

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



Quarterly Newsletter
for the EHE Group
October - December 2017

the pledge

Edition 11



Contents

Welcome.....	1
Highlights.....	2
01 Patient Support and Advocacy.....	4
02 EHE Research.....	10
03 Fundraising.....	16
04 Upcoming events.....	23
05 Other news.....	24

Welcome

We warmly welcome all our readers to this eleventh edition of “**The Pledge**”, the quarterly newsletter of the EHE Group. We hope you enjoy this newsletter, covering the fourth quarter of 2017.

We also want to take this opportunity to say a huge thank you to all our supporters for their contributions.

Whatever the form of support that you provide, and regardless of magnitude, they are all critical to our success and ability to ultimately defeat EHE.

Every fundraising event or one-off donation, every message or act of support, every patient supported, every time awareness of EHE is increased, they are all critical.

Thank you to all of you.



Highlights

Clinical trial of Mekinist (Trametinib) continues

The Phase II clinical trial of Mekinist (SARC033), based on the research undertaken by Dr Rubin, is continuing in the USA for EHE patients with unresectable or metastatic EHE. To date 10 patients are enrolled in this trial, with more to follow.

EHE Facebook membership exceeds 1,300 and adds China!

The EHE Facebook page now has over 1,300 members across the globe. We were especially excited to link up with a small EHE group in China who are now part of our EHE family.

Dr Rubin's research approaches important milestones in several areas

At the end of the year several areas of Dr Rubin's research are approaching important milestones. Drug screening, mouse model development, and genetic screening for secondary gene fusions are all progressing well with key results to be delivered hopefully in early 2018.

Giving Tuesday fundraising events prove to be huge

The EHE Foundation in the USA and the EHE Rare Cancer Charity in the UK both secured sponsors to offer matching donations for their Giving Tuesday campaigns. With unbelievable support the two campaigns together raised just under \$200,000 for EHE research.

Australia's 10,000 steps campaign massively successful

The Australian 10,000 steps campaign was a huge success, promoting fitness and health, and raising substantial additional funds.



01 Patient Support and Advocacy

Spreading awareness of EHE, and supporting EHE patients everywhere

Supporting those diagnosed with EHE is one of our core objectives. We will do this, wherever a patient may live, while at the same time increasing awareness of EHE amongst the general public, government and in some cases the medical and research community. We will also endeavour to increase understanding of the impact that living with a rare and frightening cancer has on a person's life. We thank all our supporters who have contributed to this critical part of our activity, examples of which are provided in this section.

10,000 steps challenge spreads awareness

The EHE Rare Cancer Foundation Australia launched their **10,000 Steps** campaign in October to raise awareness of EHE, promote greater fitness and health, while also raising funding for EHE research. Jane Biddlecombe, President of the Foundation, led the campaign and was clear about the importance of spreading of awareness. *"More important than money is raising awareness of EHE and the inequity of care for rare cancer patients worldwide. I spoke to each of the workplaces that joined the challenge on this very issue and they were so shocked to learn how little rare cancer research receives in funding and how hard it was to get researchers to even look at EHE."*

Jane is also passionate about the fitness aspect of the campaign. *"I chose a steps challenge as when I was first diagnosed I could hardly walk and there was talk of amputating my leg at the hip. I am so grateful I can walk, ride and sit pain free today thanks to what I learnt on the EHE Facebook page and the huge amount of support I received from so many on this social forum. With every step taken by our supporters we are one step closer to finding a treatment or cure for EHE."* Jane even put herself forward to act as the poster-girl for the campaign!



Australian politician shares news of the Australian campaign

Jane Biddlecombe posted her thanks to Natasha Fyles, Northern Territory Attorney General in Australia, Minister for Health and Leader of Government Business, and Janes local MLA. Natasha kindly included a section in her Newsletter raising awareness of the work of the EHE Rare Cancer Foundation and supporting the 10,000 Steps Workplace Challenge in October which raised \$21,512 for vital front line research. We also want to thank Natasha for her support.



Justin's story inspires many

Cortney Herald Walters posted a heart-felt message concerning the video that she had produced about her dear brother, Justin, and his EHE story.

"Good Afternoon! EHE family and extended family. I wanted to share a video that I created to help bring awareness to EHE and also bring in donations. My lack of knowledge in videography is apparent (ha ha). However, as I continue the more I learn. The video below, which I've posted to many social outlets, is to encourage awareness and donations for The EHE Foundation. I've already posted this to the donation Facebook page, but I also wanted to share it with all of you. It's very personal to myself as well as my family, because it does give a glimpse into my brother's life who joined God and his angels this past January. I encourage you to take a few minutes to watch the video and to help spread the word for those who are in this fight."

The video was originally intended for Facebook, but I thought "why stop there", please enjoy and any feedback is greatly appreciated. Thank you all, god bless!"

The video is extremely moving, and we thank Cortney for making such a moving tribute at what is a very difficult time. We also think that Justin would have been very proud of what she has and is doing. We thank her for doing such a wonderful thing to help spread awareness of EHE and help in our collective battle against this horrible disease.



Justin's story and his fight against Cancer

I wanted to share a glimpse into my brother's fight against a very rare form of cancer called EHE (in short). Justin was...

YOUTUBE.COM



01 Patient Support and Advocacy

Anna Wadro launches Creative Lab for EHE

Inspired by the work of Courtney Herald Walters, Anna Wadro reached out to the EHE community to enquire if people were interested in bringing their creative skills to the EHE battle.

