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

Quarterly Newsletter
for the EHE Group
Oct - December 2019

the pledge

Edition 19

Contents

Welcome

Welcome to **“The Pledge”,** our quarterly newsletter covering the activities of the EHE Group.

This is our 19th edition, for the fourth quarter of 2019. We hope that you enjoy reading it, and are inspired by the stories included within it.

We want to say a massive thank you to all our supporters for their contributions. We also want to take this opportunity to wish everybody a very happy, successful and healthy 2020.

Just live

Highlights

‘Matching’ helps raise significant funds for EHE research

Matched funding from wonderful supporters led to the EHE Foundation in the USA raising over $200,000 on Giving Tuesday. Canada meanwhile has matched funding that will result in the first $50,000 raised up to the end of February being trebled. These amazing sums will help us drive EHE research.

EHE mouse model is successful

EHE research funded by our community is progressing. There was huge excitement this quarter as Dr Rubin confirmed that his genetically engineered mouse model is working. This delivers the first ever viable EHE animal model, a huge break-through for EHE research.

Charlie Medwin rows the Atlantic for EHE

A team of three men are currently rowing the Atlantic Ocean for charity in the Talisker Whisky Challenge. Each is raising funds for his chosen charity. Charlie Medwin is rowing for the EHE Rare Cancer Charity UK, and to support his younger brother who has EHE. We are so proud of these three amazing guys.

Mariana Coutinho at the European Parliament

We love any chance to increase awareness of EHE. So we were delighted when EHE patient Mariana Coutinho participated in a European Round Table event to talk about cross-border medical care for rare diseases.

Exciting reports and potential from CTOS discussions

Jane Gutkovich attended the CTOS annual conference in Japan and was able to hold a number of important and encouraging meetings with doctors and researchers about EHE.

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

The EHE Group strives to provide support to everybody diagnosed with EHE. At the same time we work hard to increase awareness and understanding of EHE amongst the general public and all other relevant groups. These two goals are at the core of the patient support and advocacy objectives that are common to all the EHE foundations. But we can only achieve them with the tireless energy and contribution of so many of our members, many of them being EHE patients themselves. So as always, we want to thank all our supporters who have contributed to this critical part of our activity, examples of which are provided in this section.

Wonderful Ambassador

In early November Mariana Coutinho participated as one of the main speakers in a round table event at the European Parliament, in Brussels. The round table was hosted by Youth Cancer Europe and discussed cross-border healthcare with an audience of MEPs and key stakeholders. Mariana posted *"I was invited to share my story, since I reside in Portugal and I am getting medical treatment in the UK (my oncologist, Dr Robin Jones, works in London and I underwent Nanoknife IRE procedures, also in London)."*

Mariana also explained some of the background to the subject, and its importance to rare diseases. *"Directive 2011/24/EU on patients' rights in cross-border healthcare states that EU citizens have the right to access healthcare in any EU country and to be reimbursed for care abroad by their home country. This subject becomes even more relevant for us, being rare cancer patients, who most of the time struggle to find a specialist in our disease in our own countries which need specialized treatment (such as Nanoknife/IRE). Other circumstances in which this directive might apply is cases of patients that need an urgent organ transplant that could be offered to them more quickly in another EU member state or patients that are eligible for a clinical trial that is being conducted in another EU member state, for example."*

We were not surprised either when Anna Wydro, an EHE supporter in the UK and friend of Mariana, posted an article about the event with the news that Mariana's speech had gone down very well indeed. Anna said *"Another perfect job done by Mariana Coutinho! Congratulations! I am so proud of her. I see how much time and dedication Mariana gives to cancer advocacy and wanted to support her and show that we are proud of what she does. It is also amazing as Mariana, after her diagnosis and lack of expertise at home, had to educate herself about the gap in her treatment options, and still faces obstacles to effective treatment today."*

Healthy Living is the Focus

Many of our members have read extensively about, and implemented, dietary changes in their response to their cancer diagnosis. Together with her family, Melissa Clark McPherson has gone further by setting up a new, dedicated Facebook page to promote simple health solutions.

