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

Quarterly Newsletter
for the EHE Group
January – March 2019

the pledge

Edition 16

Contents

Welcome

We warmly welcome all our readers to this edition of **“The Pledge”,** covering the first quarter of 2019.

As always we want to start by saying a massive 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.

Thank you to all of you, and we hope that you enjoy this newsletter.

Highlights

EHE Foundation adds new Executive Director

The EHE Foundation was delighted to introduce Medha Deoras Sutliff to the worldwide EHE community. Facilitated by a generous grant, Medha brings extensive experience and expertise to the Foundation as their new Executive Director.

Cynthia Pollak honoured in Australia

Cynthia Pollak, who established the very first EHE registry in the world in 1998 was awarded the Order of Australia Medal for her service to community health.

New EHE research projects advance in USA, UK and Australia

An international review of EHE medical charts and a study of EHE genetics have been started in the USA; the UK has initiated a PhD study to investigate EHE effects on endothelial cell development; and a study of IRE ablation of EHE tumours has been initiated in Australia.

Canadian EHE research confirmed

The inclusion of EHE into a study seeking to characterize the immune signature and molecular profile of EHE tumors was confirmed in Q1. Funding is available due to a single donation of C$50,000, raising Canadian research funds to circa $75,000.

Unbelievable funding support continues

Extraordinary funding support for the EHE Group continued through the first quarter with the UK receiving its largest single donation to date from Women on the Move Against Cancer (WOMAC). Charity balls, half marathons, single donations, groups-of-friends, and individual fundraisers also contributed to another important quarter of fundraising for EHE research.

Further details on these stories, and much more, can be found in this edition of The Pledge.

01 Patient Support and Advocacy

Supporting those diagnosed with EHE

One of our core objectives is ensuring that we provide support to all those diagnosed with EHE. We will do this, wherever a patient may live. At the same time we will strive to increase awareness of EHE amongst the general public, government and in some cases the medical and research community. We will also work hard to make clear what 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.

Medha Deoras-Sutliff joins the team

The EHE Foundation (USA) was thrilled to introduce their new Executive Director, Medha Deoras-Sutliff, in January, facilitated by a generous grant to specifically hire an experienced professional for the position to help deliver the longevity and stability of the organization. Jane Gutkovich noted, *"Medha joins us with extensive public health and non-profit management experience with a focus on grants for cancer research. Her vast experience and background will help us propel our growing progress as she works hand-in-hand with our Board of Directors and volunteers."* You can read more about Medha on the Foundation's website at **www.fightehe.org.** We welcome Medha to the EHE Foundation, and the EHE Group worldwide, and wish her every success in her new role.

A passionate advocate and supporter for EHE

The first quarter was a difficult period for many in our EHE family, when we received the very sad news that one of the original founders of The EHE Foundation, Heidi Chatterton had lost her battle with EHE. Heidi was a passionate advocate for EHE, a champion of patient support, a true warrior, and always had so much encouragement for everybody, literally at any time of the night or day. Her memorial service was on 16th March, and Amanda Holland spoke for so many when she said *"I'll be there of course. I wish more people lived closer and were able to come too. Still can't believe she's gone."*

We also know that Heidi would want us all to keep up the fight, love and support each other, raise funds, drive the research and ultimately defeat EHE.

She was and will always be a true champion of our cause. For sure she is up there now, smiling down on us all, and perhaps having a word or two in the divine ear in the hopes of steering our research in the right direction. Thank you Heidi for all you did, and for your example. We send our love to you, your dear family, and all your legions of friends. We will indeed fight on.

Shining a light on sarcoma

Last year Lisa De Young was nominated and selected in the USA to join a new organization called the Sarcoma Coalition, and serve as a Steering Committee member. Lisa explained, *"It is a collaborative group representing a variety of sarcoma sub-types. One of our goals is to find common ground where we can join forces in research initiatives and patient support. I'm doing this for my beloved EHE family and to shine a bright light on the underserved sarcoma community! If you have a suggestion please email me at:* ***lisadeyoung@fightehe.org****"*

Thank you Lisa for your hard work for all EHE patients and the wider sarcoma network.

SARCOMA
COALITION
We are here for you.

01 Patient Support and Advocacy

Cynthia Pollak honoured

In late January Jonathan Granek, Director of the EHE Rare Cancer Foundation Australia, posted the wonderful news that Cynthia Pollak had been awarded the Order of Australia Medal for her service to community health. This honour recognized, amongst other things, her work in Rare Cancers including Co-Founder and Vice President, CRAVAT Foundation, since 2008; founder of the website registry, **www.cartwheel.org**; and founder of HEARD Support, 1998-2000. The HEARD support group provided information to EHE patients worldwide, more than 10 years before our current EHE Group was formed.

When Cynthia's son Danny was diagnosed with EHE at the age of 19, she was told there was not enough money for research into such rare cancers. Cynthia then started an international support group and 350 people joined. She went on to create a registry of rare cancers with details of each case (now adapted and continued as the EHE Encyclopaedia). Danny died in 2008 and the website registry, **CART-Wheel.org**, was created with help of A/Prof Clare Scott and is dedicated to him. **CART-Wheel.org** is the first international, ethically-approved web portal co-ordinating patient information, research studies and clinical trials for rare tumours.

Cynthia's dedicated work laid the early foundations from which the current EHE Group and its community have grown and thrived. We want to join the EHE Rare Cancer Foundation Australia in congratulating and thanking Cynthia for her compassion and focus. As Jonathan noted, "she continues to inspire us every day through her shining example of strength and determination".

DONATE TO CART-WHEEL

Help keep CART-WHEEL in motion. Make a fully tax deductible donation today.

Membership passes 1,600

Lisa De Young posted the news in March that the EHE Group worldwide had passed 1,600 members. *"Our treasured support group has hit a new milestone today. We now have 1600 members worldwide in 65 countries! Welcome one and all from all over the globe".*

And by the end of the first quarter that number had actually risen to 1,611. So we also want to welcome all our new members to the group. As always, we wish you had no need to find us, but we are pleased you have. Engage when you are ready. In the meantime, we hope that you might find this newsletter a useful source of positive information.

Just Live Tattoos!

Just Live has of course become a standing motto for the EHE family worldwide, and helps spread awareness of EHE when people see and ask about the tattoos.

Delaney Wahl turned 18 last Christmas. The family decided to celebrate the occasion with EHE *Just Live* tattoos on 14th January. Delaney is a true ambassador and embodies the Just Live spirit. Nine of her family members now have the *Just Live* tattoo!

JoAnna Jones and 6 of her friends also had *Just Live* tattoos in support of both JoAnna and themselves. JoAnna notes *"The EEG we used is from my EKG that was done the night before my liver transplant."* JoAnna has bigger plans. JoAnna is a champion for awareness and plans to put together a video and has offered to include others' *Just Live* tattoos and their stories. Thanks, JoAnna! We love this idea.

