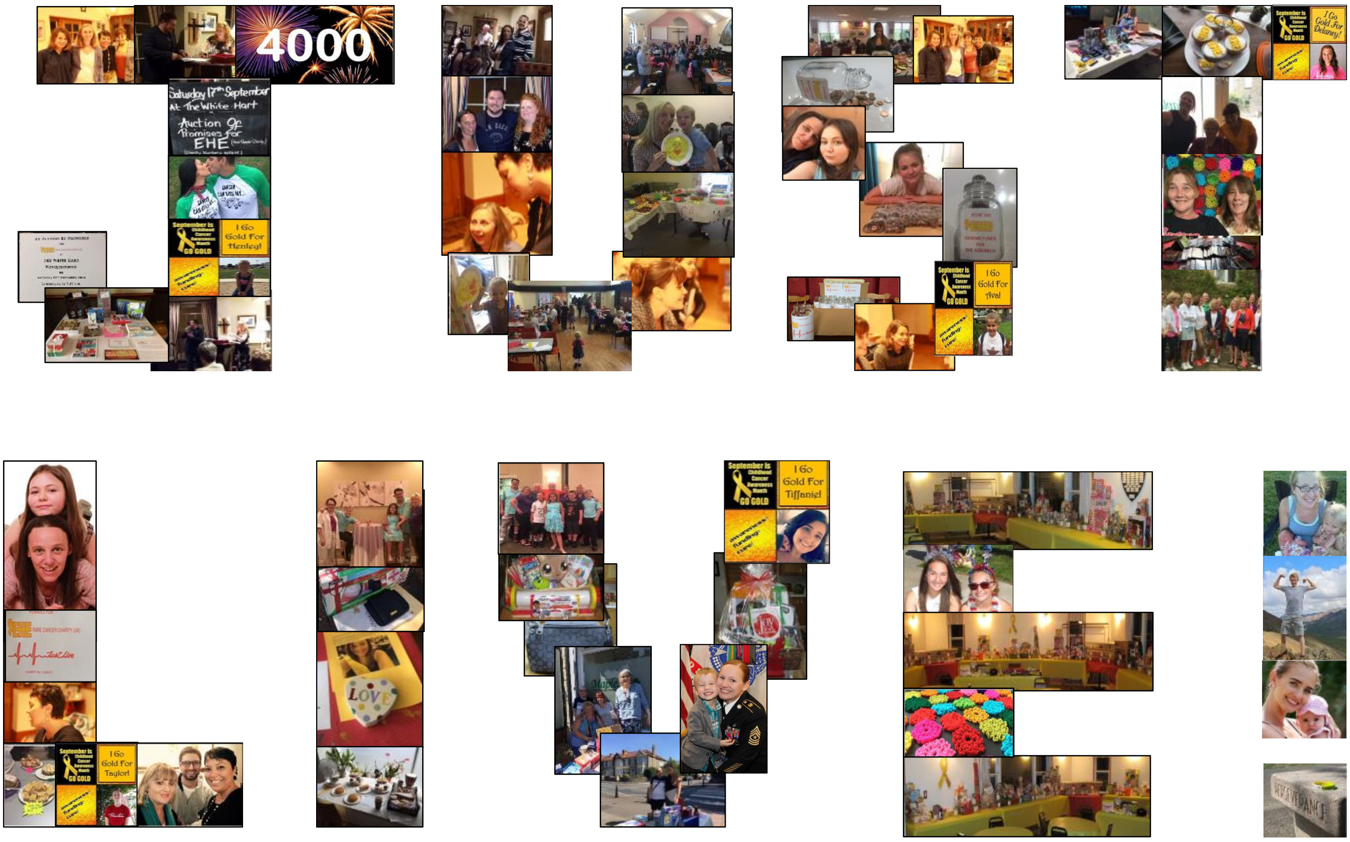
The EHE Foundation
The EHE Rare Cancer Charity (UK)
The EHE Rare Cancer Foundation (Australia)

THE PLEDGE

Quarterly Fundraising Newsletter for the EHE Group

(Edition 6 : July - September 2016)



Just Live

Welcome

We warmly welcome all our readers to this sixth edition of “**The Pledge**”, the quarterly fundraising newsletter of the EHE Group. We hope that this newsletter, covering the third quarter of 2016, will keep our members and existing donors informed about our activities and will also help to encourage and inspire new supporters to join our battle against EHE.

This quarterly newsletter provides brief reports on a number of fundraising events and initiatives undertaken in the last three months to support our ongoing battle against EHE. We are however aware that many others are supporting EHE by making direct contributions to Dr Rubin's fund, by supporting the fundraising events run by other members, by offering patient support and encouragement to our group, and by spreading awareness of EHE.

Whatever the form of support that you provide, and regardless of magnitude, we want to express our sincere thanks for your contributions. They are all critical to our success and ability to ultimately defeat EHE. Every dollar donated is critical, every message or act of support priceless. Thank you to all of you.

Highlights

Jane Gutkovich prepares for CTOS 2016

The 2016 annual CTOS conference will be held this year in Lisbon. Jane Gutkovich will be there once more to direct and encourage discussion and engagement on EHE!

Dr Rubin submits significant grant application

Dr Rubin’s overall EHE research programme progressed with submission of a significant grant application to the United States National Cancer Institute which, if successful, will provide substantial new funding for critical aspects of Dr Rubin’s EHE research.

EHE Group-funded Post-Doctoral Researcher joins Dr. Rubin’s team

Dr Rubin has confirmed that his new post-doctoral research assistant, funded by our EHE Group, will be joining his team in October.

Interest in EHE research expands

Interest in EHE research, involving biomarker identification and possible personalized vaccines in immunotherapy, is under discussion with labs in the USA and Israel.

EHE Fundraising Page Launched

The EHE Group was delighted to launch the EHE Fundraising page to help streamline our patient support and fundraising activities. We hope that everybody will join the page, even if not fundraising themselves, and so keep in touch with the exciting things that are happening within the group.

EHE Facebook page membership exceeds 1,000 members

It is with mixed feeling that we welcomed new members to the group taking our numbers over the 1,000 mark. While we are happy that those facing EHE have found us, and that we may be able to provide support and assistance, we are also aware of the growing numbers of people affected, directly and indirectly, by this horrible disease.

While our new membership numbers have increased, the third quarter again included the sad news of several members of our ‘EHE family’ who lost their battle against this rare cancer. We mourn their passing and send our love and prayers to their family and friends. On these sad occasions we also recommit to our battle against EHE and renew our determination to bring forward the day when our motto ‘*Just Live*’ will be a reality for all patients with EHE.

Advocacy

The EHE Group is not just focused on fundraising, but also has a core objective to educate the general public, government and in some cases the medical and research community, about EHE and the impact of living with a rare and frightening cancer. We thank all our supporters who have contributed to this critical part of our activity, and have provided some examples below.

LeeAnn Deacon Conner has them in tears

On the 21st September LeeAnn Deacon Conner (seen here with her 3-year-old son Grayson) posted the information that after 22 years in the Army, she had put on her dress uniform for the last time for her retirement ceremony. LeeAnn wrote “*Not only did I use the platform to talk about EHE and all of you amazing people (and had the entire audience in tears), but I also raised over $1,000 (and counting) for The EHE Foundation. I requested "no gifts, please." I told friends & family that I wanted to "pay it forward" with a donation to the EHE Foundation if they were so inclined. Just Live!*” We want to thank LeeAnn for such a thoughtful gesture and to congratulate her on 22 years of commitment and dedication to her country.

