Today was his first Taxotere administration. We are receiving the treatment here in Arlington Texas but the care is being directed by Dr. Patel in Houston. On another note, San Antonio CTRC has a new drug trial using something called MP470. They thought they had several chemo regimines that this would work with with EHE. Note to editor – new drug mentioned MP470. Later June 2008 - We have gotten patient's pain under control. We went to the pain specialist at UTSouthwestern Medical Center - Dr. Sharma. He has put patient on Methodone (currently at 15 mg 3 times a day moving up to 20 three times a day), Lyrica, darvacet and liquid morphine for breakthrough. Patient is doing very well with this regimine and can work and go about his daily business. He is still losing weight though. Aug 2008 - hanging in there. The pain is under control. He is on a chemo regimine of Avastin and taxotere. It has had some good impact on the tumors in the bone, and held the other tumors stable. The issue now are the tumors the lungs. they are producing lymphocites and collecting fluid in the plueral lining. So we are pleased with the impact of the chemo- he plans to continue as long as he can - and we are planning on doing a proceedure that will remove the fluid from the plueral area and put talc there to help seal it up. Hope that that works and that the Avastin kicks in soon. Oct 2008 - Patient passed away this past Tuesday from complications of EHE. He had been in the hospital for over a month, trying to get over MRSA pneumonia. He had plueral cathereters inserted that helped him breath, but the fluid seemed to then infiltrate his lungs instead of the pleural area. After several intubations he decided no more. Patient was 61 and had been diagnosed for only three years, but with the amount of lesions throughout his peritoneum at diagnosis, he must of had it for some time prior to diagnosis. Patient and I had been married for only a little over a year and I will miss him greatly.

PD7999	Diagnosed Feb 1999 aged 19 Updated Sept 2008	DECEASED Multiple tumours in multiple sites - right leg, knee, left and right shoulder, left thigh, hip, pelvis, ribs, spine, spleen, skull, collarbone and both lungs. April 1999: Radiotherapy on knee and shoulder. Aug 2000: Sharp increase noted in lung spots. Mild hemoptysis. March 2001: Interferon. Retinal hemorrage, and slight liver toxicity. Unsuccessful. Sept 2001: tumours are growing in lungs, and many bone sites – in particular at T10, which had already crushed a vertabra. Had radiotherapy on the spine. Oct 2001: Thalidomide 1200 mg nightly, for 4 months – hemoptysis reduced but scans showed no reduction in tumours and so thalidomide was stopped. Scan 2 months later as baseline before chemo showed marked decrease in lung tumours – possibly as a result of withdrawal from the thalidomide. April 2002: Doxorubicin monthly for 5 mths – unsuccessful, lung tumours initially reduced, than started growing again. Sep 2002: resumed thalidomide, 1200 mg, plus 3200 mg Gabapentin (Pendine), and Zomeda infusions. Lung tumours are stable, active tumours in spine, right pelvis, and right knee. Dec 2003: Tumours stable. Trying Doxycycline antibiotic 100mg twice daily. Changed from fentanyl patches to methadone for pain relief. Mar 2004: Feeling OK. Tumours stable, except severe pain in right pelvis. Commenced full time employment. Aug 2004: All OK, same medications, occasional pain flare-ups, generally under control. Takes Vioxx as needed. Coping fine with work and social life. Nov 2004: Vioxx was withdrawn from use. Swapped over to Naprosyn. Coping fine. Jan 2005: Scans taken after 6 month interval, show no marked change. Medications unchanged. June 2005: 6 weeks ago, irritated the groin/hip/femur area, and had pain since. Very limited in activity, walking only necessary short distances, and using crutches. Scans show no further growths. Today has had a SINGLE administration of radiotherapy to the groin, as an attempted method of pain relief. (A month later – pain is less in pelvis!) July 2005: Titanium rod inserted in left femur – small tumor activity has caused the pain and is putting the bone at risk of breaking. Out of hospital in 2 days, drove to shops on the third!!. Sept 2005: Commenced 5 days of radiotherapy on left thigh. Feeling good, coping well. Jan 2006: Hospitalised for transfusion of red blood cells. Otherwise, feeling fine. Feb 2006: Another transfusion, upper and lower gastroscopies and bone marrow biopsy, all were reasonably OK. Was on Voltarin for last 2 years for stomach pain, switched to slow release paracetemol, and blood counts have improved. July 2006: Blood counts reasonable. No main problems. Oct 2006: Reduced thalidomide from 1200mg nightly to a maintenance dose of 200mg. Jan 2007: Scans ok. Platelets very low (45…should be 150-400, although his are normally 80's). Put on Nexium, to rectify if any problem with ulcers, etc (even though tested last year when had similar problem). Might need to have spleen removed. Also has a rash on fingers..unknown cause…maybe due to low platelets?? Feb 2007: red blood cell count low, some edema. Had transfusions. Sept 2007: persistent low red blood cell count as well as platelets. Also swelling in leg due to blood circulation. Blood transfusion. Feb 2008: had blood transfusion because of constant low blood counts – was needing transfusion for at least 2 months, but deferred it till now. April 2008: blood transfusion. June 2008: last month scans showed possible increase in lung tumour mass, so scanned again this month. Also showed increase. Prof Toner has decided to put ______ back to the full dose of 1200mg thalidomide. He also needed another transfusion…maybe the increased thalidomide can stop the breakdown here, and also reduce his increased hemopysis. Still having monthly zometa infusions, and Prof Toner is keeping ________ on the doxycycline as it has been reported that it works with thalidomide to have a combined effect. August 2008: transfusion. Also given tablets to clot the blood, to try to reduce the hemoptysis. CT scan set for next month to see if the thalidomide is working. End August 2008 – the tablets helped to reduce the hemoptysis straight away. Scan revealed no new infiltrates in the lungs, and possible reduction in the recently acquired ones. Reb Blood Cell count good! 22 September 2008 - _________ unexpectedly passed away in his sleep. It is suspected that one of the myriad of leaking blood vessels, split, thought maybe his heart just gave out. His body was in 'sleep mode' – we assume it was instantaneous and painless. The doctors have now told us that they are amazed he survived so long. MHDSRIP
PF6784	Dx 1984aged 17 Updated July 2007	DECEASED 1984: Diagnosed with hepatic EHE which progressively healed through a spontaneous calcification process of all neoplastic lesions. 1998: involvement of the right lung ileum was detected which maintained a stable profile with some indications of spontaneous remission. Spring 2003: as a consequence of some back pain, a vertebral osteolytic lesion of L5 was observed (which was smaller but already evident on CT of 1999). Treated with radiofrequency thermoablation followed by a vertebroplasty with acrylic bone cement. The biopsy confirmed the diagnosis of EHE evidencing no mitotic nuclei. Currently asymptomatic and enjoying a normal life. Sept 2003: CT-PET scan confirmed the presence of two sites of moderate glucose hypermetabolism at the level of L5 (which could be also consequent to post-surgical inflammation) and at the right ileum of the lung, with no other site of altered metabolism. July 2007: Patient passed away.
PV6910	Dx 2010 Age 58 CODE 304UK15 Updated Aug 2012	DECEASED EHE in liver Oct 2010 - lower back pain, thinking it was a stomach ulcer they put camera down the throat and spotted the legions on her liver. Endoscopy, MRI showed approx 30 tumours on liver. Nov 2010 – biopsy diagnosis of EHE. 2 large turmours, one 4cm and 6cm. No treatment yet. Pain increasing. Doctors hoping to do liver transplant but are unhappy about doing this without knowing what the pain is about. Feb 2011 - started Celebrex, which is an anti inflammatory in low dose and a anti angiogenic in larger doses, and Lenalidomide which is a new version of thalidomide with less side effects. We're going to start that today when we have the full support of the Palliative Care team around. We are using Prof Judson at the Royal Marsden in London and he has consulted with Dr. Benjamin at the MD Anderson Cancer Clinic in Houston and Dr George Dimitri at the Dana Faber Institute in Boston. Aug 2012 – We received notice from patient's sister that she has passed away.