Charleen Darinski also posted a photo of her tattoo and said, *"As I embark on my second EHE journey, this was a must!"*

Spreading the word

Allana Parker joined our EHE family in 2018. Early in the new year, Allana completed the process of making the face mask in preparation for her next radiotherapy 'journey'. *"At the signing of consent my usual oncologist at that hospital was ill so another oncologist stepped in. He had never come across EHE before and was very interested to talk about it. It does feel great knowing another oncologist was walking away today with knowledge of EHE. The more the merrier"* posted Allana. *"It can only be a good thing for all of us".*

We agree Allana, and want to say thank you for having the forethought at a difficult time to discuss EHE and help spread the word. We also of course want to wish you every success with your future treatment plans.

01 Patient Support and Advocacy

Strength and perseverance!

At the end of January, Malcolm Barrah wanted to share some thoughts with the group. It was a simple message; *"Don't let the conditions you have get you down"* he said. " *I was diagnosed with DCM in October 2017 and lost my fitness completely to the point where I couldn't walk 5 yards without getting seriously breathless. Today, 1 year and 3months later, I have completed a season beating, driving birds over rough and normally hilly terrain."*

Malcolm explained *"A year ago myself and my family would never have thought I would have been able to take part ever again in this hobby I love greatly. A year ago one of my doctors thought that I was on my way out, but I have faced, adapted and overcome so many obstacles that not many thought was possible. I can now once again enjoy taking a long stroll across rough grounds with my dogs".*

Its brilliant news and a brilliant message Malcolm. Keep going.

A message of thanks

Natasha Kilfoil was with Dr Vinod Ravi in mid-February and wanted to send a simple thank you from her and her family.

"I hope others were able to enjoy a great Valentine's Day, especially our amazing EHE doctors! Tomorrow is far from promised, but helping us make it so that we can enjoy today makes all the difference!"

We want to endorse that message, and also send our thanks to the wonderful doctors, radiologists and all the other professions who together help our EHE members through tough times.

Bridgett Koval's simple challenge

"Living with Cancer can consume our lives, but if we wake up each day and put one foot in front of the other, we are moving forward.... The question is, how many steps are you going to take today? Tomorrow? This week? This Year? #justlive2019".

Great spirit Bridgett. We hope that the running is going well, as you pound your many steps each day. And remember everybody, you don't have to take up running to make healthy life style choices.

Looking great and feeling great, 5 years later

Jessica Impera is 5 years post-transplant and doing well. She shared, *"yesterday I turned 5 years from transplant... grateful to life but especially to my donor... and I wish everyone, who is waiting or who is passing the same to heal soon..."*

EHE represented at major conference

Getting our EHE story and message out to the research community is a key objective of all the EHE foundations. We were excited that Medha Deoras-Sutliff, EHE Foundation Executive Director, represented the Foundation and connected with interested researchers and other advocates at the annual meeting of the American Association for Cancer Research

01 Patient Support and Advocacy

Strutting her stuff!

Adrianna Glennie was thrilled to be able to post the news that she had been chosen to participate in Aberdeen's annual 'Courage on the Catwalk' charity event. *"Every year there is a catwalk event in Aberdeen to raise funds for friends of ANCHOR. These volunteers come round cancer wards offering massages, newspapers, a sweetie trolley and anything to make a patient's stay more comfortable."*

The event models, who will walk the catwalk, are all cancer patients. It has wonderful support from the community, with great press coverage.

"Here's to raising EHE awareness this year" noted Adrianna. *"What a weekend it will be, catwalk then get my next scan results the following day."*

And Adrianna has involved the worldwide EHE community asking for suggested strap lines about EHE, as well as ideas on what she might say to EHE if it was a person. As far as slogans go, many people liked ***"My cancers rare, let's make it extinct"***

We wish Adrianna good luck on 12th May.
It will be brilliant.

Australian Foundation holds first webinar

Under the banner 'ALONE WE ARE RARE -TOGETHER WE ARE STRONG!", Jane Biddlecombe and Jonathan Granek held the first webinar for Australian EHE patients, family & friends on 9th February. It was a great success with many messages of thanks.

Jane posted *"What a fabulous afternoon! 14 of our 25 patients attended (would have had 17 but some late apologies), alongside researcher Dr Holly Barker from WEHI Stafford Fox Rare Cancer Program. We talked about the excellent research internationally and followed up with Australia specific opportunities. Thank you all for attending. Events like today are so important to bring each and every patient on the journey with us!"*

EHE

Rare Cancer Foundation Australia

Patient Conference: Saturday 9th February 2019

Local Start Times:
Melbourne / Sydney – 3:30pm
Adelaide – 3.00pm
Brisbane – 2:30pm
Darwin – 2:00pm
Perth – 12:30

Alone we are rare –
together we are strong

Mentioned 'in dispatches'

On the 4th February the Victorian Comprehensive Cancer Centre (VCCC) in Australia held its World Cancer Day lunch and live-streamed their Q&A session across the globe. Jane Biddlecombe was delighted to be able to share with the EHE community that her fellow director, Jonathan Granek, had been mentioned by Prof Clare Scott in the discussion. Jane posted *"because of the work of Jonathan Granek, the EHE Foundation Australia is well placed to be at the forefront of research opportunities. Thank you Jono!"*.

We also want to thank Jonathan for his relentless work in elevating EHE's profile in Australia.

"I am…I will"

I am grateful for everyday I am stable with EHE; an extremely rare and incurable cancer

I will advocate for improved care everyday in everyway to improve the lives of patients living with EHE now and make the EHE journey easier for those yet to come.

Jane Biddlecombe (Founder EHE-RCFA)

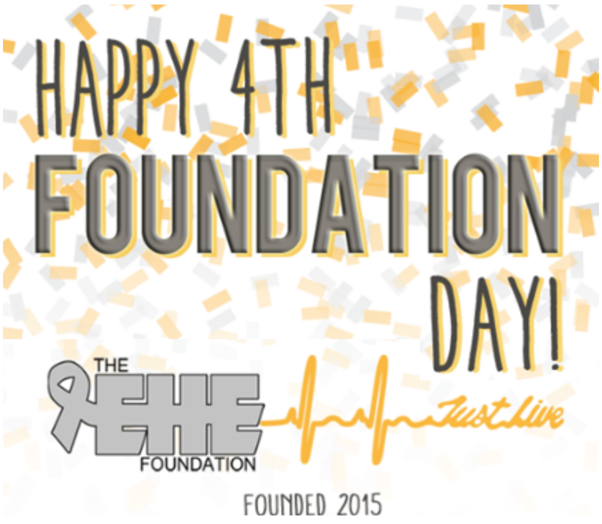
Teresa's transplant story

Teresa Cumbie was able to spread awareness of EHE by posting her story about her liver transplant at Duke Health. Teresa had missed a chance to take part in a clinical trial at Duke, but was then qualified for a liver transplant. *"I am a fighter with 2 grandchildren and 2 great-grandchildren that I want to be around for. I was extremely fortunate that I was qualified for a transplant and that it was a success"* posted Teresa. She also could not speak too highly of Duke Health and her medical team. *"This is the finest hospital system that I have ever come in contact with. They have an awesome team and I would recommend anyone close to the Southeast US, or for that matter anyone from anywhere worldwide, to try them out. They are truly awesome."*

We want to thank Teresa for being prepared to share her story, spreading awareness of EHE and Duke Health. And we also want to thank Duke Health for caring for one of our EHE family so well.