EHE Profile raised in 4th July Parade

Julie Rivers Wahl posted photos of the 4th July Parade held in Gladstone, Michigan. The opportunity to raise the profile of EHE was taken through some minor modifications to LeeAnn Deacon Conner's mom and dad's car, or more specifically, its decoration. We loved the car and most of the petrol-heads in our group wanted to drive it. Awesome car, awesome idea.

EHE News Stories on the Internet

Every week, Jane Gutkovich takes a few precious moments to search the internet for any stories or articles about EHE. On 16th July Jane found the article below on the Upmatters.com website about Delaney Wahl and her EHE. Then in September she found the Exeter Express and Echo article about James Breese, a TV celebrity auctioneer, who would be presiding over Tamzin Jones’ Auction of Promises in the UK for EHE. These simple articles are great examples of media coverage that help hugely in spreading the word and raising the profile of EHE, one of our core EHE group objectives.

Laney's Story: Finding a cure for EHE

Laney Wahl is a high school freshman, an all 'A' honor student and excels in athletics. She is also living everyday like it could be her last.

UPMATTERS.COM | BY JAKE DURANT

Buzz of excitement as celebrity TV auctioneer heads to Wiveliscombe to raise funds for EHE

CELEBRITY TV auctioneer Jamie Breese is heading to Wiveliscombe this week to help raise funds for rare cancer charity EHE. EHE - epithelioid...

EXETEREXPRESSANDECHO.CO.UK

A memorial project

Diana Donohoo posted a Facebook message during August to let the EHE family know that she had started her ornament project at the Siteman Cancer Center in St. Louis, Missouri. Diana added that there is going to be a plaque in memory and that she wants to “*list all our friends and loved ones who have lost their battle against the monster that is EHE*”. We think that this is a lovely idea, and a wonderful way to remember some very special people.

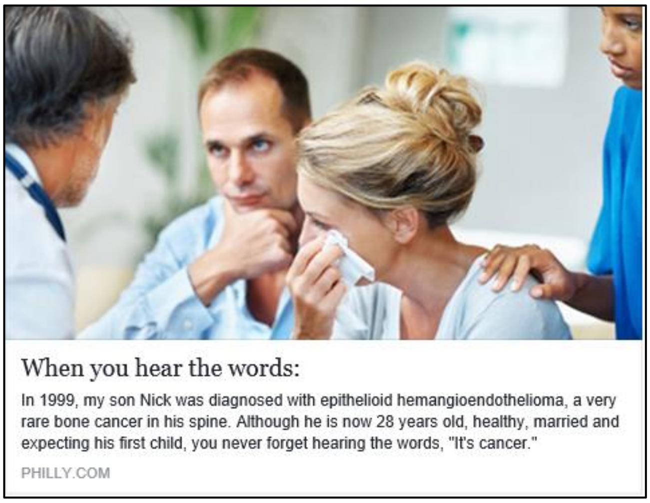
Diana went on “*I have sent some of you ornaments and it would be great to have a few people take some pictures with them. I already have a few great pictures!! This means a lot to me. I have got ornaments all across the country, trying to help spread awareness about this cancer we are dealing with daily. Thanks to all in advance.... Thanks to Dr. B VanTine for doing what you do!!! Thanks Jane Gutkovich for all of your time and help as well!!*”

We think Diana’s spirit and desire to help is an inspiration, and hope that as many people as possible will send her those photographs. We also hope that Diana will post photos of her ornament project at the Sitemen cancer Center when she can.

“It’s Cancer”

In August Sean McCartney posted a link to a moving article written by Cathleen Petrucci, describing the moment that she heard the words “its cancer” from the doctor treating her son Nick. Cathleen wrote “In 1999, my son Nick was diagnosed with epithelioid haemangioendothelioma, a very rare bone cancer in his spine. Although he is now 28 years old, healthy, married and expecting his first child, you never forget hearing the words, “It’s cancer.”

The moving article described a moment in time, an experience, shared by too many people in our EHE community, and indeed by patients of all cancers everywhere, and gave advice regarding how to handle having cancer. It reminded us again about why we set up the EHE foundations, why we spend so much time and effort raising funds, and why we continue to push to expand and accelerate EHE research. We want to thank Sean McCartney for sharing the article, and Cathleen for having the courage to write it, and by doing so, help raise awareness of EHE and dealing with a cancer diagnosis.



When you hear the words:

In 1999, my son Nick was diagnosed with epithelioid hemangioendothelioma, a very rare bone cancer in his spine. Although he is now 28 years old, healthy, married and expecting his first child, you never forget hearing the words, "It's cancer."

PHILLY.COM

An EHE Documentary

On 17th August, Yen Tu shared a link to a documentary by Kris Carr focusing on her diagnosis with EHE and exploring treatment options. While this documentary has been produced independently of our EHE group, we applaud Chris Carr for making this documentary and therefore increasing public awareness of the disease.

Crazy Sexy Cancer Documentary Trailer

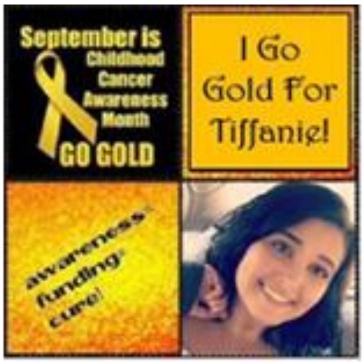
Learn more about the film here: http://crazysexycancer.com Buy the film here: http://amzn.to/hfpGOC

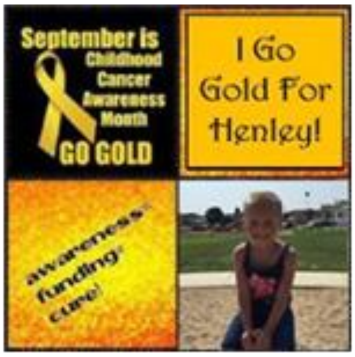
YOUTUBE.COM

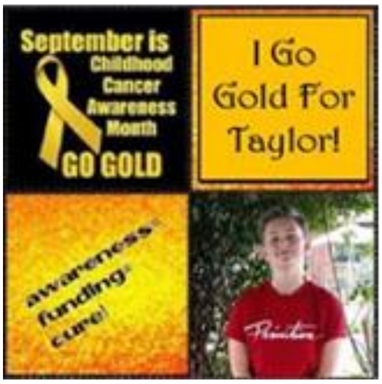
Child Awareness Month – our heroes

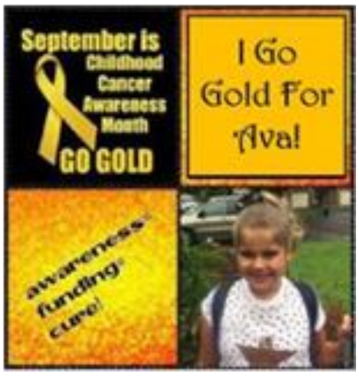
On 1st September, Julie Rivers Wahl reminded us that September was Child Awareness Month, recognising and celebrating all children and teenagers with cancer. Julie posted her new "gold" profile picture for September, featuring Delaney, together with offers to help others create similar profile pictures. Several took up the offer and we are pleased and proud to reproduce them here.

We too want to celebrate the lives of all our younger members with EHE. You are a very special group, leading your lives with energy and drive, determined not to let EHE dictate your life style, or life choices. You frequently amaze us with your courage and humble us with your love and consideration. Whether your picture is here or not, know that you are our inspiration, our heroes.