"I'm thinking about making a 'working group' for EHE. Anyone who has any artistic or technical skills, knows any type of software, or is good at organising or works in CS, I would love to talk with you. I have been thinking for a long time to do some stuff to make EHE more visible in a creative way to tell the stories by pictures, animation, design or by making additional things on the EHE website to support the EHE foundations in their everyday work so they could focus more on medical matters which I cannot do. Their work is, after all, done for all of us, so inside me there is a need to do something for them, for this effort they put in to making research happen."

Anna is thinking of several different possibilities, including corporate CSR activities, movies, animations and support in posters and/or graphic design for ongoing EHE activities. Anna is keen to work with others and encourages people to ask any questions. *"I would love to look for a partner to do stuff, not just*

on my own, or to just simply exchange ideas. Even if this is just talking about ideas that came into our heads, it is good to brainstorm a little and not to sit on my own thinking." Anna hopes there are more people willing to do something like her and would love to chat with anybody who is interested in getting creative!



EHE Group webinars continue

Jane Gutkovich held the second EHE webinar teleconference on 4th November. She used the time to review some EHE published studies to explain their limitations and how these can in fact negatively affect patients' treatment.

Jane also reviewed the EHE Encyclopaedia, and how this data resource can be used to find, to follow, and to get in touch with patients who have similar clinical presentation of EHE to the reader. She also explained how the data can be used to collect, analyse and publish a solid review of EHE history and treatment outcomes.

Finally, Jane reviewed the research strategy of the EHE foundations, explaining which projects have been started and which are in a preliminary stage, and also outlined what the EHE group plans are for the future. Jane noted of course that there will be many challenges and difficulties as we progress, but with all three foundations working together we will continue to make progress and will eventually find ways to manage and then cure EHE.

Harrison Pluta is blogging once more

In October Missy Stewart Pluta posted to say that her son Harrison was once again writing in his blog. Harrison's writing is a powerful story and presentation of what an EHE diagnosis and battle is like. We congratulate Harrison for being able to produce such a strong record while fighting this difficult disease



Spreading The Laugh

Helping those affected by cancer and chronic illness



Ninel Wiseman – a special lady!

In November, Hugh Leonard got the chance to finally meet and have tea with Ninel Wiseman in London. When the UK charity was set up in 2015, Ninel's husband David was one of the patients in the UK. He lost his battle that October. Sadly this was more due to the massive reaction to his first chemo dose rather than his EHE.

Ninel continued to exchange emails and continued to support the EHE cause, raising funds through Ebay. Hugh said that if she was ever in London it would be great to meet. Out of the blue she emailed Hugh to say she was coming to London, and so they finally met.

"We chatted for 2 hours about David, her family, EHE, what our group is doing world-wide and in the UK. Ninel wants so much to defeat this disease, and wants to stay part of the team, which is wonderful. She is ready to help where she can and we have already exchanged some ideas."

Ninel does not do social media, so she does not see the EHE FaceBook page, but Hugh just wanted to let the EHE group know that Ninel is still 'up for the fight'. She is another hardy EHE warrior, to join all the other EHE warriors within the group.



01 Patient Support and Advocacy

Mariana Coutinho posts from Portugal

The EHE group has members across all continents and in many countries. The Facebook contributions are truly global in nature. In 2017, this international coverage included Mariana Coutinho who travelled to visit the Royal Marsden as her own doctors in Portugal have no experience with EHE. As a result of these consultations, Mariana is now looking to have IRE ablation in the UK. Mariana was delighted with the care and advice she got.

"Anyway, I just wanted to share my experience" posted Mariana "since it might help someone else, and once again thank this group because without you I would never get here."

We are so happy that Mariana was able to make such good progress. We wish her luck for her future treatment in London. It is not always easy for international patients to secure the treatment and care they desire, for a number of reasons, but we will continue to assist them in any way we can.



'Thanksgiving' thoughts from a sister

Ashley Simpson Hutchins posted an update on her sister, Allison, who was four months post liver transplant.

"She is feeling great and will have her next scans in April. As we approach this Thanksgiving, we cannot help but remember the many blessings she and our family have received over the past two years since her diagnosis. What a difficult journey it has been."

We will forever be grateful to Lisa Hartle De Young, Jane Gutkovich and Emily Morrow Jones for befriending us and helping guide us on this journey. I hope this encourages you all, and we continue to pray for a cure and for healing for all of you affected by EHE. Just Live!"

We are also celebrating Allison's great progress, and thank Ashley for her lovely messages of thanks and support. 'Just Live' indeed.

Chinese connection

Lisa Hartle de Young was hugely excited to share with the group that she had joined a Chinese EHE group on We Chat. The group have been very warm and welcoming. They have over 50 reported cases of EHE, although the number of EHE patients in China is obviously greater than this.

Lisa asked our group to give a warm welcome to Lisa Li who is the moderator for the group in China!

We welcome Lisa to the group with open arms and hope that we may be able to share and compare EHE treatments and understanding with those in China in the future.

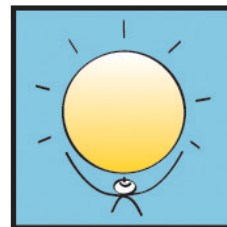


Make-a-wish foundation introduced

In December Elizabeth Downey posted to introduce the EHE group to the Nikolas Ritschel Foundation. The Foundation is an amazing group that basically delivers make-a-wish for young adults, 18-24 years, with cancer.

Elizabeth confirmed that the Foundation were sending her family to Disney. They had also asked Elizabeth to spread the word as they are looking for more recipients. They are based out of Rockford, Illinois but will do wishes for people outside of Illinois state.