RC0006	Dx: 4/2006 Updated Aug 2008	DECEASED EHE in liver, hip, spine and lungs Jan 2006 - gastro problems - under the impression it was irritable bowel syndrome. April 2006 - CAT scans, MRs, PET scans, biopsies and finally a laparoscopy for diagnosis of EHE. At that point patient was very sick and he had constant visits to the ER. We were told his only salvation was a liver transplant. July 2006 - went to the MAYO CLINIC in Jacksonville where we had to go through another two weeks of tests. Patient's MELD score was 25 and he couldn't sit or stand anymore. On June 26th we got his transplant. He was in the ICU and dying at that point. The doctors tell us that all lymph nodes removed had EHE and possibly one cancerous lymph node was left behind because it was hard to reach. Aug 2006 – 3 months post transplant and patient is doing really well. Jan 2007 - PET Scan and a CT Scan every 6 weeks because we knew from transplant time some probable cancerous lymph nodes in the chest area had been left behind due to very complicated transplant and being extremely weak and ill being prior to transplant. Dr. Maki (oncologist), Dr. Nissen (his surgeon) and a thoracic surgeon decided to monitor the lymph nodes rather than operating. He is also on Rapamune as of 2 and a half months from transplant. It was a bit risky to switch then from Prograf but research shows that Prograf actually promotes tumor growth while Rapamune has tumor fighting qualities. In the meantime patient is feeling great and has just gone to h first international journalist assignment. April 2007 - Surgery to remove lymph node (at Cedars Sinai) and repair hernia. Went very well. May 2007 - Hip/leg pain. All scans and blood work still normal. Liver doc could not figure out why he had leg pain. June 2007 - Went to Neurologist outside of Cedars. Scan showed presence of EHE in hip. EHE had returned in new liver, hip, spine, and lungs. July 2007 - Consult w/Dr Jan Buckner at Mayo Rochester, MN. Devised chemo+rad plan to be carried out back in LA. Consult w/new oncologist at Cedars, Dr Forscher. And radiologist, Dr Yampolsky. Started 3 weeks of daily radiation to the hip which was very effective! Relieved pain. And also started chemo (Gemzar). Very few side effects from radiation. But developed a rash and some swelling under the arms and on the chest from the Gemzar, which did go away. End of July 2007 - Taxotere was exchanged for the Gemzar. Tolerated well. Aug 2007 - Avastin (also tolerating well) added every other week to Taxotere. Latest scans were good! No new sites and stability and/or dying tumor in the previous spots - except for the liver lesions which have grown a bit. Jan 2008 - Switched to Nexavar and Abraxane. He takes zometa every four weeks. Currently feels remarkably good (with the exception of frequent and severe hip pain) and is living an active life. June 2008 - Patient's scans weren't so good last week. He will switch chemo because the Avastin + CPT11 isn't stopping the growth. August 2008 – not been a good couple of months. Just started 7 day Ifosfomide, chemo pump, day and night. Not going too easy. Patient passed away August 15th, 2008. We were all by his side.
RL9600	2/1/2002	Son was diagnosed with EHE in the lungs and liver, in the fall of 2000 and died at the age of 5 1/2 years old in Feb 2002.
RP0014	6/1/2015	DECEASED Peritoneal EHE Diagnosed in 2014. 8 rounds of Taxol and initial good response before tumour started growing again. Then onto Pazopanib but only lasted 3 weeks because had bad liver response and tumour growth seemes to accelerate. June 2015 - Have been on no treatment for weeks because have been in an out of the hospital with bowel obstruction and surgery. Oncologist considers me too sick for any treatment. Patient passed away August 2015
SC6107	Dx: Aug 08 Age: 46 Updated Feb 2009	DECEASED EHE of the liver May 2007: Pains on upper right quadrant. Various scans revealed large tumour in the liver. Suspected diagnosis: hemangioma. Sept 2007: Confirmed diagnosis after liver biopsy: EHE. Proposed treatment liver transplant. Nov 2007: Liver transplant with husband as living donour. Good recovery and almost normal life again. May 2008: PET scan and MRI do not show any abnormalities. July 2008: Liver parameters (transaminases) remain high. Stenosis in one oft the bile ducts. Small thrombosis in a large blood vessel (vena cava). Treatment with anticoagulants and dilatation of the bile duct.Liver parameters remain high. Sept. 2008: Liver biopsy (performed to exclude chronic rejection) shows recurrent tumour growth in the liver (again EHE). MRI and PET scans show that a large proportion of the liver is affected by the tumour, again. No indication for tumour growth (metastasis) in other parts oft the body. Proposed treatment with angiogenesis inhibitor (probably Avastin – active ingredient: Bevacizumab). Feb 2009 – sadly passed away
SC7408	Diag 11/2007 Aged 33 Updated Nov 2008	DECEASED EHE in vertebra 2006 - he started having pain in his side. He went for an Xray, and they said that one of his Vertebras was condensed - he was told that he probably had cancer and then told that everything was alright and he did not. This went on for the next 2 years... 2007 - he had 2 Biopsies this year (needle not surgical) but the pathologists could not make out the results. We then changed hospitals, and he was diagnosed with a very rare disease called S.A.P.H.O, a rhumatological disease. February 2008 - Another biopsy and now diagnosis of EHE. I beleive that 2 doctors have confirmed this, one in France and a Doctor MCCarthy in Boston. Sept 2008 - treated at Gustave Roussy, an amazing Cancer Institute in France. Patient suffered a pneumothorax. It actually saved his life as "thanks" to that they unfortunately discovered that he had metastase on his lungs/thorax... Commenced a strong bout of chemo for 4 months, but didn’t help. Also had a pulmanary emboli (which didn't help). He is starting on Sutent. Curerntly in massive pain, has been fitted with a morphine pump. 23 Nov 2008 – Sadly, patient has lost his battle with this cancer.

SG3306	Dx: 6/2006 Updated July 2006	DECEASED EHE in hip and leg 1956 - First experienced excruciating pain in left hip area, a pain that has come and gone, recurring most severely during the past five-six years. Could EH have been present that long ago?? – same pain area. June 2006 - diagnosed with EH via biopsy. In retrospect, realize there was mis-diagnosis 5 years ago when hospitalised for treatment of what was viewed then simply as multiple sclerosis. In fact, she also has MS. Sep 2006 - Dr. Eckhart is considering surgery but first however, before surgery, oncologist Dr. Louis Vandermollen at Hoag Hospital is recommending five weeks of radiation therapy to attempt to shrink the tumor in the hope that pain will be reduced. She has severe pain and is on morphine at the present time (about two weeks now) and MS Contin every 12 hours. Dec 2006 – sadly Patient lost her fight with this disease.
SP0007	Diag 07/07 Aged 46 Updated Feb 2009	DECEASED EHE confirmed in both lungs, pleura and lymph nodes in neck and chest. Sept 19, 2007: Papillary Thyroid Carcinoma diagnosed. October 31, 2007: EHE diagnosed as a result of pre-op chest x-ray (for thyroid surgery) showing mass in right lung and multiple nodules in both lungs. Multiple lymph nodes removed from 10/2 thyroid surgery confirmed EHE as well. No medical professional feels these 2 cancers are related. February 6, 2008: Thoracotomy removed 1/3 of right lung due to infection of the primary tumor. Biopsy of right pleura confirmed EHE in this location as well. September 2, 2008: After a brief growth spurt earlier in the year, the EHE has been indolent for 6 months now. Chosen to wait on treatment until signs of growth appear again. CT scans are taking place every 3 months or sooner if suspicious symptoms appear. Dec 2008: Due to tumor growths and some deterioration in breathing ability, a regiment of Adriamycin and Avastin was started. Feb 2009: Sadly passed away
SR6204	Dx 6/2004 Updated Jan 2005	DECEASED EHE in liver June 2004 - EHE diagnosed as a result of doctor visit for stomach pain (stones, gall bladder removed); sonogram indicated lesions on liver and biopsy indicated EHE. No present pain or discomfort. Referral by Dr. Marek for appointment at M. D. Anderson in August. Jan 2005 - Was hospitalized end December for a fever over previous 3 weeks. Drs did all kind of guess procedures and finally diagnosed a urinary tract infection and pneumonia (which we didn't think was right), but after 1 week in the hospital patient was frustrated and wanted to come home so Dr's released him on 1-3-05 at 8:30 pm... Same night at 9:15 pm patient got a call from Houston that they had a liver match and he was scheduled for transplant at 9:00 am next morning since donor was still living. Drove the 350 miles to Houston and waited...12 hours past the appointed time, still waiting, then just before surgery Rick got the fever again and operation didn’t proceed. 27 Jan 2005 – “This is __________'s wife and I would just like to advise you that he will no longer be in pain or suffering for he went to be with the Lord in Heaven on Thursday 1-27-05. Thank you all for your support and I hope they find a solution to E.H.E.