Melissa stated *"If you are looking for help with plant-based lifestyle and simple solutions for your family, my daughter and I started a Facebook group and you are all welcome to join. I feel so blessed that my entire family has supported these changes as I fight EHE. My daughter is a professional dancer, certified fitness instructor and received her degree in dance and nutrition. My husband is using whole food nutrition in hopes to prevent dementia as he watches his dad's memory slip away and my son is a collegiate athlete fuelling his body for peak performance. We will post recipes our family use, tips and nutrition based articles. Hope to see many of my EHE community join us."*

Melissa's page is called *"Healthy Living and Wellness w/ The McPherson's"*. Melissa invites everybody to get on board and join her. We think it is a wonderful idea and congratulate Melissa and the McPherson's for such a great idea.

Knowledge is Power – Community is Strength

A critical area for any foundation is having a robust database of its members. The EHE Foundation embarked in the fourth quarter in a program to improve the information held on all members. Medha Deoara-Sutliff, Executive Director of The EHE Foundation, explained. *"The more we know about our EHE community, the better we can showcase our needs to potential grantees, researchers, and outside agencies. Knowledge creates credible information, which is essential when establishing trends, statistics, and well-organized information. We are transitioning to a new, state-of-the-art database and we hope you will help us by completing our brief survey to update our data."*

Medha asked our members to spare 5 minutes to help The EHE Foundation by filling out a brief survey. The survey is for everyone affected by EHE; patients, caregivers, supporters, health care providers, family & friends! Completing these questions should take less than 5 minutes. In addition Medha confirmed that The EHE Foundation will not sell or share the information with third parties.

We would be very grateful if anyone who has not completed the survey could do so now. Here is the link: https://www.research.net/r/EHE_Foundation

01 Patient Support and Advocacy

Updating and Informing our Worldwide Community

A key role for the EHE foundations is to ensure that our members are informed and updated about research we are funding and the progress that is being made. This is the least we can do as part of our patient support objectives, and in light of the amazing fundraising efforts that are regularly seen.

The latest conference presentation took place through the Zoom platform on 2nd November. All who were able to attend received an overview from The EHE Foundation's Director of Research, Jane Gutkovich, on different aspects of EHE, and were then provided with a research update from the three foundations in the USA, UK and Australia. Feedback was very positive. Existing and new members found the session both informative and uplifting.

Joe's a Fighter

Patients undergoing EHE treatment often have amazing resilience. This is particularly true of one of our younger members, Joe. His Mom, Jennifer shared his uplifting story in early November.

Two days before surgery, Joe's excitement was clear as he celebrated his baseball team's first division win for Hudson Valley. Joe threw the last pitch and won! The day after 9 year-old Joe had a several hour surgery to remove the rest of his EHE tumor, they were again waiting for biopsy results when he told his mom, *"Mom, I am going to be OK!"* Jennifer also shared this picture of him at Memorial Sloan Kettering and said, *"We love them there!"* Two weeks later he was already getting pitching lessons from former Mets pitcher, Nelson Figueroa.

Young Joe embodies the definition of resilience and we are privileged to share his inspiring story. Thanks for showing us all how to *"Just Live,"* Joe.

Ex-Student provides Great Coverage

Fiona Louise was delighted to be able to post a local news article about her EHE campaigning, what she is trying to achieve, and the wonderfully generous support she has been given. This wonderful exposure for EHE and the Canadian activities was particularly warming as the article was written by one of Fiona's favourite former students. We want to thank Karen Martin-Robbins for taking the time to write her story and so help raise awareness of EHE. And we agree Fiona, it is a cute photo of your dog.

CALEDONENTERPRISE.COM

'An amazing opportunity': Canadian research into rare sarcoma cancer finds private donor

02 EHE Research

Text to go here

We will ultimately defeat EHE because the questions that we do not have answers to today will be answered by the research we are funding, and the future research that we continue to promote and facilitate. This research will also lead to the generation of new drugs and treatments to manage and defeat this rare cancer. The following notes provide an update of some of the research we are involved with.

We have a Mouse!

In late October, the three EHE foundations (US, UK, and Australia), were excited to share the breaking news that the World's first EHE mouse model was developed. Thank you to all our supporters who have donated, fundraised, or volunteered in support of the EHE foundations since 2015. Your support has helped Dr Rubin develop the world's first EHE Mouse Model, which appears to be a very strong analogue to human EHE.

This breakthrough will help to study: (i) cancer gene function; (ii) the biology of cancer; (iii) the role of environment in cancer and its interactions with genetics; and (iv) interactions of drugs with cancers. The model will also serve as: (i) a key tool in the screening for effective drugs; (ii) a source of cancer cell lines; (iii) final efficacy screening before clinical trials; and (iv) an interpretation tool for results of clinical trials.