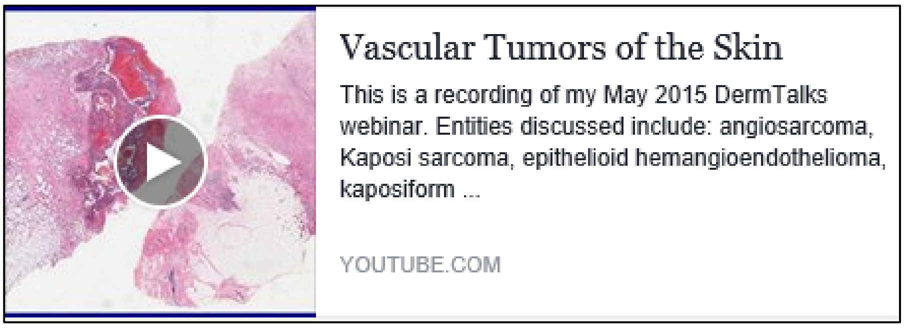




Jerad Gardner shares videos

In September, Jerad Gardner, a member of our EHE Facebook community and a soft tissue pathologist with a special interest in vascular tumours like EHE, posted information on, and shared, two of his presentations.

The first was Jerad's annual webinar on vascular tumours in which he reviewed different sarcomas, including EHE. While the presentation is aimed at pathologists and is therefore quite technical, it contains lots of microscopic pictures. Jerad thought it might be interesting for many of us to see how a pathologist views EHE.



Vascular Tumors of the Skin

This is a recording of my May 2015 DermTalks webinar. Entities discussed include: angiosarcoma, Kaposi sarcoma, epithelioid hemangioendothelioma, kaposiform ...

YOUTUBE.COM

Jerad's second post was copy of a lecture he gave in Houston, Texas, about his experience as a pathologist working with patient support groups like our EHE family. EHE is mentioned. Jerad wrote "*Thank you all for teaching me so much, for sharing your stories, and for welcoming me into your group. It has convinced me that this is the future of cancer education and research. After all, what I have to say isn't that important. It's YOUR stories that make a real impact on my colleagues. Thank you for letting me be a story teller on behalf of EHE.*"

Pathologist Involvement in Patient Support Groups on Facebook

My lecture at the 2016 Cancer Biomarkers II conference at Houston Methodist Hospital, Houston, Texas, USA. I discuss my involvement in patient...

YOUTU.BE

We of course want to thank Jerad for including EHE and helping raise the profile of such a rare cancer. The reality is that no group on its own can succeed in defeating a disease like EHE. It requires commitment and engagement from patients, families, doctors and researchers, all working together to achieve a common goal, namely to reduce suffering and save lives. And people like Jerad do so much for us in spreading the word. Thank you Jerad.

{*Jerad's presentations are not playable from this publication but can be found on the EHE Facebook page.*}

Conference Participation

EHE Group will be at CTOS 2016

The Connective Tissue Oncology Society (CTOS) will hold its 2016 annual conference in Lisbon, Portugal. The conference will be attended by Jane Gutkovich from the EHE Foundation. Jane is organizing a number of key meetings at CTOS, with research and clinical specialists, to discuss a wide range of issues relating to EHE. One of the meetings will include Prof Izhak Haviv, Professor of Cancer Genomics at the School of Medicine, Bar Ilan University in Israel, who will be discussing his EHE research proposal at a key meeting to coordinate possible European-wide support. Further information about Prof Haviv can be found in the following sections of this newsletter.

Jane will be working the corridors and meeting with specialists to promote and encourage engagement around EHE research. Jane will, as always, be reporting on her progress on the EHE Facebook page and we will cover the CTOS meetings in the next edition of The Pledge in early2017.

Research Update

New post-doctoral researcher, Kepeng Che, joins Dr Rubin's team

Last February the EHE group was excited to be able to provide a grant of $180,000 to Dr Rubin at the Cleveland Clinic to fund a new post-doctoral researcher in his EHE research team. Recruitment was not however straight forward, with Dr Rubin's first pick from a very wide geographical spread deciding to take another post.

We are excited therefore to now be able to report that Dr Rubin has succeeded in finding a very strong post-doc candidate far closer to home, namely from within the Cleveland Clinic itself. In introducing his new team member, Dr Rubin wrote:

"*After completing her PhD studies from the Chinese Academy of Sciences in 2002, Kepeng Che joined the laboratory of Dr. Michael Gelb at the University of Washington where she worked on protein-related projects focused on measuring cell membrane proteins. In 2007 she moved to the Cleveland Clinic where she worked with Dr. Donald Jacobsen on Vitamin B12 and with Dr. Erik Pioro on proteins associated with amyotropic lateral sclerosis (ALS). She has extensive expertise in protein biochemistry, molecular biology, and mouse models of human diseases. She will be a valuable addition to the Rubin lab as she will focus her efforts on* *developing methods to identify new therapeutic compounds for EHE and to characterize a genetically engineered EHE mouse model*"

Kepeng will be starting in Dr Rubin's lab in the middle of October. The EHE Group welcomes her to the fight against EHE, and of course we wish her every success in her endeavours to find new therapeutic compounds and with the further development of an EHE mouse model.

Dr Rubin submits important grant application

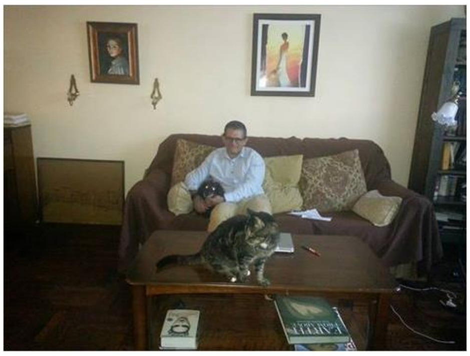
Dr Rubin spent a significant amount of time through the first half of 2016 preparing an important grant application entitled "Developing Prognostic Biomarkers and Novel Therapies for the Treatment of Epithelioid Haemangioendothelioma" relating to his ongoing EHE research. The project is one of four major sarcoma-related projects chosen for inclusion for the SARC sarcoma SPORE renewal submission submitted in September to the United States National Cancer Institute, and covers a project bringing together several talented physicians and scientists as well as the collective resources of several great institutions, including SARC, to address problems that are critical to our EHE community.

Dr Rubin's project will have three main objectives. Firstly, to determine genetic mechanisms of tumour progression in EHE; secondly, through drug screening, to identify direct inhibitors of the TAZ-CAMTA1 fusion for therapeutic development; and thirdly, to evaluate the clinical activity of a MEK inhibitor (trametinib) in patients with advanced EHE.

If successful, the grant will provide approximately 1.75 million dollars for EHE research to Dr. Rubin and his collaborators over 5 years. This submission would not have been possible without the support the EHE foundations have provided which allowed Dr. Rubin to develop preliminary data required for this proposal.

The application now enters a review period. As always with grant applications, there is no guarantee of success, but we hope that the project will be successful. We also want to thank Dr. Rubin for his ongoing dedication in leading EHE research.

Prof Haviv opens up interesting EHE research potential



Jonathan Granek, Director of the EHE Rare Cancer Foundation Australia, introduced Professor Izhak Haviv to the EHE group. Prof Haviv is Professor of Cancer Genomics at the School of Medicine, Bar Ilan University in Israel. The introduction was made after receiving an approach from Prof Haviv regarding the possibility of running a research project into personalised vaccines to boost immunotherapy. His proposal involved running the project for us from his institute in Israel, an exciting aspect, with the possibility of opening up a new research resource for EHE. His proposal also included possibly tying the project to the European Union Horizon 2020 funding programme.