TB6604	Dx 11/2004 Aged 38 Updated Jan 2005	DECEASED EHE in lungs, spine, ribs, pelvis, skull and maybe liver. Aug 2004 - Lower back pain in August. Diagnosed with vertebrae edema in a number of vertebrae in lower back. Physiotherapy, acupuncture and Ibuprofen suggested. Pain became extremely intense. October 2004 - MRI, bone scan and cat scan in Eugene Oregon revealed the lesion sites. November 2004 - Needle biopsy of lung. EHE suspected. Referred to Dr. Butrynski, Seattle, WA. Had section biopsy done. EHE confirmed. Many small lesions in lungs; lesions also in pelvis, spine, ribs and skull. All tumors quite small, less than 1 cm. Lesions in bone not in the marrow. December 2004 - Began Zometa (Bisfosfinates) once a month to prevent bone damage. Had 16 radiation treatments as a palliative measure for the tumors on the spine which were causing pain. Lungs rescanned, growth not sufficient to warrant additional measures. January 2005 - Having 15 daily naturopathic intravenous drips. Feb 05 - Recent Cat scan showed minor shrinkage of two tumors on his lungs. Planning to return to work next month, though considerable pain in hips. Aug 06 - about to begin treatments with AVASTIN every two weeks. He also has started being treated with Samarium – a radio isotope which will target his body systemically as opposed to the directedness of normal radiation. Sept 2006 - Patient took a downward spiral on September 10th. Pain and deterioration mounted considerably. Pain meds were changed to Fentanyl patches. He had had 2 treatments with Avastin, at that time, which all 3 of his oncologists do not believe caused this downward turn. They are now suggesting that he continue with the Avastin and add Adriomyicin. Tumors show signs of small growth. Patient is very weak, lungs severely compromised (he uses oxygen often now), bone pain has impaired mobility and the last month has left him very weak and barely functioning in a normal fashion. Oct 2005 - He is taking Thalidomide. Has developed a rash, which is subsiding. He was not strong enough to do the Adromycin. Nov 2005 - He continues to lose weight, throw up, be very weak, sleep a lot, eat little, have chest congestion. We continue with the Thalidomide, and Doxycycline, as well as infusions of Vitamin C and other strength building things which the Naturopath administers. The oncologist suggested Hospice be called last week. April 2006 He is on full time oxygen, uses a wheel chair or walker to get around. He is horribly thin. His lungs have been drained twice of over two litres of fluid in the past month. He had a morphine pump put in his body, as all medication combinations were not sufficiently managing the pain. He takes Dilaudid for break through pain, when he needs it. He had a second round of radiation on his upper back a few months ago, but it did not seem to alleviate the pain. The oncologists gave up quite a few months ago and today the naturopath did the same. Nothing seems to be working as it did before. 28 April 2006 – sadly patient passed away today

TM0014		DECEASED EHE in lung and bone He had DVT in his leg in 2007 - he saw many Doc's all the way until 2014 for his leg pain. August 2014 - He started with the chest pain and shortness of breath. He was told he had a blood clot in his lung (PE), even though when I read the report it was neg for PE but showed a narrowing of the right bronchus. He had several CT scans in August and September. Same hospital 5 days apart, one doctor said he had a large right lung infiltrate and large Lymphadenopathy, hilar - subcarnal, etc but did not mention nodules on the left lung. The other doctor did not mention the enlarged lymph nodes and did mention the nodules, but stated no follow up was required since they were under 8mm (which is ludarcris!). I don't believe they ever mentioned anything about the bone m but did mention a curvature of his spine which was part of the mets. November 2014 - Mayo did his CT and Pet Scans. They did his broncoscopy showed the EHE. Patient passed away December 2014
TO0014	1-May-2016	EHE in liver, lungs, abdominal wall, and pelvis. July of 2014 - a nagging back ache. She went in for the CT and before she could get home, the hospital called her asking her to go back for an MRI as soon as possible. They picked up 1 medium sized tumor (about 4 cm) and 4 small tumors (all around 1 cm) in the liver. They initially suspected Cholangiocarcinoma, which was devastating to hear as the doctors at Baylor were very pessimistic about her odds of beating it. September 19th, 2014 - they performed the biopsy and found it to be EHE. Baylor considered her for transplant, but the cancer soon became aggressive and spread to the lungs. They denied her transplant, and at the last minute reconsidered. Soon after her diagnosis, she developed pain in her upper body which was also met with a dismissive attitude at Baylor. All the while, the cancer was spreading with the doctors assuring us everything was fine, and that it was considered slow growing. In fact, they told me she wasn't considered to be an "URGENT" case. 6 months went by with no treatment, even at my request they would not consider trying to contain the growth that the imaging was showing. They had no real experience with this mysterious cancer. My concerns were just brushed off. By the time I switched her care to MD Anderson, the cancer had spread from her liver to her lungs, abdominal wall and pelvis. Her largest lesion had grown to 7 cm and her smaller liver tumors were already approaching 4 cm with many new ones sprouting and the pain worsening by the day. After a couple of months of trying to control the pain with nerve blocks, and different medications, she was finally admitted to try to immediately find a solution. She was initially put on Cytoxan prior to being admitted, and was a month into treatment at the time. The scans done then showed progression that was still undesirable, so they immediately switched her to a Gemzar/Taxotere combo. After a couple of weeks a Myelotomy was performed, where the pain receptors in her spine that sent pain signals from the brain to the midsection were permanently severed. That made such a difference! The chemo did take it's toll on her body, and after two cycles we were told it did not accomplish what the team had hoped it would. On a positive note, it did manage to slow down the progression. Her largest lesion was now at 9 cm, and she had innumerable nodules in the rest of her affected areas as well as metastasis to her lymph nodes now. She was referred for Targeted Therapy with Dr. Subbiah who enrolled her in the clinical trial for Everolimus (10MG) and Vandetenib (300 MG). End of June 2015 - She began her new treatment (it was practically my birthday present). October 2015 - We are happy to report that she has shown regression in her lymph nodes, lungs and abdominal wall/pelvis. Her liver lesions are now stable, and she shows continued progress. She had gotten down to 100 pounds by the time she began this treatment. After struggling a bit through the first month, she has now gotten to 125 pounds, and no longer needs a walker or assistance while walking. She's back to cooking and cracking jokes as well. The mother we all know and love is well on her way to living and loving life again, pain and symptom/side effect free. The only side effect that randomly pops up is acne from the medication, which only makes her feel young again! May 2015 - Sadly, patient passed away.
VC2605	Dx: 8/2005 Aged 79 Updated Nov 2005	DECEASED Osseous Epitheliod Hemangioendothelioma August 2005 - X-rays showed multiple lesions on both lower extremities. Indicated most critical problem, RHS tibia eroded away under knee. Dr Herbst repaired locally with bone cement and metal insert. Biopsy indicated OHE. Pain Medication: Synap Forte (Paracet. 500 mg,d-propoxyphene napsylate 50mg, diphenhydram. HCL 5mg, caff 50 mg). Current situation is that the leg is OK however pain is experienced in vicinity of the RHS hip. Doctor has recommended minimum weight on legs as hip might be fractured. Nov 2005 - Patient died on 7 October 2005. He was in hospital for baseline tests to monitor his EHE. It was not the disease that killed him but an infection while in hospital.
VF7507	Diag 2007 Aged Updated Sep 2007	DECEASED EHE in liver May 2007 – Diagnosed. At the moment is on waitlist for liver trasplant in Palermo in the center called ISMETT, in collaboration with University of Pittsbhurg (USA). Sep 2007 - Not on any therapy, been advised that the only solution is a transpant. Is on pain medication, is always tired, and always has pain, but still manages to go to work. Sadly my brother has passed away.