Happy Birthday

The EHE Foundation celebrated its 4th birthday on 24th February! Julie Wahl summarized the big day by stating, *"The EHE Foundation has grown so much in 4 years, thanks to the hard work and dedication of our growing board, so many volunteers, and the amazing support from our EHE family. We have big plans and we are still learning and growing and trying to accomplish the goals we set years ago. But our growth, progress in research and awareness, and commitment to making a significant impact in the future is only possible due to our dedicated supporters. Thank YOU!"*



02 EHE Research

Only through research can we answer questions and defeat EHE

We will ultimately defeat EHE because the research we fund and drive will answer questions and generate new drugs and treatments to manage and defeat this cancer. The following notes provide updates of some of the research we are involved with.

Australian IRE ablation study moving forward

Zosia Golebiowski, whose daughter Blanka was the first EHE patient in Australia to undergo IRE ablation of her liver tumours, was delighted to be able to report progress with the international study of IRE ablation for EHE patients. *"For a long time we have been putting a lot of effort into trying to establish an IRE/EHE multi-centre study to discuss important issues in this treatment. It has taken ages, mainly because of difficulties in communication with doctors and funding issues but I am so happy to say that the funded study is going ahead starting January this year, so the project will be looking for all EHE/IRE patients wishing to participate very soon!"*

The study is being led by Dr Helen Kavnoudias, Head of the Radiology Research Unit at Monash University in Melbourne Australia. IRE (NanoKnife) has been successfully used to treat EHE liver tumours, but only in a small number of cases. It is not widely accepted as a treatment modality for EHE because it has been used in so few cases, a classic challenge for ultra-rare diseases like EHE. The intent of the study is to bring together interventional radiologists from across the globe to collate, analyse and present facts about IRE ablation and how it has worked with EHE patients. The study team hope that with real data they can start to get IRE accepted as a valid form of treatment for EHE. The study group already has support from some of the most experienced radiologists who have been actively using IRE with EHE, including Dr Govindarajan Narayanan (Dr Raj), Professor of Radiology and Chief of Interventional Oncology at the Miami Cancer Institute who wrote *"I am very much in agreement in collaboration between the multiple sites that treat EHE and discussed this with Lisa. I will be glad to reach out to Dr. Martijn Meijerink in the Netherlands and Tze Wah and Praveen Pedu from the UK to start the conversation. Look forward to our collaboration. Will be glad to start with a conference call and then take it from there."*

The study team will be reaching out in the very near future to all EHE patients who have undergone IRE to tell them how they can get involved. We hope that you will all consider taking part as the group is small and so every person's data will be important to the study's success.

And for those who are interested to know more about IRE, Lisa De Young shared an interview with Dr. Raj on the benefits of this lifesaving and less invasive procedure. The video clip can be found at: **https://baptisthealth.net/baptist-health-news/targeting-tumors-nanoknife-advances-minimally-invasive-cancer-treatment/**

Canadian research is up and running

On the very last day of March Fiona Louise posted two exciting pieces of news from Canada. *"A generous Canadian patron from this group has written The Sarcoma Cancer Foundation a cheque for $50,000! That, combined with other fundraising efforts means our total is now $70,000-$75,000"*. Fiona Louise went on *"And I just heard from our research doctor, Dr. Albi Razak this morning that his EHE proposal has been approved and he will be moving forward in the very near future. Canada will be joining the US, UK and Australia and contributing to global EHE research efforts!"*

This new EHE research will be led by Drs. Albiruni Razak and Kanan Al Shammari at The Princess Margaret/Sinai Health System. They will be seeking to characterize the immune signature and molecular profile of EHE tumors. By doing so, they may be able to identify specific mutations which may be targetable by new drugs, such as immunotherapy, through clinical trials. This could potentially change practice for the treatment and management of EHE. With their study beginning around the middle of 2019 we hope that results may be available early in 2020. It is hoped that if successful, the project could lead to a larger, collaborative trial.

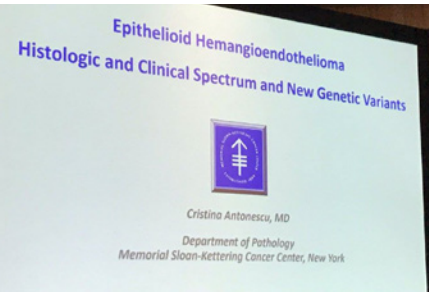
New EHE research program starts at Sloan Kettering

In early February Jane Gutkovich was delighted to be able to announce important news about a new EHE research project. *"I am thrilled to announce that The EHE Foundation has initiated the first phase of hopefully a long term EHE research program at Sloan Kettering Hospital in New York. Among other things, this particular project will study the genetics of different subtypes of EHE as well as markers for immunotherapy. We will shortly be sending out emails with more details about this project and its potential outcomes."*

The project is being led by Dr Christina Antonescu from Sloan Kettering.

As is often the case with rare cancer research, tissue availability is key. Jane continued *"Dr. Antonescu needs more tissue. We are still working out the details for an "easy" method to transfer tissue and will update you through our Facebook page and via email. Patients who can provide tissue will receive a report from Dr. Antonescu which will confirm the EHE by genetic analysis and will provide the description of some morphological features that potentially, in the near future, can determine the behavior of your EHE."*

Later in the quarter Jane was also delighted to be able to report that Dr Antonescu gave a presentation about her EHE project to hundreds of scientists at the annual international meeting of pathologists.



Epithelioid Hemangioendothelioma
Histologic and Clinical Spectrum and New Genetic Variants

Cristina Antonescu, MD

Department of Pathology
Memorial Sloan-Kettering Cancer Center, New York

02 EHE Research

It is important to try and ensure as many people as possible are enrolled in Dr Antonescu's study. If you are based in the USA and have any questions about the project, then please reach out to Jane Gutkovich **janegutkovich@fightEHE.org**, Lisa De Young **lisadeyoung@fightEHE.org**, or Medha Deoras-Sutliff **mdeorassutliff@fightehe.org**.