We thank Elizabeth for sharing the information, and the Nikolas Ritschel Foundation for such fantastic gestures and support for young cancer patients.



**Nikolas
Ritschel
Foundation**
Take one step...



02 EHE Research

Only through research can we answer questions and defeat EHE

Dr Rubin's research progresses

Dr Brian Rubin, who heads a small EHE research team at the Cleveland Clinic in the USA, is seeing exciting progress in a number of key areas. Several different streams within his overall research programme are coming to fruition, with key results likely in 2018. Here is just a brief summary.

Therapeutic drug screening:

Dr Che in Dr Rubin's team has been working to develop a drug screening assay to test a large number of potentially therapeutic compounds to see if they have any impact on the WWTR1(TAZ)-CAMTA1 fusion protein that is believed to be a key driver of EHE. The assay is now complete and Dr Rubin hopes to be testing compounds throughout February. The original plan was to test 50,000 but Dr Rubin hopes that this number may become even greater. If any of these compounds are shown to bind to the fusion protein, which is a key driving force of EHE, then greater analysis of the compound and the impact it may have will follow with a view to hopefully developing a therapeutic drug that can help us start to manage EHE. So Q1 will be an important period in the compound-screening schedule!

This project also has a special place for our group as Dr Che is the post-doc that Dr Rubin was able to recruit with the funds we provided in 2016.

EHE mouse model: at the current time there is no mouse model that we are aware of that is available for EHE research. Over the past 2 years Dr Rubin has been painstakingly working with other specialists to produce a genetically modified mouse model that has EHE. This has been done by genetically modifying the mice so that they have the key WWTR1(TAZ)-CAMTA1 EHE gene mutation and will produce the fusion gene that is believed to drive EHE. Earlier in the year Dr Rubin's team had managed to achieve germline transmission of the gene mutation in the mice (the transfer of the gene mutation from the parents to their young during reproduction). These mice have been bred and allowed to grow, and in January 2018 Dr Rubin's team will sacrifice some of the mice for the first time to see if they have in fact developed EHE tumours. If they have, we may finally have an EHE mouse model that can be bred and shared with other researchers interested in working to understand the disease. This would of course be a huge step forward.

EHE genetic mutations: Dr Rubin has also been working through 2017 on evaluating if other secondary gene fusions (mutations) may be present in progressive EHE. Of 30 patient samples included within his study, all tumours had the primary WWTR1(TAZ)-CAMTA1 gene mutation which is believed to be disease defining as it is seen in nearly all EHE tumours. 14 samples had only this primary fusion. However, in the other 16, secondary gene fusions were also identified, with between 1 and 4 additional mutations being present. Initial analysis suggests that the patients with secondary mutations had progressive EHE which in turn suggests that these secondary mutations may be key to EHE becoming more progressive. Dr Rubin will now be doing further work to try and identify more detailed clinical information for the different patients to see if he can build an even clearer picture of how these additional gene mutations are affecting the disease's progression. Dr Rubin was able to present these findings at the 2017 CTOS conference in Hawaii where his poster was included within the programme.

Mekinist drug trial: 2017 saw the launch of the Mekinist (Trametinib) clinical trial for EHE patients with progressing EHE. This is the multi-institutional-trial that Dr Rubin had alerted the group to earlier in the year. The trial is led by Dr Schuetze from University of Michigan who is the Principal Investigator. This trial is designed based on Dr Rubin's preclinical research on EHE biology. Dr Rubin was delighted to have had 10 patients enrol by year-end, and believes that others are in the 'pipeline'. This is important as this is sufficient to complete the first arm of the trial. It also demonstrates that the EHE community can be contacted and mobilised in sufficient numbers to make EHE research viable,

something that had been openly questioned when Dr Rubin was proposing this trial. We are also supporting this trial financially as our EHE group have provided funding for the biopsies that Dr Rubin hopes people will agree to so that the real impact of Mekinist on EHE cells can be understood.

As part of the EHE Foundations patient support role, the group has also established a confidential closed Facebook page for patients taking part in the study so that they may be able to assist each other as they continue through the trial. We wish them all success as they participate in this important trial.



Dr Rubin

Immunotherapy: The EHE Foundation in the USA is in advanced discussions with one of America's pre-eminent specialists in the field of immunotherapy, with a view to undertaking research to explore the development of 'personalised vaccines' for EHE patients. This project will start with the premise that fusion proteins involved with a cancer can act as an antigen which will be recognised by a patient's immune system and attacked. We know that the TAZ-CAMTA1 fusion protein is a key driver in EHE. So the first stage of the project will include seeing if this fusion protein is indeed recognised by our immune cells.

In addition to the TAZ-CAMTA1 fusion protein, the project will also genetically sequence samples from approximately 40 patients, comprising 20 progressive and 20 indolent cases. This sequencing will be used to identify other gene fusions and then predict likely antigens that will be specific to that patient's tumours. Once these groups of neoantigens have been identified, they can be used as a vaccine and re-introduced into a patient to stimulate the patient's own immune system, educating their T cells to attack the cancer in their bodies. In some cases the use of the vaccine may be enhanced with the use of different immunotherapy drugs.

This project represents an exciting possibility for combatting EHE. Encouragement for the research is provided by the fact that EHE is seen to go into remission in a very few patients, suggesting that in these cases the patient's own body has begun to recognise and attack the cancer cells. In addition, in some cases, female patients have seen their EHE tumours disappear during pregnancy, again suggesting a strong response from their immune system, possibly linked to the strengthening of the female immune system in the last trimester of pregnancy.