VJ8109		EHE in liver June 2009 - jaundice, in the eyes mainly. Otherwise asymptomatic, save a slight swelling in the upper abdomen. Took blood tests, Ultrasound and CT of abdomen. Reported multiple nodules in liver in both lobes, some up to 5cm calcification. Suspected HCC. July 2009 - biopsy of liver. Results from local hospital (Los Alamitos, CA) were inconclusive. Slides were sent to Stanford. July 17 2009 - CT scan of chest was performed and multiple nodules in left and right lung suggest possible metastases. July 20 2009 - diagnosed as EHE. July 23 2009 - First appt with oncologist. Has heard of this condition. Further consultation with colleagues to assess best treatment plans. Commenced on Doxil. Oct 2009 – Notified that patient passed away. 4 months after diagnosis.

WD5614	10/1/2015	DECEASED EHE Age at diagnosis: 58 January 2014 - Went to the doctor with ache in groin area. Had experienced a couple of fungal infections during the previous year with skin rashes but nothing came of this. Also had had successful inguinal hernia surgery in 2010 and thought that the ache was a returning hernia. Wasn't thought to be urgent so was left until April 2014 when it was becoming more bothersome. June 2014 - radiating pain in groin area and back and mild painkilling drugs not seeming to work. Sent for ordinary x-ray as different doctor thought problem might be hip-related. Mention was made to doctor about being bitten by insect in Greece and being scratched by cat. Nothing conclusive so sent to local orthopaedic hospital, The Horder Centre, Crowborough, Sussex, UK. 30 August 2014 - MRI showed suspicious area on acetabulum area of pelvis with high T2, low T1 signal. Rise in inflammatory markers in blood. Sent for CT scan + bone scan. 10 September 2014 - bone scan showed thoracic spinal and left ischial suspicious appearances. 8 September 2014 - CT Thorax, abdomen and pelvis with contrast showed: 2cm lytic lesion in left ilopubic rami, close to acetabular area. Findings indicate a mildly aggressive lesion with cortical loosing. Similar lesions are noted in T3 and T6 vertebral bodies. Multiple splenic nodules and masses are noted. a 13mm calcium containing Left Upper Lung pulmonary lesion is apparent. A second, non specific nodule 5mm in diameter is seen in the Right Lower Lung. Images suggest presence of malignant pathology with osseous and splenic dissemination. Origin is not apparent. Pulmonary lesions are inconclusive. 8 October 2014 - Sent for needle biopsy at Royal National Orthopaedic Hospital, Stanmore, England Report: bone tumour, left acetabulum: a malignant vascular tumour of bone. The differential diagnosis includes an epithelioid hemangioendothelioma, which we favour, and a low grade angiosarcoma. Excision was recommended (Not carried out due to spread of disease). 22 October 2014 - CT Chest for staging of bone sarcoma. Multiple lung nodules and lytic bone lesions, in keeping with metastatic disease. 22 October 2014 - MRI pelvis. Infiltrative lesion in the medial acetabulum of left hip with suspicion of cortical breach at hip joint. Two further foci of similar signal characteristic higher in the left ilium which are concerning for further lesions. Diagnosis: epithelioid hemangioendothelioma/low grade angiosarcoma. Sent to University College London Hospital, London, England. Part of the London Sarcoma Service. Consultant: Professor Jeremy Whelan, MD FRCP, professor of cancer medicine and consultant medical oncologist. 11 November 2014 - See Professor Whelan who explained diagnosis of EHE which is known as a type of vascular sarcoma. This was affecting his bones and spleen and possibly his lungs. Unfortunately there are no standard treatments known to cure EHE. Arranged for PET, MUGA and EDTA in readiness for possible chemo at a later date. However, no hurry to start treatment – watch and wait to see how the disease progressed. Pain controlled with paracetamol + slow-release anti-inflammatory drugs. Also takes omeprazole to prevent stomach irritation and oral fentanyl for severe pain episodes. 2 December 2014 - Pain in back and hip not diminishing so palliative radiotherapy to thoracic spine (T5-T70 – 20Gy in 5# and left hip 30Gy in 10#) completed. Pain lessened. January 2015 - further radiotherapy 8 Gy single fraction to T11. However, pain around middle area, under ribs. April 2015 CT - Scan – liver lesions now apparent. No size given. Suggested treatment with doxorubicin. Not undertaken due to commitments and feeling well. April 2015 – saw homeopath within same UCLH group. Acupuncture for pain + oral mistletoe therapy and several homeopathic pills. May 2015 CT Scan – liver lesions apparently worse but no sizes given. Still feel well and worried about treatment with doxorubicin as there is no firm evidence this will help. Continuing with homeopathic/acupuncture. Mentioned sirolimus to Professor Whelan and he didn't think it would be of use in patient's case. 7 July 2015 - CT Scan and follow-up appointment with Professor Whelan 17 July. Meanwhile, trying to live an ordinary life as best as can and still hoping for a perfect treatment/cure. October 2015 - patient passed away.
WJ3601	Dx 7/2001 aged 65 Updated May 2004	DECEASED EHE in lungs, liver and bone sites. Sept 2001 – dry cough for a few months, xray diagnosis of pneumonia, and 'infiltrate' in right lung. Misdiagnosed w/needle biopsy as carcinoma, 2.5cm tumor in lung, multiple glassy opacities. Diagnosed EHE with surgical biopsy, confirmed with immunohistochemical stains for cytokeratin and positive for vascualar markers CD31 & CD 34. Oct 2002 – Endostatin trial for last 6 months unsuccessful. Small lesion in liver, multiples in spine, 50% compression right lung airways. July 2003 – 8 months on Taxol - reduction in primary tumor, opened airways. Dose reduced to due to side effects – thereafter minor tumor reduction. Nov 2003 – Alternative treatment Mexico – Laertrile – shark cartilage enema, various vitamins and enzymes, strict diet. Minor growth in 6 lung tumors – stopped because liver enzymes very high. Jan 2004 – Pleural cavity effusion. Start of lung pain, ultrasound guided thoracentesis removed 1.5 liters fluid, some remaining fluid too thick to remove. Pleural lining thickening due to length of time fluid remained. Feb 2004 – Gemcitabine. Premedications: Decadron 10mg, Xofran, Aranesp. Celebrex. April 2004 – Cat scan – stable. May 2004 – Bone survey – multiple bone tumors – pelvis, ribs, spine.. Aug 2004 – Pet scan revealed nine vertebra and the sacrum are affected. Also other bone involvement. Taxotere will be alternated with the Gemcidabine. Will also have Neulasta 24 hrs after the Taxotere to help keep the white ce count up. July 29 2005 – Sadly, patient passed away on this day. She had been very ill for almost a year. She experienced quite a bit of pain and suffered from shortness of breath, even though she was on home-based-oxygen. Her family was beside her as she found her peace.

WJ9114	1-Nov-2015	EHE in lungs and bones. July 2014 - Diagnosed, (23) mass in the lung, underwent 5 rounds of chemo and radiation January 2015 - new growth in the lung. New chemo regiment: -Premedication with ondanestron 8 mg IV -Gemcitabine 400 mg/m2 IV day 1 and day 8 -Doxorubicin 20 mg/m2 IV day 1 and day 8 -Docetaxel 20 mg/m2 IV day 1 and day 8 Cycles are 28 days long. This translates to "2 weeks on, 2 weeks off" March2015 - PET scan it showed less metabolic activity which was interpreted as response to chemo. May 2015 - PET showed continued imporvement in SUV value. July 2015 - PET showed increased activity. Stopped current chemo regiment. Treated now in Santa Monica Cancer Center, on a clinial trial. Pazopanib plus TRC150. November 2015 - bad pnemonia. Scan showed cancer progression so taken off the clinical trial, Going to see Dr Ravi in MDA. December 2015 - per Dr Ravi recommendation, was put on cyclophosfomide. Had very bad side effects (upset stomach), decided to take a break for February 2016 and restart in March. March 2016 - hospitalized with bad pnemonia, put on O2. Too sick to undergo chemo. April 2106 - sadly passed away.