USA drives multi-institutional retrospective medical chart review

In 2019, The EHE Foundation initiated a global multi-institutional retrospective chart review of EHE patients in order to describe EHE biological behavior, treatment utilization, and outcomes across various EHE locations. This is the first large-scale EHE study which will further inform clinicians and researchers for future treatment decisions and research initiatives. The project will start in the USA and will try to generate a more meaningful data set for overall evaluation and study.

Focusing on tissue and fluids collection

One of the big issues faced by rare diseases is the extremely limited availability of tissue and fluid samples that are critical to any research programme. The EHE Foundation (USA), The EHE Rare Cancer Charity UK and the EHE Rare Cancer Foundation Australia are all working to put in place ways to capture these important samples, and to try and ensure that no samples are lost.

In the USA tissue and fluid capture is being coordinated through the Rare Cancer Research Foundation's 'pattern.org' system. Lisa De Young explained *"It's a simple registration process to capture fluid (ascites or pleural) and/or fresh tissue from surgery. The organisation will coordinate contact via the Rare Cancer Research Foundation (RCRF) with your doctor/surgeon to capture and ship the specimen."* Lisa went on to explain *"the initial feed-back I have received thus far is very positive and they are very impressed how our EHE members have mobilized and how eager they are to support research. Let's keep the momentum going and flood them with tissue/fluid samples so we can find a cure! A video clip is available on their website to walk through the registration process. Go to pattern.org today!"*

RCRF
THE RARE CANCER RESEARCH FOUNDATION

In the UK, focus is on building an ongoing relationship with the Royal Marsden/Institute of Cancer Research. Hugh Leonard explained *"we have agreed and are committing to fund the role of Tissue Manager within the ICR to help us coordinate all aspects of tissue capture and storage, eventually creating a UK-wide EHE biobank. We hope that this may also enable us to coordinate more efficiently with sarcoma biobanks in Europe as well, and engage with and contribute to international collaboration programmes. We hope to have more news on this front in the very near future."*

ICR The Institute of Cancer Research

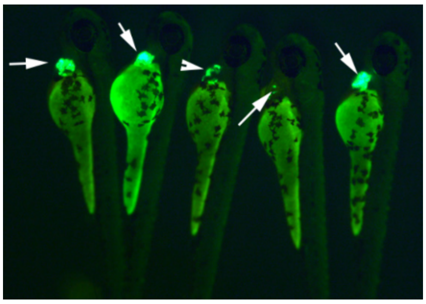
In Australia, a similar focus on tissue and fluid samples is being coordinated through the WEHI Stafford Fox Rare Cancer Program. This programme has been established to discover novel therapeutic targets within the biology of rare cancers, of which EHE is a cohort. Jonathan Granek explained *"The program uses blood and tissue samples from patients to study the cancers in detail. This includes Genetic Research (WGS), Protein Research, Immune System Research, and ongoing research such as the development of cell lines etc. We are looking to collate medical information, blood samples*

(30ml up to 3 samples per year) and tissue samples (archival, and fresh/future).”

Cell lines and animal models

Another critical component for any cancer research is the development of either cell lines or animal models of a specific cancer. Developing either of these has been a major challenge for EHE, despite significant focus. However, there are other avenues to explore and at the current time several projects are underway to try and find a solution.

In the UK the Bateson Centre at the University of Sheffield is in the process of developing a zebrafish model with the WC Fusion gene mutation that will express the fusion protein that drives EHE. Early progress was good with the mutation successfully introduced and transmitted through the germ line. In mid-March, Hugh Leonard, Kate Hooper and Liz Milligan, all trustees of the UK charity, visited the Bateson Centre to review progress. The very latest results had thrown up a surprise with the apparent absence of the Taz-Camta1 mutation in all endothelial cells. The project leader said that this was a surprise, not seen before, and certainly unexpected. The team are now investigating whether the methodology of the mutation introduction is causing the failure, or whether this is in fact something being caused by the biology.



A second project in the UK, a PhD under Dr Valerie Kouskoff at the University of Manchester, is looking to understand what effects EHE has on the development of endothelial cells. This project only started in January but has apparently already thrown up an interesting result. The charity trustees will be visiting in late April to go through the science of the PhD as well as hear about progress to date. More information will be provided in due course.

In the USA, the EHE Foundation is collaborating with the Rare Cancer Research Foundation's pattern.org sample capture program and The Broad Institute to further the development of an EHE cell line. Jane Gutkovich comments *“Cell lines are the main model to study cancer behavior and response to various therapies. Cell line development can be a very complex process which begins with coordination between patients and providers on tissue donation. EHE patients are demonstrating exceptional understanding of the importance of donating their tissue to research and we continue to support patients by providing easy access to a well-coordinated tissue donation program.”*

Also in the USA, Dr Brian Rubin is working in collaboration with a specialist team seeking to develop an EHE model using drosophila flies. Early progress has been limited as the flies die when the fusion protein is introduced. But they have not given up and continue to work to find solutions that may lead to a successful model.

02 EHE Research

A lot of effort and focus is clearly being spent on the development of models and cell lines. While no sustainable cell line or animal model has yet been produced, we hope that the different teams involved will succeed. We also believe that the sharing of results and observations between these different groups may also lead to further advances and ultimate success.

Australia are promoting ISKS

The EHE Rare Cancer Foundation Australia was active in the first quarter in promoting the International Sarcoma Kindred Study (ISKS) which is being run by Prof David Thomas, based at the Garvan Institute in Sydney, Australia. Jane Biddlecombe asked *"EHE Worldwide Family; join us in helping answer a fundamental question asked by anyone diagnosed with EHE .... WHY ME? We need as many patients as possible to sign up to the International Sarcoma Kindred Study, run by EHE Medical Advisor Professor David Thomas."*

The objective of the study is to create a unique global resource to enable study into genetic risk factors for EHE. It is hoped that understanding the genomic risks of EHE may lead to early detection. It also has two important benefits of being free and also very easy to sign up and participate. All you have to do is email **isks@garvan.org.au**, mentioning EHE and asking for a participant kit. You will then need to provide a blood sample or hair follicle, and fill in a relatively simple questionnaire.

Jonathan Granek explained *"This is a truly international study with connections at all major US, UK, and European Research Hospitals. Most important, as patients, your role in driving research is crucial. Every bit of information is part of a larger puzzle that we are trying to piece together."*

Jane Biddlecombe is happy to provide any further information and answer any questions. She also provided copies of study fliers put together by our Australian foundation. She is very happy to provide copies of these too, to anybody who wants them.
Jane can be contacted at:
jane.biddlecombe@ehefoundation.com.au

ISKS INTERNATIONAL SARCOMA KINDRED STUDY

Register today to receive your ISKS Test Kit: isks@garvan.org.au

WHAT IS ISKS?