02 EHE Research

Important Immunotherapy Conference

CANCER IMMUNOLOGY AND IMMUNOTHERAPY: From Conception to Delivery October 12th - 13th, 2017 Overview Program Registration General Information / Directions	
CANCER IMMUNOLOGY AND IMMUNOTHERAPY: From Conception to Delivery Masur and Lipsett Auditorium, Bldg 10 National Institutes of Health, Bethesda, MD Sponsored by the Center of Excellence in Immunology, NCI This two-day national symposium addresses recent advances in the field and should be an exciting forum for discussion and debate on the current understanding of cancer and immunology and immunotherapy.	General Information For conference related questions please contact: Julia Lam 301-846-8957 Kathy Easterday 301-846-5763

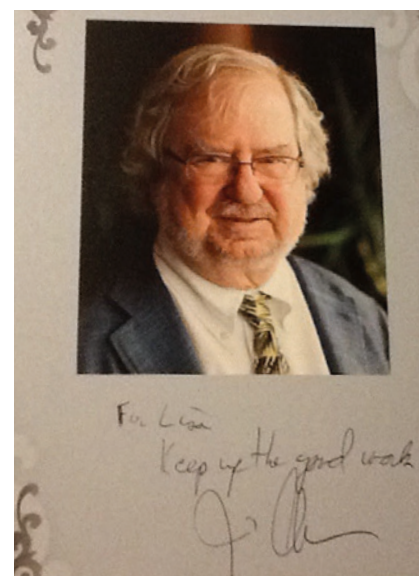
Early October saw Jane Gutkovich attending the National Cancer Institute conference 'Cancer Immunology and Immunotherapy: From conception to delivery'. *"I'm attending an amazing conference on immunotherapy at the National Cancer Institute. The very best of the immunotherapy 'gurus' are reporting on the progress in the field which is so promising!"*

This was a key conference for the immunotherapy community and included presentations from some of the world's leading experts in the field, including Dr Robert Schreiber who has agreed to act as Principle Investigator for an immunotherapy research project involving EHE.

On her return from the conference Jane was able to update the group on the research involving EHE and on the great progress being made in the field in general. *"I just got back from the NCI immunotherapy conference and I am very happy to report that I had a great meeting with Matt Gubin, a scientist from Dr Robert Schreiber's lab. Just to remind you that Robert Schreiber, a famous immunologist, agreed to become a principal investigator in an EHE project. This project will have several steps with a final goal to develop a personalized vaccine for EHE patients."*

Jane also noted *"At this point we don't know anything about the mechanisms that can be used to activate our immune system against EHE. What we do know however is that brilliant minds, solid science and reliable tools are already here to figure it out."* However, this research will need to be funded as always. Jane again commented *"We will need to fully sponsor the first stage of this project before we can count on any support from the government."* This is an excellent example of why our group spends so much time and effort on fundraising.

Jane was as always taking the chance to discuss and introduce EHE to those present at the conference. This included another of the world's experts and one of the 'founders' of immunotherapy, Dr James Allison. Jane also took the chance of getting a signed photo from Dr Allison for our very own Lisa Hartle de Young, a huge Dr Allison fan.



Session I: The Basis of Tumor Recognition

Chair: [Larry Samelson](#)

- | | |
|------------|---|
| 08:30 a.m. | James P. Allison (MD Anderson)
"Immune Checkpoint Blockade in Cancer Therapy: New Insights and Opportunities" |
| 09:00 a.m. | Nicholas P. Restifo (National Cancer Institute)
"Basic principles of cancer immunotherapy" |
| 09:30 a.m. | Steven Rosenberg (National Cancer Institute)
"Cell targeting of unique cancer mutations: A general approach to the immunotherapy of metastatic cancer" |
| 10:00 a.m. | Robert Schreiber (University of Washington, St. Louis)
"Cancer Neoantigens as Targets for Natural and Therapeutic Anti-Tumor Responses" |

NanoKnife and IRE Ablation

Discussions about IRE ablation of EHE tumours have continued, and were spurred on by posts from Zosia Golebiowski in Australia about the work being done in Australia. Zosia was excited to be able to report that *"The Radiology Research in the Alfred Hospital in Melbourne, where the first IRE clinical studies took place, will be commencing a project on IRE for EHE, leading to a publication on this treatment modality. I so much hope that the project will make more people familiar with IRE (and, hopefully, also encourage insurance companies to approve it)! (The first IRE for EHE paper published in 2013 described the treatment of my daughter's tumours. IRE saved her liver, and possibly, her life.)"*

Zosia went further and explained *"Irreversible Electroporation (IRE) is used to destroy soft tissue tumours of the liver, lung and kidney (but with lung tumours there is a chance of pneumothorax.) The device sends a low energy direct electrical current between 2 to 4 probes that are placed directly into or around a tumour. The current permanently opens the cell membranes and causes the cancer cells to die. This permanent opening of the cell membrane is called Irreversible Electroporation (IRE). It is similar to Radiofrequency Ablation (RFA) but the difference between the two is that IRE uses a low energy direct current to destroy cancer cells and RFA works by converting*

radiofrequency waves into heat, the heat then kills the cancer cells. So RFA relies on heat to damage cells while IRE is not thermal which is important in the case of EHE which is a vascular tumour. RFA ablation can be incomplete near blood vessels which create a protective "heat sink" effect of local blood flow."

In the USA Dr Raj Narayanan is leading the IRE charge, based in Miami, and is also in the process of writing a paper about the EHE patients he has been treating over the past three years.