ZR0002	1-Feb-2016	Recurrent EHE in liver, lung pleura, bone 1996 - Diagnosed with Budd Chiari syndrome, which caused build-up of bile in the abdomen, poor liver function etc.. Placed on fluid retention tablets and monitored closely. She suffered muscle cramps and was getting about 8L of abdominal fluid drained every 2 weeks for 6 months prior to transplant, heavily reliant on aldactone for fluid removal. 1998 – Suffered from Henoch Schonline Purpura – 6 months of problems with rash and severe inflammation and swelling. 2001 – Unable to work, severe swelling in abdomen, weight loss and fatigue, cramps. December 27 2001 - Received liver transplant. January 2002 – Doctor advised real cause was hepatic EHE tumour, found after analysis of old liver. We were advised it is a benign tumour, no problem, not malignant. After several months with some problems, especially with Tacrolamus and change to Cyclosporan, everything stabilised and we went back to normal lives. November 2007 – while living in China, Rebecca developed some nodules on lung which were detected on annual health check in Shanghai. Returned to Australia, biopsy did not suggest EHE (granuloma)February 2008 – fell pregnant with son. June 2008 – developed problems with jaundice, gestational diabetes and cholestasis. Returned from China to Australia, admitted to Mater Womens Hopsital and monitored closely. September 2008 – Son born at 31 weeks, many complications but after 3 months, released from hospital and now very healthy. July 2012 – While on holiday in Australia from China, developed a very bad case of chicken pox. Took one month to recover and was very sick. September 2012 – complained of lower back pain, initially we thought it was a strain. After one week developed breathing problems. Went to Shanghai, scans showed multiple (>15) nodules on liver, suspected HCC, also minor fluid on lungs. Returned immediately to Australia, biopsy confirmed EHE recurrence. Initially CT, MRI and PET scans showed no mets. Placed on liver transplant assessment program for OLTOctober 2012 – After worsening breathing and severe pain, doctor drained lung fluid. Fluid quickly returned, they then did talc pleurodesis and biopsy of pleura. Scans and biopsy confirmed multiple pleural and visceral nodules. Bone scan then found 3 lesions on leg bones. Transplant cancelled due to mets, chemotherapy and anti-angiogenesis therapy planned. 20 November 2012 – started first cycle of Doxorubicin – 20mg/m2 weekly for 3 weeks, 1 week rest, 20mg/m2 for further 3 weeks (weekly). Current symptoms are severe thoracic pain, inflammation of arms and legs has been finally controlled with prednisone. Lost 9kg in 2 months and is now 53kg, poor appetite. Continued Doxorubicin until May 2013. June 2013 – Started Pazopanib (Votrient) 400mg/day. Treated for 14 months. Completely ineffective and terrible side effects – cyclic and high level pain, tiredness, nausea, hair all turned white, inflammation and facial swelling etc. By mid 2014 - extensive and uncountable tumours in liver, bone, spleen and lungs. September 2014 – Changed from Pazopanib to Cyclophosphamide daily oral chemotherapy 100mg/day. Initially halted the progress of the tumours for about 6 months until it progressed. Side effects tolerableEarly 2015 – changed immunosuppressant from Cyclosporan to Sirolimus for the mTor inhibitor effect. Initially targeted 8-12 Sirolimus in blood (1.5mg/day) and increased to 12-15 (2mg/day). Has shown no effect. September 2015 – Stopped Cyclophosphamide chemotherapy due to low blood platelets and haemoglobin, general poor health. February 2016 – all treatment options have been exhausted and she is too weak and sick. Now being cared for at home with assistance from palliative care team. Note: Patient has never smoked or drank alcohol, and has always had a healthy diet March 2016 - Sadly she passed away.

ACTIVE PATIENTS (WITH VASCULAR CANCERS - NOT EHE)

Patient ID	Date of update	Story
*D0610	2012-08-01	Dabska tumor, initially diagnosed as Benign Vascular Malformations in the Abdomen (primarily the omentum). March 2006 - Emergency trip to hospital with pain in his abdomen, which resolved just as suddenly as it appeared, however a CT scan revealed large amounts of fluid in the abdomen as well as numerous soft tissue masses. July 2006 - exploratory surgery and a biopsy of the masses on the abdomen. The biopsy revealed that the tissue samples were benign vascular malformations. The samples were also reviewed by pathologists at MD Anderson and t University of Michigan hospital. ______ tolerated the surgery well at first...however a short time after the surgery, he went down hill fast. I took him to the emergency room again, and found he was bleeding internally and had lost 7 units of blood. He received a transfusion and was fine. Instructed to follow up in 6 months. Dec 2006 - CT scan that revealed some additional lesions on his spleen. Dec 31 2006 - Emergency room again for a sudden onset of extreme abdominal pain and ascites (fluid in abdomen). Additionally, his blood counts had dropped, indicating a slow bleed internally. After a 3 week stay and many additional tests, we are stuck with the same diagnosis (or lack thereof), and the doctors are very uncertain how to treat the condition. There has been some talk of surgery; however because of the bleeding during the surgery in July, doctors are apprehensive. Additionally, a "wait and see" approach has been discussed. May 2007 - The meeting at Mayo went pretty well... the doctor there, Dr. Okuno, had never seen this particular tumor before (the Dabska Tumor), but from what he had read that many times once this particular tumor is surgically removed, it will not come back. It is generally lumped in with the HE type tumors. Dr. Okuno has several patients with HE and EHE, so he did have some thoughts on how to proceed with ______'s treatment. Dr. Okuno was a bit concerned, though, because this tumor presented itself in a very abnormal way in my husband - on his omentum (the fatty apron that covers your internal organs), but it is usually seen on the skin. So, for now, we are going to follow up every 3 months with scans, and if the tumors look like they are coming back, then they will start my husband on either thalidomide or avastin. With the history of these tumors bleeding in my husband, however, the Avastin may not be a good option. Aug 2007 - _______ is feeling great - his hemoglobin is actually in the normal range, which is a good indicator that he is not having any major bleeding like he was before. He has been having some discomfort in his right side, where the doctors removed a benign bloody cyst during his surgery in May; however given that they found Dabska tumors and lymphangioma elsewhere in his abdomen, the oncologists at U of Michigan are somewhat concerned. His scan in July also showed that even though the cyst was removed in May, there is something growing again in the same location, and obviously a scan cannot tell us what it is. We are hopeful (as some of the doctors have suggested) that is residual fluid from the surgery or the benign cyst regrowing. Next checkup is in 3 months. June 2008 - My husband _____was diagnosed with Papillary Intravascular Angioendothelioma - Also know as a "Dabska Tumor" in his abdomen last May after having an exploratory surgery to explain the hemorrhagic ascites he was having at the Mayo Clinic in Rochester Minnesota. He was having a paracentesis every 2 weeks and removing up up to 5 liters of fluid. At the surgery - they removed 8 liters! They also removed several small tumors from his abdomen. They left several additional smaller tumors on his diaphragm and did not want to attempt to remove them at that time given the level of irritation in his abdomen. His surgeon at Mayo had never seen anything like this. Furthermore, we have contacted several leading pathologists who have done studies on this particular tumor, and so far, it seems like this is one of the, if not the only case, where this precise tumor was found inside an abdomen. Usually it is a tumor of the skin. After the surgery, ________ was doing well, but the residual tumors continued to grow, so his doctor back at home, Dr. Rashmi Chugh at University of Michigan, had him start Interferon A injections 3 times a week - he takes 10 "units" - which is a very small dose. Dr. Chugh recommended ______ get a second opinion on this course of treatment, given the rarity of his tumors, so we travelled to Houston to MD Anderson and got a second opinion from Dr. Jonathan Trent. He agreed with the course of treatment. After being on the medicine for 3 months, the growth of ________'s tumors appeared "stable"- and then 6 months after starting it, 2 of his tumors had disappeared, 2 others had shrunk, and the last one stayed the same size. _______ has another scan in July, and I pray that things will stay on the same good path. ______'s doctors have suggested that if this treatment stops working, he could try Avastin. July 2009 – Not much new to report. His physician at University of Michigan has decided to move his scans to 6 months from 3, as he has had several stable scans in a row. The Interferon A seems to be working, however, the side effects at the new higher dosage (15 IU injections 3x per week) have been taking a toll - my husband is exhausted all the time and has a very difficult time keeping on weight. We will reassess the effectiveness of this new dosage at his next appointment in September. His doctor may consider cutting the dosage of the Interferon A and adding Celebrex. Jan 2010 - ________ was recently approved by our insurance to try Sorafenib (Nexavar), 200 mg, twice a day. It is much easier for him to tolerate this medication than the interferon A he had been taking. He has been able to gain some weight in the last few weeks as well, as the Sorafenib does not seem to make him as sick to his stomach as the Interferon did. His doctors are considering doing another surgery as my husband has developed several hernias, one inguinal hernia and a ventral hernia, along his old surgical incision. In order to limit the total number of surgeries my husband must have, and given the fact that he has such a high risk of bleeding during abdominal surgery given that is the location of his tumours, the doctors are considering repairing these large hernias and doing a debulking surgery all at once Aug 2012 - My husband is having wonderful success with propranolol - a blood pressure drug. A specialist in Cincinnati suggested he try it and he has been stable for a year! This is a first for us since he was diagnosed in 2007. His doctor said he has no fluid in his abdomen (one of his biggest problems) and he has been able to get his weight back to normal. ****Jane Gutkovich contacted for an update in November 2014 and received no response.