Dr Rubin was also delighted with the progress achieved and the apparent quality of the model. "*I've done a thorough review of the mice that have been used to generate histology so far and we are seeing EHE's in all anatomical areas seen in humans. Additionally, I have immunohistochemical verification (CD31 and CD34 positivity) that the lesions do show endothelial differentiation. This model is remarkable and truly does represent a breakthrough. We are now working on freezing tissue for development of cell lines, xenografts, and for molecular / expression profiling analysis.*"

Jane Gutkovich said, "*The absence of a viable EHE animal model has been one of the most detrimental roadblocks to EHE research. A long list of important studies that can be carried out only in an animal model has not been available for EHE research. So I am overjoyed that Dr Brian Rubin at the Cleveland Clinic has successfully developed an EHE mouse model!*"

Supporters of the three EHE foundations (US, UK, and Australia) helped us provide Dr Rubin with a large grant in 2016, which funded his new post-doc, Dr Che, for two years. Dr Che played a significant role in recent research progress with the mouse model and EHE drug screening. The three EHE foundations also provided additional grants to Dr Rubin's team in 2017. Dr Rubin's team has also been supported by the CRAVAT Foundation.

We would again like to say a huge thank you to Dr Rubin and all his team for their commitment and dedication in finding effective treatments and a cure for EHE.

Natural History Study is Now Open to EHE Patients

As of October, NCI's Natural History Study of Rare Solid Tumors is enrolling EHE patients now! This study is a natural history trial taking place at the NIH Clinical Center in Bethesda, Maryland. The purpose is to collect information and samples from people with rare tumors and their relatives, and track their health history over a long period of time. The NCI hopes to learn more about how rare tumors develop and progress and new ways to control them. The EHE Foundation will share more details as they become available, but if you are interested in learning how to participate, email NCICCRRareTumorClinic@mail.nih.gov Also, eligibility and other trial info can be found on the study's website page at: https://www.cancer.gov/pediatric-adult-rare-tumor/participate/natural-history

We hope and encourage all our patient members to participate in this important opportunity.

The Importance of Tissue

One of the problems with ultra-rare cancers is that tumour tissue is very scarce, and this in turn has a hugely negative impact on research possibilities. For this reason all three of the EHE foundations are working with organisations in their respective countries to try and capture EHE tissue and fluid samples wherever they can.

In the USA the site that is instrumental in tissue capture is www.pattern.org. Lisa De Young, Director of Patient Services at The EHE Foundation, continues to emphasize the importance of tissue donations for EHE research especially as a surge of new members occurs. She explained "*In the US and Canada (fluid donation only), the key is registering at www.pattern.org which takes 10 minutes. Additionally, it is essential this be done at least 7-10 business days PRIOR to your surgical procedure to allow transport. Your tissue sample can make the difference!*"

We cannot encourage all our EHE patient members enough to engage in this effort. Your tissue is vital to the EHE research effort. Please don't let it go to waste. The EHE community worldwide will be so grateful.

However, we accept that rather 'dry' posts about tissue collection can leave the idea of research feeling somewhat remote. So we were thrilled when Medha posted photographs of her visit to the Broad Institute of MIT and Harvard, where the tissue samples are being used in real EHE research, trying to establish viable EHE cell lines. Medha was attending the Rare Cancer Dependency Map Initiative Symposium in Boston.

Medha shared snapshots of what she experienced at The Broad. She said *"The brightest minds are hard at work trying to crack rare cancer cell line development. Thank you to all who support this partnership with donations, not just money, but your tissue through pattern.org!! It truly will make a difference."*

02 Research

Zebrafish Team may have Found the Problem!

Last year the zebrafish team at the Bateson Centre in Sheffield in the UK created transgenic zebrafish lines to express the human WWTR1-CAMTA1 fusion protein that is the major cause of EHE, in the endothelial cells of the zebrafish. Endothelial cells line the blood vessels and are the cells that form EHE tumours in humans. Unfortunately, despite obtaining numerous lines that transmitted the construct, none showed the expected expression in the blood vessels. This was highly unusual, and the team speculated that this might be because the WWTR1-CAMTA1 oncogene is toxic to cells.