In the UK in December, Hugh Leonard held separate meetings with three interventional radiologists, Prof Edward Leen (Hammersmith and Princess Alice Hospitals); Dr Praveen Peddu (Kings College and London Bridge Hospitals) and Prof Tze Wah Wah (Leeds Teaching Hospital and Chair of the British Society of Interventional Radiology). All three were keen to see EHE treated with IRE. However, it is not approved by NICE for NHS usage so the access at the moment is almost entirely private. We say 'almost' as Dr Peddu thought there could be cases where they might be able to argue for EHE under the NHS. Prof Wah in Leeds has offered to try and make sure that EHE is in the society's annual programme, but probably this would need to be in 2019. Hugh is hoping to have a follow up meeting in Leeds this month with Prof Wah to discuss EHE further.

Hugh took the chance to ask if the radiologists thought it would be sensible to try and organise a meeting of oncologists and interventional radiologists to discuss its use for EHE. They thought this was a good idea and were happy to put aside some time if such a meeting took place. This has now been discussed with Dr Robin Jones at the Royal Marsden who also agrees that a meeting and sharing of ideas and information would be useful. Dr Jones has his own retrospective study underway of different local treatment techniques, and as soon as this is completed we will organise the meeting.

The EHE foundations will continue to promote IRE ablation for patients in their respective areas, as well as promoting and facilitating collaboration between the different experts in the different countries. As part of this important development of a collaborative network, Prof Wah and Dr Narayanan were connected by the EHE group so that the UK could gain access to Dr Narayanan's growing expertise.



02 EHE Research

Hugh Leonard attends Research Open Day

One of the core goals of the EHE foundations is to increase awareness of EHE, and one of the ways of doing this is by reaching out to charities and foundations that are working in similar areas. The Bone Cancer Research Trust (BCRT) was one such group, and when they invited Hugh to attend their open day to see the research they are undertaking at the University of Sheffield Medical School in the UK, he jumped at it.

Hugh posted on the EHE Facebook page *"I spent a great afternoon today at the Bone Cancer Research Trust open day where the research they fund at the University of Sheffield Medical School was presented, with a tour around their facilities. Really interesting work and lots that is similar to the research we are looking at. As always others have trodden the road we are passing down and can guide us and help us as we go. Just live!"*

The EHE Rare Cancer Charity is continuing the dialogue with several different research establishments in the UK to identify those that are interested in engaging in EHE research.



Collaboration with Dr Valerie

Kouskoff: Dr Rubin is also collaborating with Dr Valerie Kouskoff, who is leading a University of Manchester research team, in a new study of EHE. This research will use new methods not previously used to study EHE.

The purpose of this project is to create stem cells that have all the molecular characteristics of EHE tumor cells and that will allow studying of EHE in greater depth. Powerful stem cells can be created (or “induced”) by changing cells from your body, such as skin cells or cancer cells, into pluripotent cells in a laboratory. “Pluripotent” means that the cells can turn into any kind of cells such as endothelium, blood, brain, heart, or kidney cells. For this reason, induced pluripotent stem cells can be used to study, and maybe one day help treat, diseases or injuries that have caused patients’ cells to die or become damaged.

Dr Valerie Kouskoff hopes to create induced pluripotent stem cells using patient-donated tumour cells. These pluripotent stem cells will represent a unique and powerful approach to study the biology of EHE as this remains a poorly studied and understood disease. The research will aim to understand better how the EHE cancer cells arise and proliferate. This research will also aim to generate and maintain enough EHE cancer cells in the laboratory to test drugs that could stop the proliferation or kill these cells.

Carrying out this research requires tissue samples from patients with EHE, and this remains a key focus for the charity going forward. However, Dr Kouskoff has not been idle while awaiting rare tissue donations. She has created an endothelial cell lineage by treating embryonic stem cells with growth hormones.

Dr Kouskoff will now place the EHE fusion protein into these cells, with the ability to turn the expression of the protein on and off at different points within the Hippo Pathway, to see what effects this may have on these cells, and so hopefully build a better understanding of what is happening within the natural biology of EHE. The Hippo Pathway is a key process in the body that regulates the generation and growth of new cells as well as the death of old cells, and ultimately controls the size of all human organs. A key component of EHE is the deregulation of the Hippo Pathway, leading to the proliferation of EHE cells and resultant EHE tumours.

Biobanking: one of the key areas that is hindering wider research into EHE is the lack of appropriate patient samples, such as blood and tissue, with which to work. The charity is currently in discussion with two U.K. institutions with regard to setting up an EHE biobank to ensure that such samples are captured going forward.

This will involve the completion and approval of an appropriate sample capture and storage protocol under which the biobank will be administered. The charity is also looking to fund the set up and ongoing administration of this biobank which we hope will go live in 2018.

Zebra Fish model: in addition to Dr Rubin’s mouse model, the EHERCC is also investigating the setting up of a collaboration between an institute in the U.K. and Dr Rubin to explore the feasibility of creating a valid EHE model using Zebra Fish. These fish are used widely to model human diseases due to a large degree of genetic similarity. Some very preliminary experimentation has already shown some interesting results, and we hope we can build on this idea in 2018.

The attraction of Zebra Fish is that they breed and grow very quickly and in large numbers. A valid model therefore allows for greater and faster testing and experimentation of drugs and hypothesis on a living organism.



03 EHE Fundraising

We are raising funds to support critical EHE research

EHE rare cancer 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 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.

10,000 steps fundraising campaign a huge success



The EHE Rare Cancer Charity Australia launched its 10,000 steps campaign in October. By registering, participants were sent a pedometer funded through a generous grant from the Darwin City Council. The challenge? To walk 10,000 steps a day for a month, get fit, and raise funds for EHE research in the process.