BWUS1012	2012-11-01	Hemangiopericytoma October 2010 - Have had 5 surgeries and have had 32 tumors which have all been benign. Last surgery was November 2008 and had a CAT Scan in July which revealed no new tumors. Chemo was tried in 2008 but did not shrink the tumors. Have other medical problems but now do feel fairly well. November 2012 – DX is hemangiopericytoma. I have been fighting it for 7 years and have had excellent care but these tumors keep coming back. It is a very rare type and not much research has been done.
CSUK1011	2011-05-01	HE of nerve sheath Back to 2010, I have felt pain in my inner thigh, a few inches above my knee, but dismissed it as a strained muscle. December 2010 - I awoke in excruciating pain January 2011 - I went for an ultrasound which showed lesions. I was immediately sent to a soft tissue lump specialist at Southampton University Hospital March 2011 – I had an MRI and the consultant diagnosed me with Nerve Sheath Tumour and referred me to a plastic surgeon at Salisbury Hospital to have it removed on April 6, 2011. Beginning of May 2011 - I contacted the hospital who referred me to my GP. My GP was informed by the hospital that my tests had come back inconclusive. I then went back to Southampton for more tests. I spoke with a histologist at Southampton and was told the tumour was malignant and that it had been diagnosed as Hemangio Endothelioma. The doctor had not heard of this condition before and could offer no advice other than I may have to have a larger area, from the site of the tumour, removed.

EA0910	2010-07-08	HE in hand February 2009 - noticed pain on palm of his right hand. August 2009 – more pain, tumour spreading, more tests, finally diagnosed as HE at M D Anderson with several focal points. September 2009 - Met with Dr. Pappo who recommended Interferon shots or chemo with aggresive surgery as the best options. Sept / Oct 2009 - started on Interferon A, 3 times a week, with weekly liver screening, to be done in Austin at Dr. Lockhearts clinic. - Dr. Lockhart had him admitted to Dell Children's to start the Interferon shots - inpatient treatment allowed for psych eval due to aggresive behavior at home. - taking time release Morphine, Lexapro, Colase, Pepcid, and Lorazepam. - Psych time added serquel and clonidine. - Had flu like symptoms from the Interferon shots. - Headaches got really bad, mainly on the right side of his head and ended up at ER because of breathing prob. - Has developed several cafe au lait spots on his stomach. - Pain in hand is still the same. - He is homebound. School doesn't want him on campus if he is on morphine. October 2009 -The pain in his arm hasn't changed, he is actually complaining that it goes up higher in his arm now. Biopsy site seems to be getting swollen again but headaches are better. Dr. Lockheart decided to start him next week on Calcium infusions because he has lost most of the bone on his thumb. Nov 2010 – MRI at MD Anderson shows that bones on fingers are growing. Starts on Neurontin. Dec 2010 - He is severely depressed, Serquel and Lexapro are removed. Starts on Zoloft. Café ole spots gone. Feb 2010 – MRI at Strictly Pediatrics shows same results as Nov MRI. He is not feeling as much pain as before. He refuses to consistently do the Interferon shots because of the side effects. Only on Abilify now. May 2010 – Complains of numbness in his arm but no other concerns. (struggling to get him to appts). Mid June – Notice a small bump on his left arm. MRI Scheduled for July. July 8 2010 – Small bump on left arm still there but hasn't changed. New larger bluish bump now on right hand between thumb and index finger. His oncologist decided to only scan his right arm. He has two new growths on his hand. She suggested steroids as a possible treatment and said there was nothing else out there. I'm not too happy with her, but there are only 8 pediatric oncologists in Austin and they work together. I don't think I can get him to follow through with any treatment that is done at home. He stopped taking the Interferon and psych meds in Feb and I haven't been able to get any help with him. His behavior is a major issue but I can't get him admitted to any of the psych hospitals because of the tumors. Also, because what he has isn't considered to be cancer, he doesn't qualify for other programs that could keep him from being so depressed and mad.
ES0715	2015-06-01	HE Sept. 2007: Surgery to remove what the surgeon thought was a calcified lymph node near my collarbone. The biopsy later showed it was a hemangioendothelioma. Because there was some vascular involvement, the surgeon didn't get it all so I'm now being referred to a vascular surgeon for removal of the remainder of the tumor. Previous medical history: My family is very prone to lumps and bumps (specifically lipomas and ganglions). I had had this particular bump for five years but it started causing me pain around a year ago. Prior to this event, I've enjoyed almost perfect health. A test 10 years ago showed that I have horseshoe kidneys. Nov 2007 - saw Dr. Ernest (Chappie) Conrad at the University of Washington Medical Center. He did my second surgery to remove the remaining tumor. Yesterday, I went to see Dr. Krueger (Dr. Conrad's Fellow) and was told that there were clear margins. However, the chest CT showed there was the smallest of spots on one of my lungs. Dr. Conrad says he isn't too concerned but he did want to be prudent so I'm scheduled for another chest CT in three months. Then in another 3 months I'll do another chest CT and a neck MRI. Feeling great! Feb 2008: Chest CT unchanged. No new scans scheduled at this time. Everything is fine and I'm feeling great! Jan 2010 - I have not had any health issues since my tumor was removed in late 2007. I continue to have annual chest x-rays because the doctor is watching a small spot in one of my lungs but I feel great and have no health complaints. Aug 2012 - I don't have any new information to report – thankfully!! July 2015 - everything is clear, still watching tiny nodules in the lungs.
HT0912	2012-08-01	HE in liver July 2009 - symptoms, fatigue, abdominal pain, stomach discomfort and shortness of breath. Originally diagnosed with hepatocellular carcinoma at Tampa Moffitt Cancer Center. Later came up with HE. He has an oncologist in Ocala too. Mar 2010 - He has been in pain since before the diagnosis which was in May of last year. His pain is in his upper right side and he has pain in his back as well. He also has occasional bloating. He just underwent chemoembolization and goes back next week for a scan. He has been told by several doctors that a transplant is his best option and he is considering it. Feb 2011 - _____ had a liver transplant last Friday and he is doing well. Aug 2012 – ______ is doing well. ****Jane Gutkovich contacted patient's wife for update in January 2015 and received no response.

JAEN7010	2010-06-01	HE in sacrum, possibly lung and liver too. LATE 70's - ROYAL VICTORIA INFIRMARY (R.V.I) Newcastle U.K. Following a bout of liver pain, an exploratory operation uncovered a small tumour in liver. It was found to be benign and at that time doctors were unable to diagnose type. No further treatment. EARLY 80's - (R.V.I) After repeated bouts of bronchitis, a lung x-ray revealed a small tumour. Test results showed it was benign and no treatment followed. Leading up to 2004 - my mother experienced intermittent sciatic nerve pain / spasms and cramps in her legs. She developed what she described as 'itchy nerve pain' into her buttocks and an internal numbness into her vagina and an irritable bladder function which would self release. Following a consultation with a gynaecologist/ urologist it was thought that a bladder prolapse was the probable cause, and an operation to rectify this followed. Symptoms continued to persist and following the operation, her bladder function never returned. My mother continues to 'self catheterise'. November 2009 - Neurologist (Dr.Duddy) ordered MRI scan at Wansbeck District Hospital, Northumberland, UK. A 14 cm round tumour completley filling the Sacrum Cavity was discovered. Mother's mobility limited and painful; Takes Tramadol and Ibuprofen for nerve pain. Bowel movements were difficult as she had lost alot of the ability to 'push'. Two biopsy's were taken at General Hospital at Newcastle and diagnosis was a Chondrosarcoma. May 2010 - Consultation with Mr. Nissen and Mr. Gibson,(Senior Spinal Consultant). Informed that surgery to remove the tumour would be very difficult due to the location of the tumour and the amount of nerve damage that would occur. Chemo not an option as the tumour would not respond to this treatment. June 2010 - Tried embolisation. Within 3 weeks there was a definite improvement in her mobility, and she described the feeling as 'pressure had been eased'. She no longer takes any pain killers and can walk well. A second opinion was sought and her notes were referred to Mr Spooner / a specialist in Oncology - Queen Elizabeth Hospital in Birmingham UK. Diagnosed as HE. Mr Spooner says that embolisation had definitely shrank the tumour although not yet rescanned. He advises that further embolisation be considered after monitoring the tumour. Thinks she has had the tumour many years and as it has grown so slowly, and is non aggressive, a 'wait and see' approach is best.