- ISKS is a free to participate global genetic, biological, epidemiological, clinical resource developed to understand the genetic basis of sarcoma in a population.
- ISKS has created a world first, one of a kind, database that is accessed by doctors, researchers and scientists across the globe.
- ISKS was developed by Australian EHE Medical Advisor David Thomas and his team at the Garvan Institute.

WHY WE NEED IT

- To create a unique global EHE resource to study genetic risk factors for EHE.
- Contribute to a growing international body of knowledge to support patients, clinicians and researchers now and into the future.
- Understand the genomic risks of EHE may lead to early detection strategies into EHE or sarcoma more broadly.

HOW YOU CAN HELP

- Sign up today by emailing isks@Garvan.org.au to receive your ISKS test kit requiring you to fill in a brief questionnaire and supply a blood sample and/or hair follicle.
- Your support will contribute to EHE knowledge which may impact patients now and in the future.

EHE RARE CANCER FOUNDATION AUSTRALIA

GARVAN INSTITUTE OF MEDICAL RESEARCH

ISKS INTERNATIONAL SARCOMA KINDRED STUDY

The ISKS was established to address a fundamental question faced by all of us diagnosed with cancer **WHY ME?**

EHE RARE CANCER FOUNDATION AUSTRALIA

What is involved

Complete a questionnaire about your occupation, health, lifestyle, family medical history and your attitudes towards genetics and genetic research.

Provide a blood sample – a blood kit will be supplied at no cost. The blood will be stored in a central laboratory where genetic material (DNA and RNA) will be extracted and sometimes long living cell lines will be established.

Allow medical information about yourself and deceased relatives to be collected from cancer registries and similar health organizations.

ISKS

2,300 families recruited from 21 centres across 7 countries

ISKS has clinical information on over 71,000 relatives of sarcoma paitents

To date only 18 EHE patients have enrolled in ISKS until now...

ISKS is a global, genetic resource developed to understand the genetic basis of sarcoma in a population, in our case EHE.

Register today: isks@Garvan.org.au

Publications arising from ISKS

An increased incidence of Hodgkin's lymphoma in patients with adult-onset sarcoma
Downing et al, Clinical Sarcoma Research 2012,

High frequency of germline TP53 mutations in a prospective adult-onset sarcoma cohort Mitchell et al, 2013 PLoS ONE Vol 8 Iss 7 e69026.

A genome-wide scan identifies variants in NFIB associated with metastasis in patients with osteosarcoma
Mirabello et al, 2015 Cancer Discovery 5(9): 920-31

For more publications and to see what projects are currently utilizing ISKS go to http://www.australiansarcomagroup.org/sarcomakindredstudy

Prof. David Thomas
Sarcoma Expert

Director - The Kinghorn Cancer Centre

Division Head - Cancer
Lab Head - Genomic Cancer Medicine
Garvan Institute

GARVAN INSTITUTE OF MEDICAL RESEARCH

Register today to receive your ISKS Test Kit: isks@garvan.org.au

Alone we are ***RARE*** - *Together we are* ***STRONG***

03 EHE Fundraising

We are raising funds to support critical EHE research

The EHE Group is dedicated to raising the critical funds needed to finance, drive and accelerate our 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.

4 friends embark on year-long campaign

Allana Parker joined our EHE family in 2018. On the first day of the year she posted news of her 4 brilliant friends who have taken up a year-long challenge.

"I would just like to share with you all about my wonderful friends who have decided among themselves to do a year-long EHE fundraising relay with the first of them being Natalie Ellis who is doing a 100 day 'dryathalon'. She posted her go fund me page this morning and has already hit £85! On the 11th April she will be passing the baton onto Samantha Power for a further 100 days (her challenge to be decided yet) then Sophie and ending with Ellen. These four have fully supported me since being diagnosed and are turning into little EHE experts reading everything available. I think we all agree our friends and family make this fight so much stronger and easier to handle, I don't know where I would be without them"

Natalie is now approaching the end of her first leg of the relay, and with gift aid added, has raised over £1,000 already. She has also been getting EHE collection pots out to local businesses, which is fantastic. We also know that Ellen will be completing a triathlon style challenge of 568 miles (twice the distance from Allana's house to the Royal Marsden hospital and back) by running, swimming and biking miles each week for 100 days. We want to thank these four amazing ladies for their brilliant support for Allana and the charity, and wish them every success. Watch out for future updates.

And we cannot agree more with Allana's comments about friends and families. They are so important!!

What a night!!

Nicola Henderson is an EHE patient based in the west of England. On the 2nd February, Nicola and 2 of her best friends hosted an unbelievably brilliant masquerade ball in aid of EHE research. 270 guests attended and took part in an amazing night!

Just before the event started Nicola posted: *"We're going to raise lots of funds and most importantly awareness! A lot of hard work has gone into this event and we have found local and national business to be so generous with donations for auction prizes etc. I'm still waiting for my transplant call but when I stand back and reflect on what we have achieved, and how much support you can get when you reach out, I feel strength and pride. Wish us luck! "*

Wow, what a night it was. As one guest put it *"This place is throbbing!! What a fantastic evening - lots of laughs, some tears, huge support for EHE."* We want to say a huge thank you to Nicola, Kerry, Danielle and their other halves for the huge amount of time and effort that was put into making it such a great evening. And of course for raising over £14,000. Awesome.

And these four ladies are EHE 'sisters' Sally, Nicola, Janet and Emma who were all present on the night to have a great time and support each other.

Birthday gifts to fight EHE and other fundraisers

Several of our EHE family members have used their birthdays to help raise funds for EHE research, simply by asking people to donate to their local EHE foundation as a birthday gift.

Jessica Carlson did exactly this in January! Jessica posted *"This past May, my mom was diagnosed with EHE, a very, very rare form of cancer. There are over 330 million people in the US, and less than 1,000 patients diagnosed with EHE. For my birthday*

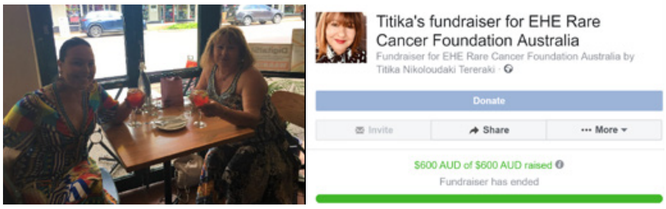
03 EHE Fundraising

this year, I'm asking for donations to The EHE Foundation. I've chosen this non-profit because their mission means a lot to me, and I hope you'll consider contributing as a way to celebrate with me. Every little bit will help me reach my goal."

Sara Mizzi in Canada also asked friends and family to donate. *"Feeling pretty grateful for all of the wonderful people in my life who supported my Birthday Fundraiser! We were able to raise $1280 to go to the Sarcoma Foundation of Canada. Fiona Louise has graciously assisted me in ensuring that the funds will be directed towards EHE research. Please consider this for your upcoming birthdays. We desperately need to shed light and resources on EHE so that we can continue to advance our knowledge and understanding and hopefully one day find a cure."*

And Elina Hernandez launched her own birthday fundraiser. *"I'm working along with my family to fundraise for the EHE Foundation as much as we can. Unfortunately, this rare cancer has hit close to home."* Elina and her cousin, Joe, are also planning to coordinate a group for the 5K in New York City.