The event was a huge success with the total funds raised exceeding \$25,500, beating the target of \$15,000 by a huge margin!! Jane Biddlecombe posted her heart-felt thanks to all the wonderful companies, groups and individuals that took part.

"Many thanks to the Transport Planning staff from the Department of Infrastructure, Planning and Logistics for participating in the 10K Workplace Challenge."

The Challenge; to walk from Darwin to Adelaide, that's 3,976,378 steps or 3030km!



The competition was intense, but fun. One staffer, Jacinta, walked 64,808 steps in a day just to beat her boss Bruce, who got his steps by cycling everywhere. Staffer Casey easily smashed 20,000 steps at the weekend by dancing the night away, whilst another staffer was even accused of strapping his pedometer to his dog."

Jane also sent huge thanks to the top Individual Fundraisers, Cat and Ross Farrant, who raised nearly \$6,000. Jenny Shipley impressed everybody by consistently hitting 20,000 steps a day, and so secured the crown of 'Stepping Champ' for 2017!



The Northern Land Council crew ready to roll! 30 members signed and ready to help cure EHE one step at a time. Massive thanks to Rebecca Sirilas and Ian Amy for driving this initiative!



Jane also wanted to say a huge thank you to the following 'Top End' businesses for joining and supporting the EHE Rare Cancer Foundations's first 10,000 steps challenge:

Coolalinga Shopping Village/Woolworths Complex; **Northern Land Council**; Commonwealth Bank; **Bendigo Bank-Nightcliff and Coolalinga**; Jape Family; **Frock Me @ Aralia Street**; Dragica @ Colliers NT; **Tonkin Consulting**; Masterplan NT; **Northern Territory Consulting Engineers**; Tsirpig Conveyancing; **O'Loughlin Catholic College**; Framptons Real Estate (Alice Springs); **Department of Planning and Infrastructure**; Northern Comms; **Northside Medical**; Finlaysons Lawyers; **NTeen Fashion Festival**; Cadona Family; **The Farrant - Olsen Family**; Tracey Vincent; **Fatima Tam**; Paul Hendix and Co; **Jenny Shipley**; Stephen Jenkins.



03 EHE Fundraising

Our Lady of Calvary School raises \$1,000

Stacey Stefan was delighted and very excited to share the news that her son's school had raised \$1000 for the EHE foundation!!

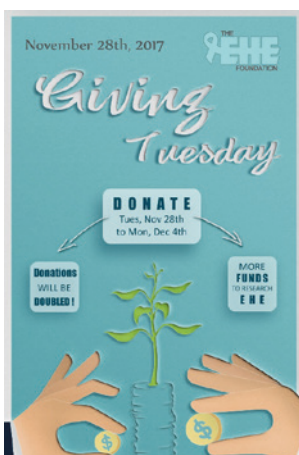
We are so grateful to the school for this wonderful gesture, and to Stacey for passing on the great news.



'Giving Tuesday' matching campaigns a huge success

Giving Tuesday is the Tuesday after Thanksgiving and is a day that encourages everyone to take part in charitable giving. The EHE Foundation in the USA and the EHE Rare Cancer Charity in the UK both secured sponsors who offered to match all donations up to a total raised. That gave our members a huge incentive not only to donate, but to also mobilise their contact bases and encourage mass engagement with the campaigns. The initial offers to match were for a fabulous \$20,000 in the USA and £10,000 in the UK.

The campaigns were launched and we held our breath. What happened next amazed us. The support from our members and the public was huge, both in the USA and the UK. Our targets were smashed with the UK raising over £100,000 in just over 10 days while America raised over \$70,000 in a week. That combined total will for example easily pay for two years of a post doc researcher in Dr Rubin's laboratory! Of course we could not have done that without the generosity of our matching donors, or all those individuals and companies that also donated.

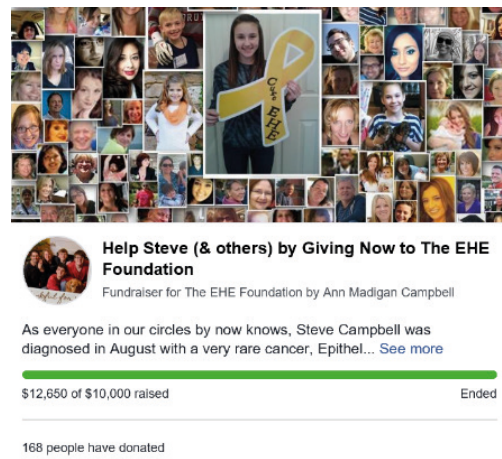


Many people also commented on the fantastic graphics that undoubtedly played a part in getting so many people to engage. We want to register a huge thank you to Anna Wadro for all the work she did for both the USA and UK campaigns. We drove her mad at times, but she delivered fantastic products. Just as an example, here is a coin she designed which captured not only the concept of currency and amount, but also included appropriate wording about the EHE group. Awesome work Anna. Thank you!



The Campbell's go big!

Ann Madigan Campbell was delighted to be able to post that their family's #GivingTuesday fundraiser has passed \$6,500 and was still going strong! Ann increased the goal to \$10,000 and shortly afterwards they reached a total of nearly \$13,000. We congratulate the Campbell's on an awesome performance and thank everybody who supported their campaign.