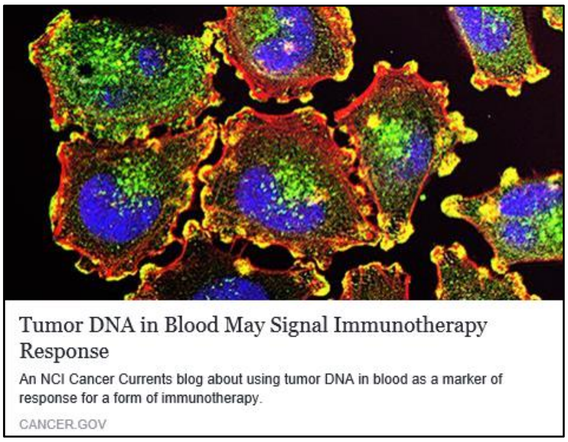
The EHE group coordinated introductory meetings between Professor Haviv and Dr Rubin in the second quarter of the year, and further meetings in the UK in July. In September, while visiting the USA, Professor Haviv spent six hours with Jane Gutkovich, including a lengthy telephone conference call with Dr Rubin. This has led to the possibility of Prof Haviv leading a research effort targeting personalised vaccines in immunotherapy. If the project goes ahead, then initially Dr Rubin will be providing genetic sequencing information while we begin to prepare to provide blood samples for the proof-of-concept phase, which will require the development and agreement of appropriate protocols. Jane noted that even if some aspects of the project are unsuccessful, others can still progress making this an exciting project.

Prof Haviv's group, using their specialists, may also be able to assist in the ongoing development of a viable EHE mouse model, a key objective for Dr Rubin and his research programme. If successful in creating xenographs, it is hoped that techniques can then be passed to facilities in the USA, Europe and Australia to allow patient engagement in these areas.

Jane Gutkovich described Prof Haviv as a research specialist who could coordinate and straddle the gap between the research and medical communities. Further meetings are planned, including introducing Prof Haviv to the advisory boards of the UK and USA foundations. Prof Haviv's early career was spent in Australia where he is already well known amongst the cancer research community. Jane noted however that the success of the project would require financial support from the EHE group and clinical support from a number of doctors.

Jonathan Granek will continue to coordinate the Australian end of this process, Hugh Leonard will be coordinating the UK/European groups while Jane will be coordinating in the USA, as well as passing on to Prof Haviv as much information as she can about EHE.

Biomarker Research



Tumor DNA in Blood May Signal Immunotherapy Response

An NCI Cancer Currents blog about using tumor DNA in blood as a marker of response for a form of immunotherapy.

CANCER.GOV

One of the research projects that the EHE group is targeting is the identification of biomarkers in a patient's blood that can be used for a number of key reasons, including acting as an early signal of disease progression. In September Jane Gutkovich also shared an NCI Cancer Currents blog that suggested DNA in blood may be a useful indicator that immunotherapy is working in a patient. The EHE group are currently in discussion with different research laboratories regarding this critical area of work.

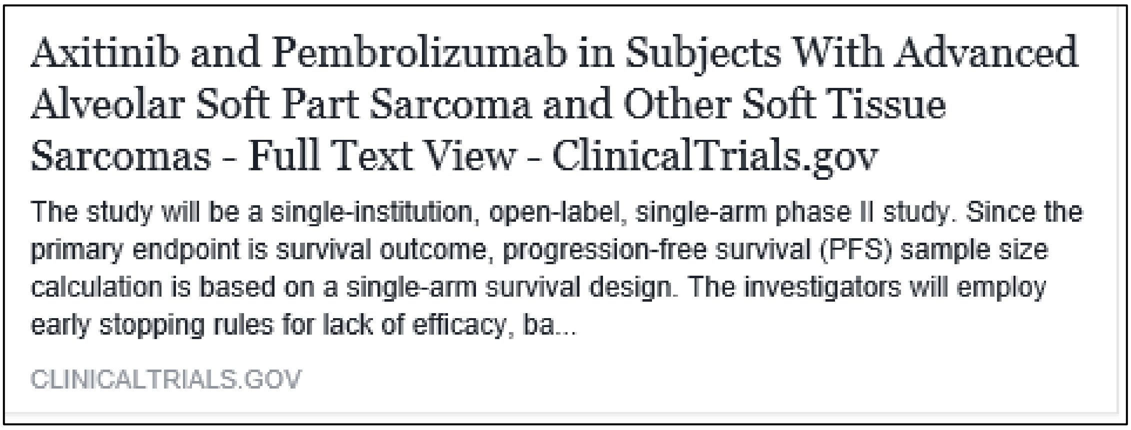
Immunotherapy clinical trials open to EHE patients

Early in the third quarter Jane Gutkovich brought the groups attention to the focus on sarcoma treatment during July, Sarcoma Awareness Month. At the same time, she was able to remind the group that promising results have been seen from a trial of Nivolumab, as reported in Clinical Oncology News. The immunotherapy drug has already shown positive impacts in one EHE patient under Dr Ravi. Additional patients will be joining the trial shortly which we hope will continue to show positive effects.

Data Show Promise for Nivolumab in Sarcoma - Clinical Oncology News

Also during the third quarter Jane Gutkovich reminded our EHE community that there is a promising clinical trial taking place, involving the combination of immunotherapy and antiangiogenic therapy, which is open to EHE patients. Both drug categories have already shown positive results for EHE and there is a hope that their combination will be even more effective. The trial is being conducted at the Sylvester Cancer Center, Miami, by Dr Breelyn Wilky. Jane was keen to keep all informed so that members who wanted to and fitted the criteria could bring the trial to the attention of their doctors for discussion.

Dr Wilky can also be contacted directly on her email b.wilky@med.miami.edu



Axitinib and Pembrolizumab in Subjects With Advanced Alveolar Soft Part Sarcoma and Other Soft Tissue Sarcomas - Full Text View - ClinicalTrials.gov

The study will be a single-institution, open-label, single-arm phase II study. Since the primary endpoint is survival outcome, progression-free survival (PFS) sample size calculation is based on a single-arm survival design. The investigators will employ early stopping rules for lack of efficacy, ba...

CLINICALTRIALS.GOV

Fighting cancer with our immune systems

The cancer research world has recently been ‘ignited’ with the astounding advances and results being seen in the world of immunotherapy, a sphere of cancer research which is looking at different ways to fight cancer by mobilising and energising a patient’s own immune system to find and kill cancer cells in their body. On 2nd August, Mark Roby shared an article about this very concept with the EHE group. Immunotherapy is also a key component of the EHE group’s research ambitions. Immunotherapy drug trials, including EHE patients, have started this year. The potential of these treatments is exciting and immunotherapy will continue to be considered and evaluated by the EHE group as a priority.

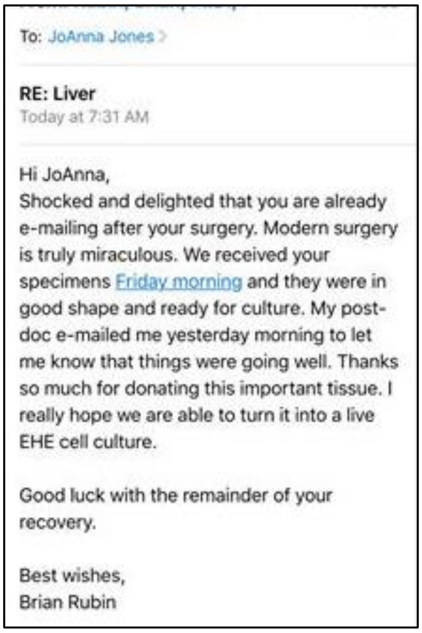
Setting the Body’s ‘Serial Killers’ Loose on Cancer

After a long, intense pursuit, researchers are close to bringing to market a daring new treatment: cell therapy that turbocharges the immune system to fight cancer.