And in Australia, Jane Biddlecombe posted her thanks to Catarina (Titika Nikoloudaki Tereraki) for hosting an online fundraiser for her birthday in lieu of presents. *"We are so grateful for the support of our extended EHE family!"* wrote Jane.



Titika's fundraiser for EHE Rare Cancer Foundation Australia

Fundraiser for EHE Rare Cancer Foundation Australia by Titika Nikoloudaki Tereraki ·

$600 AUD of $600 AUD raised

Fundraiser has ended

Birthdays were not the only fundraising events run by members, many through Facebook. So we want to send our special thanks to Tedra Gate, Rachel Huver, Olivia Wahl, Jennifer DeJean, Julie Wahl, Jessica Carlson, and Elina Hernandez, Jessai Carlson, Dale Elaine Carleton, Bridget Omara-Nicole, Zahra Ali, Patricia Ruth Hoover, David Kauffman, Ali Hipkins, Rachel Huver, Lorena Sorensen, Lorenzo Valdisserri, Diana Donohoo, Sally Kulilkamp, Lucia Tozzi, Karen Campbell Wesley, Clint Badlam, Todd Young, and Stephanie Roquet for hosting Facebook fundraisers this quarter. We are grateful for your great support.

Chocolate sells well!!

Keren Stern in the USA was excited when a simple idea to raise funds turned into a great fundraiser. *"I am excited to say that a week ago I decided to try selling chocolates to raise money for EHE. It's going better than I had hoped. I bought 50 cases and have sold 10 so far. The EHE Foundation will get $30 for every case sold. So far $300! I am happy to have found a simple way to contribute to the foundation."*

It's a great example of how fundraising does not need to be mega teams and huge events to be successful. Many smaller projects are just as important. We congratulate Keren on a great idea and hope that others may follow this simple example.

WOMAC Annual Party raises £15,000 for EHERCC

40 years ago a group of women set up the charitable foundation *"Women on the Move Against Cancer"*, or WOMAC. WOMAC is run by women all of whom work in the automotive industry. They raise funds which they use to support cancer charities, choosing a different one each year. This year we were thrilled when they chose the EHE Rare Cancer Charity after hearing the story of Isabelle Escoffey who lost her battle with EHE in February last year.

WOMAC's main fundraising event is their annual party, which took place in London on 13th February. It was a really fantastic evening with over 200 people attending. Hugh Leonard had the chance to tell them a little about what we are trying to achieve, and of course thanked them on behalf of our EHE Family across the globe. Unbelievably they presented the UK charity with a cheque at the end of the evening for £15,000!! Wow. These funds will be used to fund part of the PhD project that the charity is funding in Manchester, looking at how EHE effects the development of endothelial cells.

Here are just a few pictures of the evening. The two women together are Sally Baker and Adrianna Glennie. Adrianna flew down from Aberdeen so she could attend. Awesome.

We want to pass on our thanks to everybody at WOMAC who was involved in making the night such a success. And just to show how brilliant these women are, Georgia Fox, Chair of WOMAC, also ran in the London Landmarks Half Marathon in March as a member of the EHE54 team. We love you guys!!

03 EHE Fundraising

Canadian support keeps on delivering

Fiona Louise continued her relentless and brilliant fundraising programme through the 1st Quarter, raising another $1100 for Canadian EHE research with a wine raffle and donations event at work.

Later, in March, one of her colleagues, with the support of staff, students and the community, did a magic show to 'Stomp out Sarcoma'. *"I won't have final numbers for a while but the total has already exceeded $3000, with another two events already in the works."*

Fiona Louise is very focused on her fundraising as she is working to secure EHE access to an ongoing research programme in Canada. All help would be welcome and so she was also keen to re-post details of how others can help. *"Hello Canadian members, there is one (possibly two) big pieces of news coming out in the next few months, so I am posting this again in case you have been meaning to contribute but have not gotten around to it yet. Please help us and please consider being a part of a historic first step in Canada. REMEMBER TO PUT EHE IN THE MESSAGE BOX."*

Sarcoma Cancer
Foundation of Canada

Annual EHE Foundation Virtual 5K launches

Preparations and planning for the EHE Foundation's Virtual 5K event took off in March as April is EHE Fundraising and Awareness Month worldwide. The EHE Foundation has reached the goal of surpassing the number of registrations from last year. *"Registration for the 4th EHE Virtual 5K is now open. This 5K is for all ages and abilities. It is also "virtual," which means it can be done anywhere you are. We simply ask you finish the 3.1 miles by running or walking (or any other form of exercise) any time between April 23rd-30th. You can do it alone or with others who register."*

The EHE Foundation launched its *"Are you on the Map?"* challenge to encourage people across the US to register and take part. Thanks to everyone who coordinated a group walk. A special thanks to Katherine Czyzewski, Kristen Holding, Joe Gutierrez,

The Wahl Family, Jenni Kovach, and John Lamb for hosting large events!

In addition to the Virtual 5K, and following on from their excellent *'Faces behind EHE'* campaign that we featured in our last edition of The Pledge, the EHE Foundation has launched their new and equally powerful *"I fight for….."* campaign to run through April and raise awareness of EHE.

The EHE Foundation would like to thank the following sponsors. The EHE family appreciates your support.

You are truly making a difference! Go to The EHE Foundation's Facebook page to find more about each of the sponsors **https://www.facebook.com/Ehefoundation/.**

Platinum: BWA South; Cushman & Wakefield; Giombetti Associates, Hansen Distribution Agency.

Gold: Ryczek Construction; V&P Hydraulic Products.

Silver: Monticello and Warren Animal Clinics; Team **Laney;** Team Kristen Leigh; #teamjenni

52 run the London Landmarks Half Marathon for EHERCC

Following the success of the EHE21 who ran the inaugural London Landmarks Half Marathon in 2018, the UK charity aimed higher for 2019 and were delighted to have secured 54 places for this year. After months of hard training, and long cold nights, the runners awoke to a beautiful day, and after the inevitable pre-race team photo, ran the 13+ miles in glorious sunshine. With two last minute drop outs due to injury and travel, 52 completed the course and together raised over to £22,000 for EHE research. We could not be more grateful for their fantastic support, and for the wonderful support they got on the day, and from all the people who sponsored them to make the day a great success.