LP0812	2012-04-01	EHE in shoulder rediagnosed as hemangioma Dec 2008 – Increasing pain in left shoulder for the whole year. Had 2 cortisone injections, helped a bit then wore off. Too sore for Physical therapy, increasing pain and restriction of motion. On 800 mg of Motrin 3 times per day for pain. March 2009 - MRI of shoulder, found an 7.5 cm lesion on humeral head extending down shaft of humerus. Bone scan only showed that one "bad spot". Cat scans of chest, abdomen, and pelvis all fine. Sent to Dr.Brian McGrath (oncology surgeon) Buffalo General Hospital who did a needle core bx. (unable to get definite dx) sent back to hosp. for open bx. (shoulder epithelioid hemangioendothelioma). Dr. McGrath told me I would need to have the tumour removed by him and have a reverse shoulder replacement by a shoulder specialist (Dr Marc Tetro). April 2009 - Surgery was successfully completed. I am recovering well, waiting to see final path, medical oncology and radiation oncology at Roswell Park Cancer Centre in Buffalo. I am hoping no other tx is necessary. June 2009 – All doctors still agree on EHE diagnosis. I will keep in touch, but still not having radiation. All is fine Just got back from the Dr's. The radiation oncologist called me back and changed his mind. He said that there was a study from Mayo Clinic that showed rad. after surgery would help. I am not totally convinced and am looking for another opinion. July 2009 - I just got my pathology results back from Boston - Dr. Christopher Fletcher, Harvard Medical School. He said it looked like a hemangioma of the bone - not hemangioendothelioma. Feb 2010 - I was dx w/ EHE in my left shoulder in 4/09, I had a reverse replacement shoulder and am doing well. My 3 month and 6 month cat scans were good - they said there is a small 5 mm nodule on my lung but don't think it's anything to worry about. I still have restricted movement in my left shoulder/ arm and some achy discomfort in my arm and neck. My biggest complaint is that I still can't sleep on my side, I have to lie flat on my back, if I turn I get a lot of numbness and tingling that wakes me up, but am happy to be able to use my hand so well. I work full time in a Dr's office (I'm a nurse). I never did get the radiation that Roswell Cancer Institute recommended. I felt there wasn't enough evidence that it would be of benefit and the risks of complications/ side effects were pretty high in my opinion. The last x ray I had was in Oct, I'm due soon. May 2010 - I just had my 1 year check up since my surgery. I'm glad to report no sign of any recurrence, chest x-ray clear and bone x-rays look good. I am still working on rehabing my shoulder, light weights 1-2 lbs only but my hand and arm work! October 2010 - My body is not rejecting the cadaver bone and the prosthesis failed. I underwent a second surgery in April 2011 where they did another shoulder replacement this time with bone marrow grafting and BMP. I was lucky they didn't find more cancer. Now I'm waiting to see if the bone graft works. Feb 2011 - cadaver bone resorption, replacement failure, another reverse replacement with bone graph. April 2012 - continued resorption of cadaver bone, loose prothesis, another surgery with bone graph. Last oncology visit, no sign of cancer but still unable to take arm out of sling and move without pain (resorption). I am grateful to ha a hand, but I don't think I can tolerate another shoulder replacement!

PC0915	2015-01-01	HE in liver and lungs Jan 2009 - I am 47 years old, in good health otherwise, and have no symptoms other than fatigue. I am pre-menopausal, and have spinal joint facet degenerative disease, so any pain I may have from my liver may have been masked by the back pain. I was diagnosed incidentally. I had a lump that came up on my collar bone and the surgeon recommended a CT scan to make sure the fat tumour (harmless) wasn't down into my lungs. They found innumerable tiny nodules in my lungs, and 9 tumors in my liver, the largest one is 3.9cm. March 2009 - I had a liver needle biopsy (on the largest nodule) diagnosed it as HE. My oncologist is Mark Currie, and Lewis Gale Med. Ctr. in Salem Va. He referred me to Dr.Paul Savage at Bowen Gray at Wake Forest N.C.. Dr.Savage has had a couple cases of HE, (he's a soft tissue specialist) and recommended another CT scan and bone scan for the end of May to see if there is any growth. And to make sure there's no cancer in my bones. If it has grown, I will start on thalidomide. But if there's been no change, they will continue to scan and watch it for change. Any treatments I need will be done at Lewis Gale, near my home. July 2009 - The bone scan indicated I have abnormal fusiform uptake in my left 7th rib with numerous pulmonary nodules. The CT scan on my abdomen shows multiple lesions in my liver, no change in size and number, the largest one is 3.1cm. The CT scan of my chest shows a 1cm nodule in the right lobe of my thyroid, and innumerable uncalcified pulmonary nodules in my lungs, all under 1cm in size. No change since February. No treatments at this time, we're just watching and waiting for any change. I have good days and bad, my energy levels are down, and I tire easily. I have pain in the area of my liver, and in my chest especially on the left side. I have coughing attacks where I just can't catch my breath, and a very deep cough, this occurs whenever I exert myself. Nov 2009 - I had to go to Dr.Currie last Monday(11-9), I've been having a lot of pain in my liver, and he ordered a CT scan and chest x-rays. The scan showed that the tumors in my liver have grown a tiny bit, and one is blocking a bile duct, and he thinks that is what is causing the pain. He wants to start me on thalidomide. February 2010 - I'm doing OK. Started on Thalmid (100mg) the week before Christmas and my last CT scan shows my tumors haven't grown any. (They had started to grow, which is why I started on the Thalmid). I am tired a lot, and have some swelling in my legs but, I'm getting used to it, and hope I can return to more of my normal mom routine soon. I am a stay home mom, so thankfully I don't have to worry about going to work! June 2011 - CT scan on June 7, 2011 and the results show no change in tumors. Still taking 100 mg Thalmid daily and have some swelling in ankles and feet from the Thalmid. August 2012 - I'm still stable..my last CT scan was June 9th, there has been no growth in my tumors. I changed oncologists in January, and now I am under the care of a wonderful doctor and his staff! Dr. Richards is with Blue Ridge Cancer Center. I'm also seeing a psychiatrist for my anxiety, and am doing better than I have since I was diagnosed. I continue to take Thalmid 100 mg daily, and morphine for my pain. I still have fatigue, and the Thalmid has done permanent nerve damage to my feet, finding shoes that do not hurt my feet is an ongoing challenge, but the tumors have not grown in over a year..so the side effects are bearable. January 2015 - There has been no change in any of my scans. I stopped using the Thalmid in March of 2013. It has caused permanent nerve damage to my hands, and more to my feet.
PD1010	2010-02-01	HE Feb 2010 - recently diagnosed. It took a long time to figure out that it wasn't just my ribs. I broke 3 ribs left side in August. I bent over to pick up something off the floor and it felt like a terrible muscle spasm hit me. Took 5 months till HE diagnosis. Some year or maybe 2 years prior I mentioned to my family doctor that I felt like I had an infection or something inside my chest cavity. I think now this could have been found sooner.