NYTIMES.COM | BY ANDREW POLLACK

Tissue samples are critical

One of the most critical issues facing EHE research today is the need to develop a cell line or mouse model to provide a supply of EHE cells on which research can be undertaken. This is work that is ongoing with Dr Rubin, together with other specialists. One of the key challenges however in achieving these aims is simply the ability to access EHE tissue. This is where our group can help.



To: JoAnna Jones

RE: Liver

Today at 7:31 AM

Hi JoAnna,

Shocked and delighted that you are already e-mailing after your surgery. Modern surgery is truly miraculous. We received your specimens Friday morning and they were in good shape and ready for culture. My post-doc e-mailed me yesterday morning to let me know that things were going well. Thanks so much for donating this important tissue. I really hope we are able to turn it into a live EHE cell culture.

Good luck with the remainder of your recovery.

Best wishes,
Brian Rubin

The source of EHE tissue is patient’s with EHE. So if anybody is facing surgery to remove EHE tumours, please think about planning ahead if possible to ensure that tissue, once removed, is passed to Dr Rubin and not just destroyed. Planning and preparation are key as, without this, bureaucratic procedures and processes can get horribly in the way.

JoAnna Jones made such plans and was adamant that her liver, once transplanted, should go to Dr Rubin. That duly happened, with as much of JoAnna’s liver as could be physically sent getting to Dr Rubin’s clinic. Shortly afterwards, JoAnna got the email shown here from Dr Rubin.

We want to thank JoAnna for having the foresight to make these plans and hopefully help Dr Rubin in such a critical area.

Words of Encouragement

The following is a quote, posted by Julie Rivers Wahl, taken from a communication from Dr Rubin who heads up the EHE research team based at the Cleveland Clinic in Cleveland, Ohio. We wanted to share this with our readers as it fundamentally underlines what we are contributing to the EHE fight, and why we have to continue to build on the success of our first year of activity. It also once again amplifies how lucky we are to have Dr Rubin focused on EHE. Words cannot adequately express our gratitude for all he is doing for us.

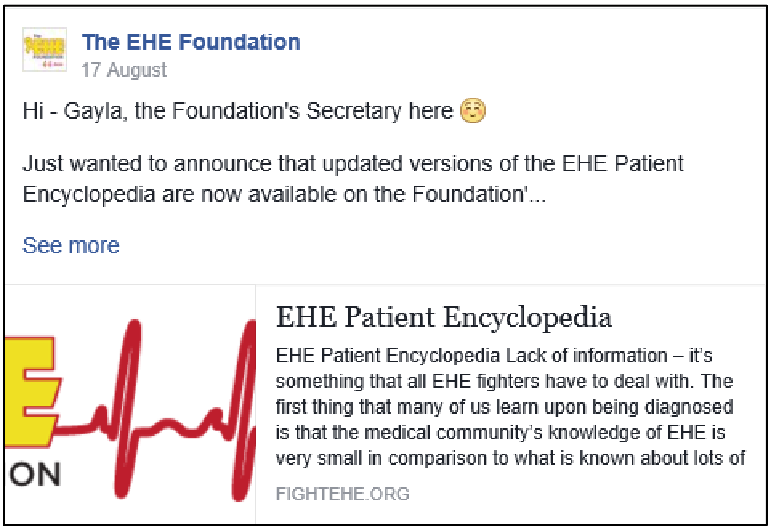
"*Grassroots fundraising has become very important to my laboratory, and we have raised $150,000 from patients in the past year, which is on the level of funding from an NIH Research Project Grant Program (RO1). So for rare cancers, it is important for scientists to go directly to patients, patient groups, and private foundations for research funding. I link to epithelioid hemangioendothelioma patients on their Facebook page, and many e-mail me with questions about their disease, and I am happy to help them.*

Despite the difficulties of research funding, I like the personal aspect of working on a rare cancer, where I know so many of the patients directly. They are invested in what I am doing, and I am invested in helping them improve and prolong their lives."

Julie added "*If you are interested in hosting, helping, or even supporting a fundraiser or if you are just interested to learn what we are up to when it comes to fundraising, please join the "EHE Fundraising Page" by going to the Facebook page and then clicking on "join"*."

EHE Encyclopedia adds value

In 2015 the EHE group issued the first edition of the EHE Patient Encyclopedia, a collection of patient stories. This document has provided many patients with a useful reference document, together with moral and emotional support. It is however also providing a valuable data resource that can be used to evaluate a wide range of aspects of EHE that in turn may assist in shaping our research programmes. As always we are asking patients around the world to support this initiative by providing the information requested by Jane Gutkovich and Gayla Loller.



The EHE Foundation
17 August

Hi - Gayla, the Foundation's Secretary here ☺

Just wanted to announce that updated versions of the EHE Patient Encyclopedia are now available on the Foundation'...

EHE Patient Encyclopedia

EHE Patient Encyclopedia Lack of information – it's something that all EHE fighters have to deal with. The first thing that many of us learn upon being diagnosed is that the medical community's knowledge of EHE is very small in comparison to what is known about lots of

FIGHTEHE.ORG

Fundraising

EHE will be managed and ultimately beaten through a dedicated and focused research effort to deliver answers to the many EHE questions that cannot be answered today. The EHE Group is therefore similary focused on raising the funds needed to finance, drive and accelerate an expanding EHE research programme. We thank all our members, their supporters and members of the public for their fundraising efforts, some of which are described below.

Many people want to help!

One of the common messages we get from our fundraisers is that when they do talk to people about EHE they find that many of them are keen to help, and in many cases want to donate or start fundraising. So often it is the initial discussion which is the critical first step.

One fantastic example of this was the recent experience of Rose Kalair (pictured here) who found herself in a conversation with a friend who has a PhD in biomechanical engineering and is now retired. He was fascinated by EHE and what we are trying to achieve. Rose agreed to come back and explain more. We prepared some documents to help Rose explain what EHE is, and describe the research we are hoping to fund, which included technical content and budget costs.

Rose was delighted to find that her friend fully embraced the story, thought that what we are trying to do was very worthwhile, and critically, felt that the documentation Rose had with her showed we were a professional group that he wanted to support. He made a sizeable donation right there and then. This is an excellent example of how discussions about EHE can lead to real support. Rose started the process through a simple discussion with her friend, and when the opportunity to engage further appeared, she grabbed it with both hands.

We are sure that there are many more people and groups out there who will support our cause. Of course, if any of our members face a similar situation we would encourage them to grab the chance, like Rose. We are ready to assist and provide any materials that might be useful, or any other assistance. Just contact one of the three EHE foundations and we will mobilise the support you need.

And of course we want to send huge thanks to Rose Kalair for spreading awareness of EHE and for securing such important funding.

Jessie Jars are launched

Jessie is a 12-year-old girl who had to deal with her mother, Kerry Hayman, being diagnosed with EHE in February this year. Jessie says that she was devastated by the diagnosis, which is not surprising. But having run a 5k race alongside her brothers to support our EHE April Fundraising Month, Jessie decided that fundraising was how she was going to fight back and help her mother.

At the start of September Jessie decided that perhaps one way was to start to collect unwanted 1p and 2p coins in a jar. She quickly realised this was an easy concept to sell to other family members and friends. She made up 20 jars and delivered them, asking people to collect coins over one school term, until the end of the year.