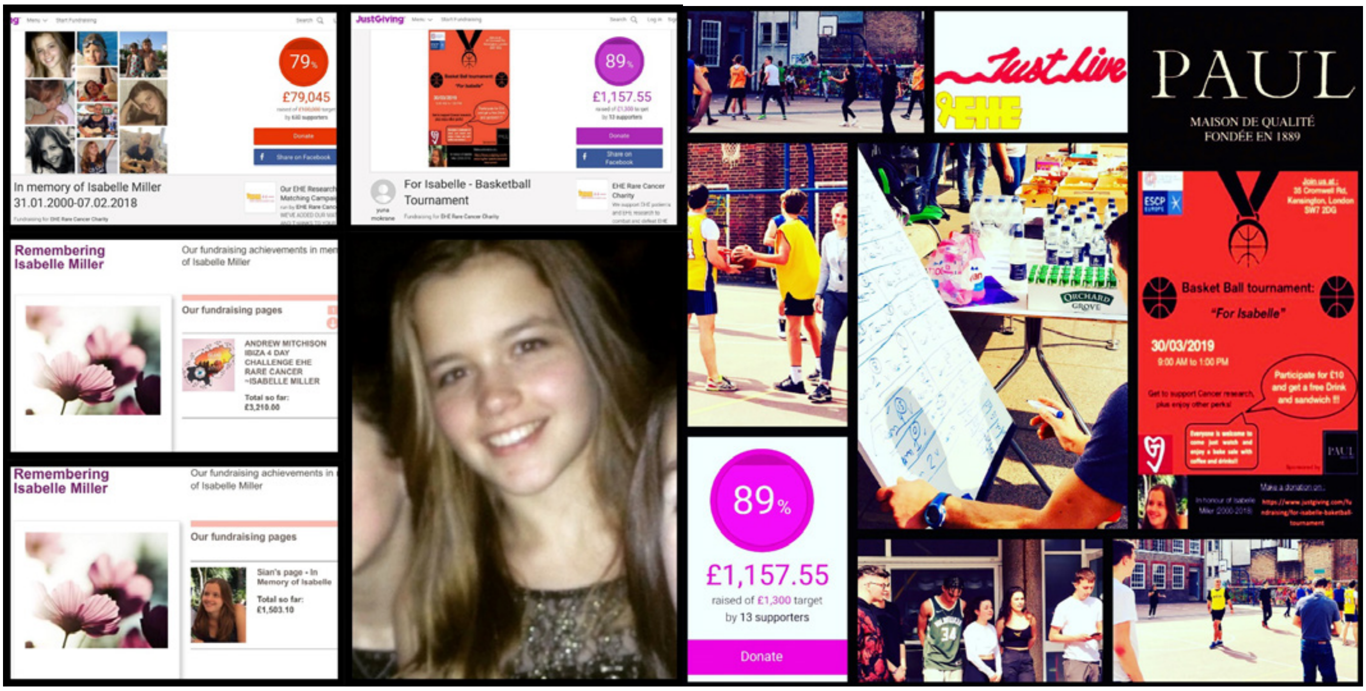
03 EHE Fundraising

Isabelle remembered

It is always with a mixture of emotions that we read about ongoing fundraising for EHE in memory of one of our EHE family. We are encouraged and humbled that families continue the fight against EHE and support the foundations in such circumstances, but also very sad because of the loss they have endured.

Claire-Anna Escoffey posted just such news with an update on the fundraising events that are continuing in memory of her daughter, Isabelle. *"Yesterday Isabelle's old school and friends organised a Basket Ball Tournament in her memory and raised £1,157 in aid of EHERCC. For those who don't know, our daughter Isabelle passed away a week after her 18th birthday in February 2018. We started fundraising for EHERCC with Isabelle and continue to do so in her name, and to date her campaign has raised over £80,000. Whilst life without our beautiful Isabelle is beyond hard for us, it fills us with pride that she has inspired the generosity of so many people, to contribute towards funding the fight to one day find a cure for EHE."*

We cannot thank Isabelle's family, friends, school, and many others, enough for their fabulous ongoing support. Isabelle was clearly a very special, and much-loved young lady. We think she would be very proud of all the support that has continued in her name. Isabelle's fundraising page can be found at **https://www.justgiving.com/fundraising/isabellemiller**

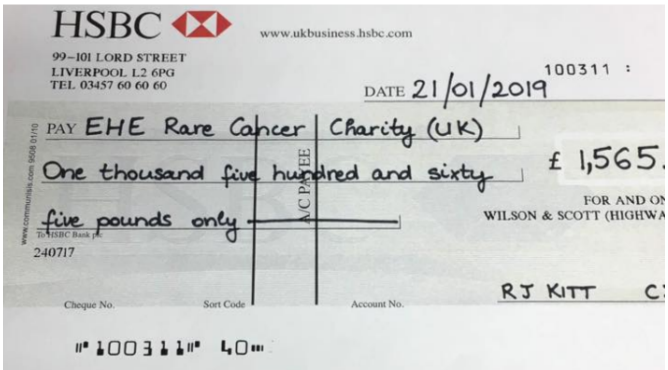


Wonderful support from employers

Kerry Hayman posted news in January about support from her husband's company. *"Once a year my husband's company donates to two charities. This year the EHE Rare Cancer Charity is one of them. A massive thank you to Wilson and Scott Highways Ltd for your kind donation xx".*

We want to also say a huge thank you to Wilson and Scott Highways for their brilliant support. In light of the number of times we talk about *"the road we have to travel down"*, and *"the journey we are on"* etc, it seems particularly appropriate that we now have a wonderful donor whose speciality is highways!

Several of our supporters who have raised funds for our cause have also received wonderful donations from their employers, either matching or one off donations. BP, Barclays Bank, HSBC, Shoosmiths LLP, Lloyd, and Ageas have all provided funding through this manner. We thank them all for their invaluable support.



HSBC
www.ukbusiness.hsbc.com

99–101 LORD STREET
LIVERPOOL L2 6PG
TEL 03457 60 60 60

100311 :

DATE 21/01/2019

PAY EHE Rare Cancer Charity (UK)

One thousand five hundred and sixty five pounds only

A/C PAYEE

£ 1,565.

FOR AND O
WILSON & SCOTT (HIGHWA

RJ KITT

To HSBC Bank plc
240717

www.communisis.com 9508 01/10

Cheque No. Sort Code Account No.

100311 40

04 Upcoming events...

Riders take on 100 mile bike ride for EHE

On the 4th August, the EHE Rare Cancer Charity UK will have a group of riders taking part in the Ride London 100 bike ride. We will be posting more soon, with details of how you can support these great people.

EHE FAMILY
WE NEED YOUR HELP AGAIN!

WE HAVE 10 CHARITY PLACES IN THE PRUDENTIAL RIDE LONDON 100 MILE EVENT
4th AUGUST 2019

WE NEED RIDERS TO HELP RAISE FUNDS FOR
EHE RESEARCH!

CAN YOU RIDE FOR US?
WOULD FAMILY MEMBERS RIDE?
WHAT ABOUT FRIENDS?
MAYBE WORK COLLEAGUES?