PR1010	2010-06-01	HE in liver March 2010 - complaining of feeling bloated, having left upper quadrant abdominal pain, and vomiting blood for a couple months. Mar 24 2010 - Abdominal ultrasound showed enlarged spleen 23 x 10 cm. Further scans showed enlarged and heterogeneous spleen 22 cm x 21 x12 cm with trace ascitis. The liver was enlarged to 23 cm. Told to consider splenic lymphoma. Mar 26 2010 - spleen removed. Is found intraoperatively that spleen is bleeding and even ruptured. Mar 27, 2010 - enlarging abdomen and unstable vitals, thought that he may be bleeding. No source identified, just oozing from multiple places. Apr 12, 2010 - Path report from spleen and liver bx intraop shows hemangiodendothelioma mild grade. May 30, 2010 - complains of neck pain, MRI shows hemangiomas in cervical spine (unclear if in bone or soft tissue). Also complaining of epigastric pain shortly after eating, feeling early satiety, abdominal fullness, small amount of bloody vomit. Jun 2, 2010 - CT enterography from lung bases to symphysis pubis shows liver has grown tremendously to 37 x 16 x 20 cm up from 23 x 10 x 20 cm. Osseous structures show multiple new lytic lesions suspicious for metastatic disease identified in the iliac bones bilaterally and multiple vertebral bodies in both lumbar and thoracic regions. Jun 4, 2010 - He had large amounts of dark colored vomit and large amounts of dark colored stools. Jun 6-9, 2010 - Multiple endoscopies, interventional radiology with possible embolization of splenic artery, CT abdomen and pelvis with contrast showing multiple liver lesions, active bleeding into gastric lumen, pseudoaneurysm of splenic artery, lytic lesions suggestive of mets, abdominal ascites, and bilateral pleural effusions. June 2010 - Remains intubated in the surgical ICU, started interferon b2 yesterday 18 million units (very high dose I am told), spike a fever the next day, they started him on antibiotics to cover for pneumonia or intraabdominal process. Remains sedated secondary to the critical nature of his illness.
Q*1010	2010-02-01	HE in liver Feb 2010 - My daughter was just diagnosed with Hemagioendothelioma. She was complaining of lower right pelvic pain. A CT- Scan showed a liver mass. The rare part is that the mass is located in the upper left lobe in the liver and she was complaining of lower right pain. The oncologist showed us the large mass which had a large blood vessel attached to it. We were told that because she is stable, she does not need immediate care. She is active and being her happy self. Surgery is planned for May 5th.

SK**08	2008-06-01	HE in spine 1990: Diagnosed by needle biopsy in neck (unsuccessful) followed with surgical biopsy. Initial opinion was the tumors were malignant and recommendation for several surgeries, removal of section of spine, fusing of new bone and insertion of steel rod. Reassessment was tumors were not malignant but should be treated as such, but surgery was too risky and radiation therapy was used instead to reduce tumors. To date: Slow growth; watched with MRI's and cat scans. Neck stiff and sore, constant back-pain, headaches. On three Roxicett daily and thyroid medication. Aug 2006 - tumors on my spine are still stable after all these years, though enduring back pain. Aug 2007 - still on pain meds and have back and neck pain and burning every day, but otherwise, nothing new. I need to go get another MRI soon. I started taking calcium and magnesium supplement I can't believe my change in energy, I started taking it for leg cramps and I already get b-12 shots every month. June 2008 - I am doing really well for being diagnosed in 1990 and haven't had to have anything else done so far except a biopsy in the beginning and then radiation therapy. The tumors are still there but so far as my last MRI, the same size. Not growing. Dr. Ernest Conrad is still my doc at the Seattle Cancer Care Alliance.
TA0012	2012-08-01	Suspicion EHE – in liver and lungs and spleen. Now suggestion is angiomatosis instead. 2000 - several large haemangiomas in my liver. 2003 - had seven eighths of liver removed. A few very small ones were left in the remaining section. 2004 - had a section of my right lung removed with the same thing. Had opinions world-wide…multiple haemangiomas with no sign of cancer. April 2006 - At my 12 month check the lesions are now growing and I have 11 in my liver and 3 in my spleen. I am very fit and well with no obvious signs of illness and apart from suffering from a swelling in my abdomen before my liver resection due to having two blood vessels which were at least 15cm in diameter each and hung down filling my abdomen. I was very well then and my liver function was and is normal. Interferon was suggested. Samples of my liver were sent over to Dr Christopher Fletcher, Director of Pathology at Brigham & Women's Hospital in Boston, Massachusetts. His findings were inconclusive as he confirms there is a mismatch between the appearance of my tumour under the microscope and the clinical behaviour. He thinks my tumours should be labelled as angiomatosis of the liver and that it is possible I have a low grade form of angiosarcoma but that there is no direct evidence for this. There is no sign of anything being malignant. Sept 2006 - CT scan showed very little growth in the tumours over the past 6 months and no new ones have developed. First time since diagnosis that there has been so little change. Back to 12 month scan and check up. Still the possibility of having my spleen removed and liver transplant in 5 plus years if the tumours grow as before. Suffering from surging hormones due to the menopause although these have stabilised during the last 6 months. Previously had discussed the fact that growth in the tumours have coincidentally happened when hormones surge. Have had problems with this for several years and took the contraceptive pill for this for many years. High doses were necessary to bring them under control. Feeling extremely well and completely symptom free so will try and enjoy the next 12 months. Sept 2008 - At the moment I seem to be doing OK. At my check up last September, for the first time in about 6 years, I have no new growths and no significant change in the ones I have. I am on no medication and haven't got to go back until September 2010, unless things change. To 'celebrate,' my husband and I are training for a half marathon this autumn! Sept 2009 - very little has changed. One blood vessel in my liver that had grown rapidly has now stopped and another one has grow quite a bit. There are a few new ones in liver but no new ones anywhere else. I still have no symptoms and no one knows why any of this is happening. Prof Lodge still thinks that in the long term I am looking at a liver transplant but not whilst I am so well and have enough working liver. Jan 2010 - At the moment I feel very lucky with my condition as at my last check up last October I found there had been very little change in the past two years and don't have to go back until Oct 2011. Aug 2012 - The following year I had some removed from my right lung. Since then I have had regular check ups and scans most years. I now have some in my spleen as well. Over the past four years there has been no significant growth and my consultant, Professor Lodge, from Leeds in the UK, plans to scan next year and if things are the same he won't scan for 5 years. I am on no treatment and have no symptoms
TP0210	2010-01-01	HE in liver, spleen and possibly lungs - > Abdominal angiosarcoma 2002 - Six years ago I started having "iffy" blood readings after taking Zocor for about 15 years for high cholestrol. Tested me thoroughly including colonoscopy and bone marrow exam. Nothing! April 2008 - liver results were out of normal ranges. I had a liver ultra sound followed by a c-Scan test which indicated tumors in the liver, along with an enlarged spleen. Sep 2008 - Liver needle biopsy which was sent to the Mayo Clinic and confirmed HE. Second indicated spots (not sure if they are malignant) on my lungs. I am now down to 148 lbs but still able to sleep at night by taking one Ibuprofen before my 4 mile walk in the morning and one just before bedtime. Oct 2008 - met with Dr. Okuno at the Mayo Clinic. I had been diagnosed with Hemangioendothelioma of liver and spleen, and advised that I am a candidate for a research study of Bevacizumab for the treatment of Angiosarcoma. Nov 2008 - I am now in Phase II study of Bevacizumab and have had my first intravenous treatment (Avastin only). Dec 2008 - dropped from the Avastin clinical program due to the increase in liver tumors. I had only completed one cycle! Jan 2010 - My clinical history reads Abdominal angiosarcoma, which I have been seeing my oncologist for the last year & one-half. I did the 6 months chemo treatment (which ended in August) and am waiting to go on Zometa in Mar to protect my bones which CScans showed have spotted areas. I will be 71 yrs old next month so I am not a candidate for organ transplant. I have been to Rush/Chicago, Mayo Clinic, and Northwestern Univ/Chicago and no one has a suggestion for treatment because they claim my tumors are very rare.
TT0909	2009-10-01	HE on the back side of the head Oct 2009 – Newly diagnosed. Was surgically operated and his HE was removed - size 10x10mm. The removed body was given for more opinions in Sofia, Paris and Heidelberg. After receiving future results it will be decided if a second surgery is necessary in order to remove bigger spot, to minimize future metastaesis. PET scan showed no other growths. We will monitor regularly.