And so her 'Jessie Jars' campaign was born. We have tried to help by spreading the campaign through the Facebook group and the EHERCC JustGiving page. Jessie is targeting as big a number of jars as possible. Businesses and sports clubs are joining the programme. Her uncle also took his Jessie Jar to his rugby club one afternoon and raised a whooping £122. Another woman asked for an extra-big jar for her hairdressers. We hope that many of our readers and their friends will do the same, and spread the word, and help a 12-year-old achieve her goal.

We congratulate Jessie on having such a great and simple idea, and thank her for helping to fight EHE.

EHE Rare Cancer Charity
Charity Registration No. [illegible]

Jessie's Jars

Jessie is 12. Her Mum was diagnosed with EHE in February this year. Jessie wants everybody to save their pennies in jars between now and the end of the year to help her Mum and others with EHE.

£283.94
Total raised

2nd Annual Day Out for EHE Research

One of the iconic EHE events held in 2015 was Julie Rivers Wahl's first annual Day Out for EHE Research. On the 17th July, Julie and Team Laney held their second such event with fantastic support and participation. With a wonderful array of prizes, raffles and other activities, Team Laney raised an incredible $9,000. Despite the weather being poor, everybody had a fantastic time. We want to congratulate Team Laney for another stellar event and thank everybody who attended, helped and ultimately contributed to this great total.

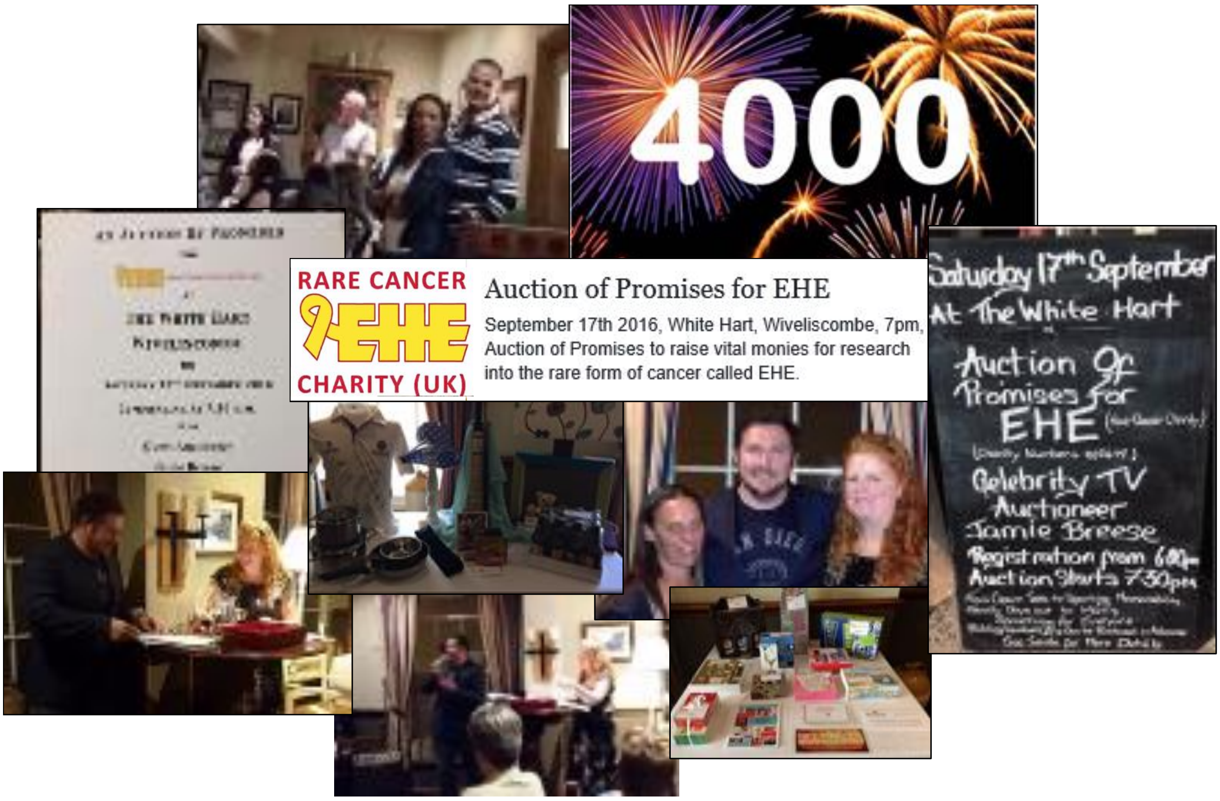
Charity Auction is a huge success!

When Kerry Hayman was diagnosed with EHE earlier this year, her close friend Tamzin Jones did not falter for one second in deciding to join the fight against EHE by first supporting the EHE April Fundraising Month, and then setting about organising an Auction of Promises for the EHE Rare Cancer Charity.

Tamzin set about collecting a wide array of wonderful prizes, promises and gifts over a four-month period. This involved hours of writing, phoning, bullying, cajoling, and just about every other type of '....ing' you can imagine, but in the end she had collected a wonderful set of items.

In addition to organising the prizes, Tamzin had to organise the venue and launch a dynamic publicity campaign to ensure the auction would be well attended. And finally there was a celebrity auctioneer, Jamie Breese, to secure for the big event.

On the 17th September this whole programme came together at the White Hart in Wiveliscombe in the UK. Huge numbers turned up to take part. The White Hart donated a charity barrel which raised £122, while Suze and Martin sold an amazing £260 of raffle tickets. With the auction then conducted under the gavel of Jamie Breese, the evening in total raised a staggering £4,242. Everybody who was lucky enough to be present agreed it was a stupendous evening. We cannot adequately express our gratitude for all that Tamzin and her team achieved, and for all those who turned up and bid on lots and bought raffle tickets and helped raise such a large sum. It really was a wonderful achievement and we congratulate all involved.



RARE CANCER EHE CHARITY (UK)

Auction of Promises for EHE

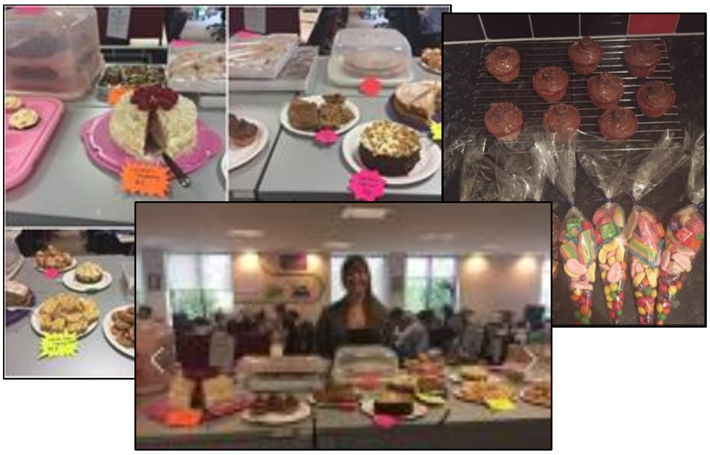
September 17th 2016, White Hart, Wiveliscombe, 7pm, Auction of Promises to raise vital monies for research into the rare form of cancer called EHE.

Team Henderson on a roll

Team Henderson has once again been actively fundraising through the third quarter, organising a number of events. The quarter started with Nicola paying in £3,000 to the charity, collected from a number of different sources.

This was followed by a coffee and cake morning where family, friends and other guests raised over £650. This was made possible with the wonderful support of the Yate Methodist Church and the Girls' Brigade. Nicola and EHERCC send them a huge "***thank you***" for all their hard work and wonderful support.

A second cake and sweet sale organised in Nicola's office was also a high-calorie success, raising a further £270 towards Mark's sky dive.