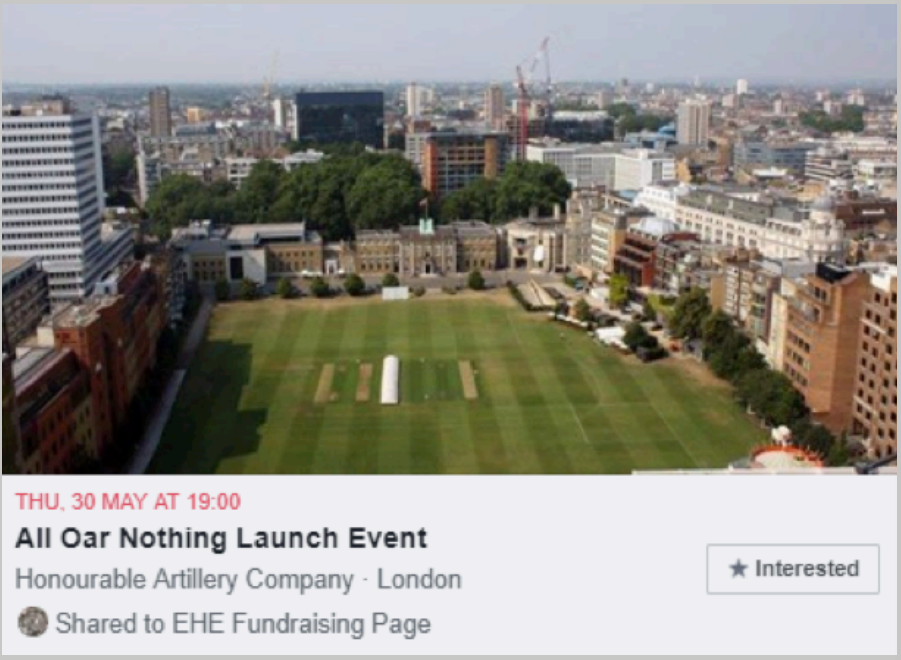
IF YOU WANT TO RIDE, OR KNOW SOMEBODY WHO DOSE
PLEASE CONTACT HUGH AT
hleonard@ehercc.co.uk

An Atlantic challenge

People take on many challenges to raise funds for EHE research. Some run, others ride. But when Charlie Medwin decided he wanted to raise money to support his brother Harry, he and three friends wanted a real challenge. And hence the plan to row the Atlantic Ocean!! Wow.

Charlie and his three friends will be launching their bid to row the Atlantic at the Honourable Artillery Company in London on the evening of 30th May. Sarah Medwin, Charlie and Harry's mother said *"If anyone can come to this event it would be great. Charlie and 3 friends are rowing the Atlantic in December, from Gomera to Antigua. Charlie is raising money for EHE as Harry his brother is a sufferer. So 25% of all money raised will go to EHE. The other money will go to other charities supported by the other rowers. They need to raise £100k to participate. So a minimum of £25k will be raised. You can see more on their website and sponsor them"*
www.alloarnothing.co.uk

We salute Charlie and his friends for their ambition and courage, and hope that some of our EHE members can make it on 30th May to wish them luck!!



THU, 30 MAY AT 19:00

All Oar Nothing Launch Event

Honourable Artillery Company · London

Shared to EHE Fundraising Page

Dancing the night away

Tamzin Jones, a great friend of Kelly Hayman, has decided to run a dance-thon to raise funds for EHE research. *"Anybody fancy a road trip to sunny Somerset, for a bit of a boogie?? It should be a toe tapping kinda night and the bar is open all night too! Even if you don't think you'll last the whole 12 hours, come and dance until you can dance no more"*.

We want to thank Tamzin for her great support and never-ending drive to help our cause. You are a star.

12 hour D~~C~~ANCER-THON

at The White Hart
Wiveliscombe Somerset
7pm Friday 5th April till 7am Saturday 6th April

12 hours of dancing through the night
to raise money for The EHE Rare Cancer Charity UK
(Charity number 1162472) www.EHERCC.org

Price: £7.50 per person (to include Hog Roast)
Teams of up to four, with at least 2 members of that team dancing at all times!

Live bands include:
GigFace, The Understairs and Engine Room
DJ's, Hog Roast, Cash Bar ALL night, Dance Instructors,
Sparkles, Glitter, Raffle, and many more surprises along the way!

Contact: Tamzin Jones on 07944 673285 for more information,
to book your team and to collect Sponsor/ Donation forms.
On Facebook (Search 12 Hour Dancerthon for EHE Cancer)
or register by visiting www.justgiving.com/fundraising/12hourdancer-thon

05

And in other news...

Photos to inspire

The first quarter saw some more lovely submissions from our EHE family photo-therapists. Here are examples from:

Robinson Ortiz Jr;
"To all those affected by EHE may you be surrounded by peace, healing and infinite hope."

Malcolm Barrah;
"I promised some photos of snow drops and here they are - the flower that marks winters end".

Raija Hirschi:
"As Max K. Wells mentioned, Carl Dickson loves sunsets and many of us are in the winter, so I have posted some Caribbean pictures which I took last month. Hopefully that it brings sun into your life!"

First place for a mogul champion!

"Wanting to share with my extended EHE family. Here is one of the reasons we all fight so hard and so long against EHE. My little one took first place in Telluride this past weekend. These moments are why we do not give up!". We send huge congratulations to Broxdon (and Carl and Elizabeth Dickson) for such an inspiring run. We cannot play the video here but hope these pictures give you a feel for an awesome performance. And we also congratulate Beckett, Carl and Elizabeth's other son, who had podium finishes in 4 out of 5 of his mogul races. That is also very impressive.

Getting together is always great

Many of our members say that meeting up with other EHE patients is very therapeutic. We always love to see photos of such occasion.

This quarter we received photos from Leanne Millard and Cecily Rose who met up in Australia when they found each other because they shared the same chiropractor. An amazing coincidence that led to a great lunch out!

Malcolm Barrah and Adrianna Glennie also got together in Scotland for a *"great wee catch up"* at the Crieff Hydro in Scotland in early January, sharing a couple of cocktails in the process. In fact the cocktails were so good that it was these that they photographed. Now that's what we call *"Just Living"*!

Celebrating our EHE Wonder Women

Anna Wydro posted this brilliant version of the Wonder Woman logo, adapted slightly to include the sarcoma ribbon. *"We have so many amazing people here, and so many cancer-affected women; mothers, wives standing by their close ones, affected by this disease. I came across this picture of 'Wonder Woman' with the cancer ribbon, in RED and YELLOW colours, and thought it perfectly fitted this group and its energy. Coincidence? I don't think so".*

We agree Anna. It is a great representation of the wonderful spirit and drive of so many women, many young, diagnosed with EHE.

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