Team Henderson are there once again

After Team Henderson's brilliant annual race night in early October, Nicola and her friends could have been forgiven for leaving the Giving Tuesday campaign to others. But Team Henderson are no ordinary support group. As soon as the campaign launched Nicola was mobilising the troops. Kerry Marks came up with the idea of a simple text donation, keeping the ask small, which worked brilliantly. Team Henderson raised over £650 just two weeks after their annual race night. Fantastic.



03 EHE Fundraising

Kingsmead School joins the fight against rare cancer

Tamzin Jones works with Kerry Hayman at Kingsmead School in Wiveliscombe in Somerset. Kerry was diagnosed with EHE in 2016 and since then Tamzin, Kerry and the Hayman family have become real EHE warriors. The Giving Tuesday campaign was no different. Tamzin realised she had little time, and

wanted to access as many people as possible. So she approached the Headmaster at Kingsmead School and asked if the school would assist by holding an 'own-clothes' day. The school agreed and Tamzin set about emailing all the parents. It was a wonderful idea and raised nearly £500. With matching that number rises to £1,000. We send a huge thanks to the school for being so thoughtful, and to all those who donated.

In memory of Diane

It is always with mixed feelings that we include information about funds raised in memory of one of our members. December saw exactly that situation when Emily Ashton posted the news that her mother, Diane Ashton, had lost her battle against EHE. For those of us who had the privilege to meet Diane, it was indeed terribly sad to think that such a lovely, bubbly and positive person was no longer with us. But her smile and laugh always will be. We thank Emily for letting us know and of course send her our dear love. Emily wanted to do something to help the battle against EHE and raised over £2,700 for EHE research. We cannot thank Emily enough for thinking of us at such a sad time



Isabelle's Page

A key reason why the UK Giving Tuesday campaign was so successful was because of the unbelievable support for a very special young lady, Isabelle. Fighting EHE, Isabelle and her family wanted to tell her story to help others in the future.

"As some of you will know, 11 months ago our world was blown apart when our 17 year old daughter Isabelle, following two years of increasing neck pain, was diagnosed with an extremely rare cancer epithelioid haemangioendothelioma (EHE for short).



Instead of enjoying friendships, worrying about end of school exams and planning her future life after school, she was thrust into a world of hospitals, IV drips, pain and fear.

In March 2017 she underwent major surgery to her neck and spine. From May-July she received radiation and proton treatment which removed the cancer but left her virtually unable to swallow. In August she started having agonising chest pain, only to then be told the cancer was now in her left lung. As a result in September she started receiving aggressive chemo, which has led her to spend weeks in hospital due to the side effects and numerous complications. In short, to quote Isabelle, 'life sucks.'

Isabelle is continuing to fight her EHE with extraordinary bravery. Her story touched many, and as is often the case, with little they can do, her friends and family supported her fundraising with unbelievable generosity. Individuals, companies, her school and members of the public all joined her JustGiving campaign in October. It is a sign of their love and admiration for her that the campaign is continuing today, and has now gone past £64,000. We cannot thank Isabelle and her family enough for being prepared to share her story in a way that has and will continue to make a difference for EHE patients in the future. And of course we send her our love and very best wishes as her battle continues.

Billy Wood's Great South Run

When Billy Wood heard that his cousin, Mike Webster, had lost his battle against EHE, he knew that he wanted to do something to help the fight against this horrible disease, and to remember Mike.

"My cousin Mike Webster was a great man, husband, father, son etc. He lost his battle with cancer last month. My run is dedicated to his memory and to help eradicate this dreadful illness."

Billy decide to take on the Great South Run, which he completed, raising £685 for EHE research in the process. We send our thanks to Billy for this wonderful gesture.



03 EHE Fundraising

A very special wedding present

When most young people get married, the pulling together of a wedding present list is part of the occasion. But Lindsey Smith and George Thyer had a different idea because Lindsey's sister Nicola has EHE.

"Thank you so much for coming to our wedding and celebrating our special day with us. Your presence is all that we want, however if you'd like to give us a gift then we'd love to see a donation made to EHE Rare Cancer Charity, a charity that is close to both of our hearts."

This was Lindsey's and George's wedding gift to EHE patients everywhere, raising nearly £1,000. We could not be more grateful to the happy couple for such a lovely gesture. We wish Lindsey and George a fantastic life together and hope that it is full of love and happiness.



Team Henderson's 3rd Annual Race Night

Early October saw Nicola Henderson, EHE Warrior from Yate near Bristol, and her wonderful support group, organise their 3rd Annual EHE Race Night. It was another fantastic success!

"Wow wow, what can I say!!!! The 3rd Annual EHE Race Night raised a staggering £3000, and with some match funding the grand total is £4000 for the EHE Rare Cancer Charity Uk. I am overwhelmed yet again with the generosity of people, it literally amazes me how great you all are. Thank you to each of you who attended, sponsored races and donated raffle prizes, I hope you all had a great evening. I looked around and saw lots of smiles so I hope you did!!! A big thank you to Darran for his amazing work on the mic, fabulous as always! And my team of girls (and Barry) who worked so hard. This money is so so so appreciated by every single EHE patient as without it we wouldn't have the hope you give us of finding a treatment or cure. I LOVE YOU ALL!!! #postivepants #justlive"

There's nothing more to say, other than to say we too are so so so grateful for Team Henderson's ongoing fabulous support!