At the end of September, Mark Henderson was planning on doing a skydive to raise funds for EHERCC. Mark wrote "*Nic is faced with the fear and uncertainty of living with EHE every day so I wanted to do something. Not only do I want to raise some much needed money but also want to put myself in a situation where I am facing my fears so I can at least feel a little of what Nic deals with, she really is brave. I figured chucking myself out of plane at 10,000ft would be a good start!*" Sadly, the jump was postponed until early October due to weather conditions, but that has not stopped Mark from raising over £2,400 for EHE research.

We salute all those who have helped Team Henderson turn in another stellar performance.

EHE Fundraising Page is Launched


https://www.facebook.com/groups/781598178608903/

With the growing membership of our EHE Facebook group, and the desire for the size of that group not to make the page too cumbersome, it was decided that we should set up a new EHE FUNDRAISING page which is where we focus most of our fundraising news and information, reports on events and progress, and results of the activities undertaken. The page was duly launched in late August.

In addition to our members, and because this is going to be all about fundraising, and what we do with those funds, we hope and encourage all our members to get all their supporters and families to join the page too. Our objective is to try and create the largest and most dynamic fundraising group possible across the globe. With nearly a 100 members on the page we are already making great progress. Our goal is to create a worldwide Facebook community, dedicated to raising funds for EHE research, excited by the challenge, actively engaged in support and expansion of our collective efforts, driving us to achieve our targets, so that we can and will secure support from many sources.

We have already achieved a lot, but if we want to continue to make progress, and accelerate the research effort so that we get to treatments to manage and ultimately defeat EHE quicker, we need to do more, not less. We need to be more focused and more dynamic in accessing the pools of funding that may be available to us. So please join the EHE Fundraising page if you can. You don’t need to fundraise either. Just having your support, ideas and encouragement will be invaluable.

Baskets raffle raises $660

In mid-September Jane Gutkovich used the occasion of her office’s annual party to raise EHE awareness, and funds for EHE research. Jane first went around her neighbourhood, visiting a few restaurants, wine stores, bakeries, beauty salons etc and collected merchandise and vouchers for her event. She topped this up with some further items and gift vouchers, including several items donated by friends. Finally, Jane created three baskets of goodies and these were what she raffled at the party, raising $660. Thank you Jane for a great effort, awesome as always!

The Bock rocks

On 17th September Colleen Afanassiev posted a simple message to say that the Bock Foundation had raised a staggering $10,000 for the EHE Foundation. Jane Gutkovich had driven all the way from New York to speak about EHE at the evening event! We were stunned at such a huge donation and thank Colleen and everybody at the Bock Foundation for joining our battle against EHE. With this sort of support, we can make a real difference in the fight against EHE, and hopefully bring forward the day when our motto, ‘JUST LIVE’, will be a reality and not an ambition.

In memory of Victoria

Antonia Bury and many of her friends met in September to play in a small tennis tournament and in the process raised an amazing £563 to support EHERCC. Antonia wanted to help our battle against EHE and has donated the monies raised in memory of her wonderful sister, Victoria Potts (nee Fitzwilliam-Lay) who lost her battle against EHE in 2011. She sent us two pictures, shown below, one of the tennis players, and one of Victoria with her son, Ned.

Antonia and EHERCC would like to thank all the tennis players for this marvellous effort. The players included Arabella Salwey, Kathie Evans, Suzy Parry, Jessica Scott, Sophie Bevan, Lucinda Wrigley, Hugh Fitzwilliam-Lay, Caroline Bruce, Clarissa Daly, Annabel Morris, Susie Keown Boyd, Louise Free, Emily Davenport, Camilla Lywood, Sarah Williams, Clare Venner, Johnny Evans, Miranda Grafftey-Smith, Henrie Moyle, Catherine Greene, Sam Davies, and of course Antonia.

We are of course also hugely grateful to Antonia too for continuing to help us. We cannot help but think that Victoria would have been very proud of her sister!

T-Shirt sales continue …

Sean McCartney posted information on the Facebook page about Shawna McCartney’s event and their new campaign selling t-shirts with the wonderful slogan:

“Cancer can kiss my  “

OCT 7 Rock a shirt & help find a cure!
Fri 15:00 in EDT
117 people interested · 146 people going

Our Facebook community loved the t-shirts!

Meanwhile, Amanda Dennis was selling EHE Just Live t-shirts from her existing stock.

We thank Sean and Shawna and Amanda for helping in our EHE battle down-under!

…and so do ‘*Just Live*’ Tattoos

Members of our EHE family continue to post photographs of their latest and greatest “Just Live” tattoos. In August it was Heidi Tolton Chatterton’s turn with her newest addition on her left wrist.

A great supporter tragically lost

Nicola Henderson has a wonderful group of family and friends who support her and our EHE cause with amazing dedication, drive and generosity. Nicola's friend and neighbour, Kathryn, was a shining example of this. Kathryn was a volunteer at a centre for adults with mental health difficulties. She gave her time tirelessly and helped so many less fortunate than herself.

Kathryn was always supportive of the EHERCC, and this quarter had helped organise and run an afternoon of events to support the charity, including a barbecue, cake sale, tombola and craft sale, raising an amazing £200 for EHE research.

It was therefore with shock and huge sadness that we received the news in September that Kathryn had passed away unexpectedly. Losing a friend or family member is always terribly sad. But it is inevitably a greater shock when that person is young and has no obvious health issues. Our thoughts and love are with Kathryn's family and friends at this sad time. We want to take this opportunity to thank Kathryn for all she has done, and hope that we can live up to her example as we continue our fight with EHE.

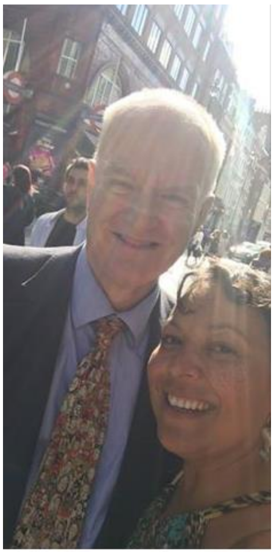
Maggie Kemp runs Gold Coast Half Marathon for EHE Australia

On 3rd July Ingrid Coddington from Australia posted on Facebook to let everybody know that her friend Maggie Kemp had raised $1,100 by running the Gold Coast half Marathon for the Australian EHE Rare Cancer Foundation. Ingrid simply said “I'm very proud of her !!!!”. We are too Ingrid. Well done Maggie and thank you so much for doing this for the EHE group.

Getting Together

Foundation Directors meet in London

On 23rd September, Jane Biddlecombe and Hugh Leonard met in London and took the opportunity to discuss a number of issues relating to the work and ambitions of the EHE foundations, and in particular, the next 12 months, and the direction each of their respective foundations will take to meet their objectives. Jane was also able to meet one of the other U.K. Trustees of the EHE Rare Cancer Charity. The only downside was that the time together passed in ‘the bat of an eye’. However, they both agreed to do it again soon, somehow, somewhere. It was a golden 2 hours



Australian directors meet in Melbourne (21st to 23rd July)

Australian directors Jane Biddlecombe and Jenny Shipley flew to Melbourne in July to meet Jonathan Granek with a view to addressing three key areas. Fellow Director Tony Wise was unable to attend due to prior commitments but sent his best wishes, and was there in spirit.

1. Personalized immunotherapy proposal

Jonathan Granek updated his fellow directors regarding a proposal involving personalized immunotherapy which, if successful, will be led by Professor Izhak Haviv, Professor of Cancer Genomics at the School of Medicine, Bar Ilan University in Israel. Thanks to Jonathan's hard work in building relationships with the top tier cancer research centers in Australia, Prof Haviv has also had meetings with the Walter and Eliza Hall Institute regarding opportunities for collaboration in cancer research. Jonathan had also introduced the project to the foundations in the UK and USA (see further coverage in the Research section of this newsletter).

2. Development of EHE Consumer Framework.

The Australia foundation is continuing to develop processes and procedures to support Australians in all facets of the EHE journey. We hope that this will also be rolled out to patient groups around the globe. Patients, family and carers in collaboration with the medical community, researchers, and hospitals can work together to ask important questions; do patients have accessible information to become capable consumers and deal with all stages of that journey from diagnosis to palliative care? Studies show that such partnerships improve the patient experience and in turn deliver better outcomes for consumers.

(To get a copy of the National Framework for Consumer Involvement in Cancer Control email Jane at Jane.biddlecombe@ehefoundation.com.au)

3. EHE Foundation - Year in Review

There were many successes in the first year of operation, and we appreciate the support of our Australian members, as well as from further afield. We feel in a good place to move forward in 2017 with a more targeted approach to fundraising. Jane is currently developing fundraising programs that can be shared by EHE members.

Four Special Women

One of the key things that members of patient groups offer each other is support and understanding based on a common challenge. While many loved ones will also offer huge amounts of love and support too, it will never be the same as the understanding and empathy offered by those fighting the same battle. It is this empathy and understanding that perhaps lies at the heart of the deep and powerful bonds individuals can form for each other even though they may live in different continents and communicate only through social media.

In the case of a disease as rare as EHE, meeting up with others involved in the group is difficult as members are few in number and spread over vast distances. It is also why the opportunities to meet are greedily taken and can generate such strong feelings.

In September, Jane Biddlecombe and family visited the UK. This was the type of rare opportunity that could not be missed, and on the 22nd September, Jane Biddlecombe, Sally Baker, Nicola Henderson and Milly Simmie all met at Hugh and Sally's house. These four wonderful women headed off for an evening together at a local restaurant, at which we can safely assume there were no awkward silences. I think it is fair to say, and they would agree, if we could fight EHE by talking, then these four alone would have the disease defeated!

Thank you for all taking the time to visit and please, come back very soon.

Sydneysiders Gather

In late August, Zosia Golebiowski called all Sydneysiders to gauge the interest in organising a friendly gathering in September, prior to her returning to Melbourne for six months. As a result Holly Mcrae, Jonathan Granek, Rita Tu, Teresa Cilona, and Zosia herself, all met. All agreed it was a really lovely get-together. "We chatted, exchanged ideas and views on doctors, and got to know each other". The group also took the chance to discuss two potentially important projects. Jonathan Granek led the discussion on the personalised vaccine and immunotherapy project proposed by Prof Haviv from Israel while Zosia led a discussion on IRE & HEHE with Dr Kavnaudias.

It was obviously a very interesting gathering and there was much to discuss. So much in fact that nobody took any photos. That just shows how good the conversation was, and photos can always follow when the group regather.

And in other news……

Neil Toering on top of the World

Kate Hennessy posted a photograph of her son, Neil, taken just six months after a wide skin based EHE excision of the side of his foot. The photo showed Neil summiting Mt. Thoro in Denali. On the trip Neil met another young cancer survivor, Josh, who climbed Mount Thoro with Neil. They also climbed a second peak together. The Toering family found the whole day inspirational, full of life and meaning; a day full of energy and symbolism.

Kate finished the post with our group motto "Just Live". Neil, we applaud your achievement and your spirit and determination not to allow EHE to rule your life. Keep climbing to new peaks, both physically and metaphorically, and know that we are by your side in spirit as you do so.

"Holy crapoly, I'm scared"

Those were the words of JoAnna Jones on 24th August, immediately after receiving a call that her liver transplant was going ahead within 24 hours. After months of agonising wait, and wondering if it would ever happen, the big event had arrived and was progressing with frightening speed. There was then an inevitable period of quiet until Cindi Titzer, JoAnna's mom, posted to say " JoAnna is in the recovery room. Doctor just came down to say all went well. They will keep Jo sedated for the next day or so. He said the new liver started working immediately. Next phase is to watch her closely." Wow, what a relief and such happiness that JoAnna had finally passed this milestone.

JoAnna continues to do well, and we celebrate her new circumstances with her. While ecstatic for JoAnna, we also do not forget that somebody donated their liver so that JoAnna could have renewed hope. There is nothing any of us could do for the donor, but we should all take a quiet moment to think about and pray for them too. While their passing is also very sad, we hope that they will be looking down on JoAnna and smiling to think that they have helped such a wonderful person.

New arrivals

The third quarter saw some very happy posts about two new arrivals.

In July Bridgett Koval posted a photograph of herself at 27 weeks, looking great. This was followed on 5th August with photos to introduce us all to the Koval's new miracle baby, Lili

Louise, born on 4th August weighing 7 lbs 5 oz. And just a week later Bridgett was out and about at the start of the soccer season.

27 weeks

New arrival

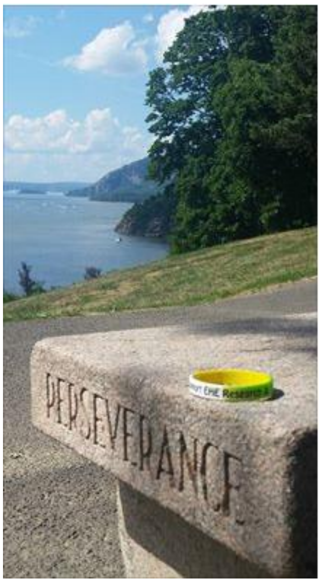
At the soccer

On 2nd September, Monika Oliwiak introduced her daughter Sofia to the EHE group. Sofia had arrived in May but Monika had waited to see her next MRI scan results before sharing the news. Monika did not hide the fact that she was scared that her pregnancy could have had a negative effect on her EHE, but to her delight found the opposite, with two tumors having disappeared while the three remaining were small.

We all send our love and congratulation to both families on their wonderful news, and wish Lili and Sofia long lives full of happiness.

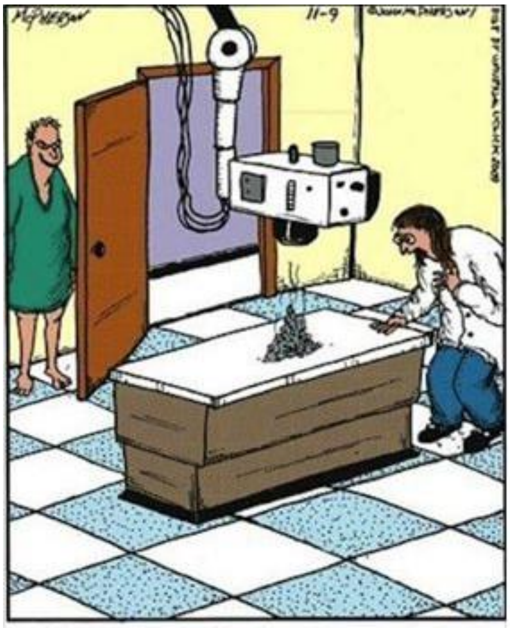
A simple message

Posted on 18th July by Julie Rivers Wahl, this is a photo sent to her by a friend. We need say no more.



Sometimes laughing helps

Julie Rivers Wahl posted this cartoon on the Facebook page. It certainly made us chuckle.



Having dumped the bag of ashes on the table, Stew hid behind the door and waited for the X-ray technician's reaction.