04 Upcoming events

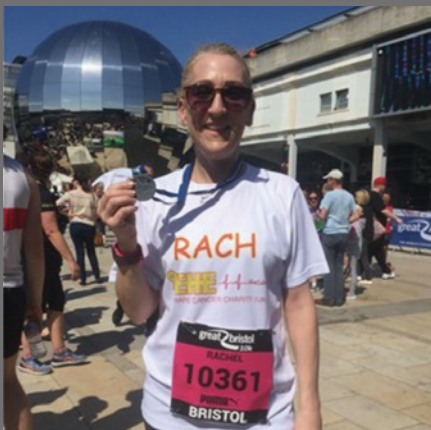
Saddle up and mosey over to the ULTIMATE HOEDOWN

Julie Lurie is organising a Hoedown on Friday 13th April at 7pm in Milton Keynes and would love for some of her fellow EHE warriors to come to enjoy the event. Food is provided in the form of a Hog roast. Julie is also organising a raffle "cos I want more of your money".

There will be games, music by Taylor'd Country, and a bar. Tickets are available for £25 each.

"Please put the date in your diary as I need all of you to make this evening possible and raise money for a cause that needs to find a cure Please bring family and friends and feel free to sell as many tickets as you can!"

Rachel Undy takes on the Cotswold Way Challenge



Rachel will be taking part in the Cotswold Way Challenge 2018. On June 30th - July 1st she will be walking 100km from Bath to Cheltenham with an aim to finish within 24 hours.

"I am taking part to raise funds for EHE to help find a cure for this rare cancer that is affecting my lovely friend Nicola. Nicola is an amazing friend, as well as daughter, sister, wife and fab Mummy to the gorgeous Owen. Nic is 31. She gave birth to her first child, Owen, in 2014. Six weeks later Nic was sadly diagnosed with Epithelioid Haemangioendothelioma (EHE), a very rare and potentially destructive cancer with no known cure!"

EHE21 to run London's newest half marathon



On Sunday March 25th an amazing group of 21 hardy souls will run the London Landmarks Half Marathon on behalf of the EHE Rare Cancer Charity. The team running shirts have been ordered, training is underway, and

the 'hard yards' are being run in cold dark evenings. These runners are determined to make a difference and raise critical funds for EHE research. We could not be more grateful and wish them every success as they continue their preparations.

But it won't just be the runners taking part. The EHE Rare Cancer Charity will be setting up a cheer station to help the runners on their way, and hopefully raise some further funds for research. We think and hope that it will be a great day.

Barn Dance in Solihull

On January 27 Helen Pollard's dear friend Jean and the lovely people at St Helens Church in Solihull are holding a Barn Dance. All money raised will go to EHE research. It's another wonderful example of people coming together and helping with the battle against rare cancers. We cannot thank them enough and look forward to seeing some great photos.



05 Other news...

Just Live - an important motto and mind-set

Michelle Benedettini Chmelko posted her **'Just Live'** picture to inspire others. "I am sharing my profile picture with all of you (me on the right, my daughter on the left) as my example of Just Live. This picture was 5 months post-op and 9 weeks post-radiation. I hope it provides inspiration for those enduring the many trials and tribulations of fighting EHE. May we all continue to fight so we can look forward to sunny days ahead. Thinking of all of you fellow warriors!"

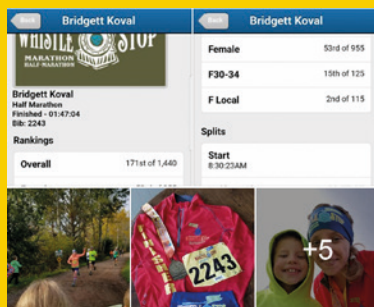


Julie Rivers Wahl was also posting **Just Live** photos of another of our inspirational members, her daughter Delaney Wahl.



"Some more to add to the **Just Live** file.... Delaney played some powderpuff football today! She ran in two conversions and had a pretty awesome 70 yard run for a touchdown!!! She plays again on Friday! So fun! **Just Live!!!**" This was particularly inspiring as Delaney had her first set of scans at Wisconsin Children's Hospital the day after!

When it comes to **Just Live**, there are few better proponents of the mantra than Bridgett Koval. Bridgett continues to make sure EHE does not rule her life, and one of her key weapons is running. We were delighted to see her take part in the Whistle Stop half marathon and spot an unbelievable time, coming 53rd out of 955 runners. Congratulations Bridgett.



Artur Rozwalak, Anna Wydro and Hugh Leonard in London.



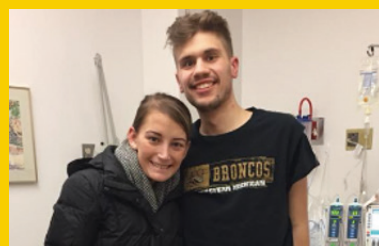
Diana Donohoo with Nancy Castle.



Lisa Hartle De Young and Jessica M Kirsan-Barbosa in California.

Mutual support matters

We know that when a disease is as rare as EHE, our group members love it when there is a chance to get together with fellow EHE warriors. The fourth quarter produced a few such opportunities that were shared with the group.



Harrison and Connie at UofM.

A new family member

Natasha Kilfoil posted wonderful news and pictures about the arrival of Isabel Marie, *"a beautiful, healthy and strong little girl"* on 4th November. We send our congratulations and very best wishes to Isabel, Natasha and the whole family for her safe arrival into the world.



Messages of love and hope

Every quarter, Robinson Ortiz Jr posts wonderful photographs and simple messages of hope for EHE patients everywhere. We love these. Here are the fourth quarter examples.

"To all those affected by EHE may light, love and hope always surround you."





The EHE Foundation (USA)

www.fightehe.org

The EHE Rare Cancer Charity (UK)

www.ehercc.org.uk

The EHE Rare Cancer Foundation (Australia)

www.ehefoundation.com.au