Dr van Eeden noted *"to try and control expression of the WWTR1-CAMTA1 oncogene better, we created new constructs where the gene is switchable. When the transgenic lines are established it is switched off, but once the line has been made, fish carrying the transgene can be mated to fish carrying a second "activator" protein. This activation protein is in this case also driven by the same fli1a control element, therefore activation will only occur in the blood vessels. We created again several transgenic lines with the switchable reporter, and crossed them with the activator, but the same problem appears to be happening."*

In a parallel control experiment, however, the team used a completely different gene (a fluorescent marker), where they did get expression in blood vessels showing that their reagents and approach are not faulty. *"This means we may have identified the real source of our problem: rather than being toxic, the human DNA sequence of WWTR1-CAMTA1 may contain sequences that prevent expression in blood vessels of a fish. Fortunately, it is possible to change the DNA sequence without changing the protein it codes for, and adapt it to fish in a way that is called "codon optimisation". We have now created such a modified DNA and have created the first constructs for injection. We are hopeful that we have now identified the real issue, and are confident our 3rd attempt at expressing this protein will be more successful."*

Research can, by its very nature, be a complex and frustrating process. We admire the dedication of Dr van Eeden's team and their determination to create the EHE zebrafish model, despite several set-backs. We wish them every success as always, and look forward to the results of their latest work.

CTOS Another Success

Jane Gutkovich, Director of Research for The EHE Foundation, was delighted to provide a bullet-point summary report of a number of very positive and productive meetings with researchers and doctors during the annual CTOS international sarcoma meeting held this year in Japan, and where Jane was once again carrying the EHE flag. Jane shared:

1. As the circulating DNA project is entering an *"active"* phase at the Mayo Clinic, I had a positive discussion with the primary investigator about expanding the search for other blood biomarkers to detect and monitor EHE recurrence, progression and response to treatment.

2 Positive discussions also took place with researchers who are front-runners in immunotherapy for sarcoma and who agreed to look into cell therapy for EHE which would involve our own immune cells finding and effectively killing EHE cells.

3. I saw continued recognition by researchers of the unique connection of EHE and inflammation. We discussed how to turn this knowledge into a practical approach to EHE treatment and monitoring.

4. EHE experts from across the world acknowledged the need to perform genetic testing and analyse the results for various subtypes of EHE. I had discussions with five doctors representing different countries about how to arrange an international database.

5. Finally, and thanks to the amazing fundraising efforts of Fiona Louise and the particular generosity of one Canadian donor, researchers in Toronto are now 'full speed ahead' in assessing the immune-micro environment of EHE.

Here are a few photos of Jane with some of those wonderful doctors and researchers. As Jane stated *"Let's keep up the great work! Just live!"*

02 Research

Call out for the International Sarcoma Kindred Study

Jane Biddlecombe, President of the EHE Rare Cancer Foundation Australia, posted an update and call out to the worldwide EHE community in November relating to the International Sarcoma Kindred Study (ISKS) being run from the Garvan Institute in Australia by Prof David Thomas.

Jane posted *“Thank you to all who have expressed interest and signed up to the International Sarcoma Kindred Study (ISKS) and returned your sample. But Garvan have indicated some consent forms / samples are still outstanding.*

So please, if you have already expressed interest and received your questionnaire and consent form can you please return to isks@garvan.org.au so they can send out your hair follicle sample kit.”

The EHERCFA’s objective is to get 100 EHE patients enrolled and so build a meaningful database. Jane went on *“The Australian Foundation is keen to start exploring the Germline DNA to see what secrets are stored in our samples.”*

For those who have not yet started but would like to be part of this program, details of the study and the email to use to contact the project team are in the poster below. Please join the study, and let’s get to that magic 100 number!!

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.

Canadian Research is Underway

We were all delighted when in November Fiona Louise posted the news that we had all been waiting for; Dr Razak’s research at the Mt Sinai Clinic in Toronto, including EHE, is underway. Dr Razak’s research is testing the hypothesis that EHE carries a genomic complexity that will have immune signature and a neoepitope that predicts response to immunotherapy. Neoepitopes are compounds in tumour tissue that can be recognised by the body’s immune system. Dr Razak’s objective is to characterize the immune signature and molecular profiling of EHE tumours and so identify possible neoepitopes.

Fiona Louise posted *“I have met the whole team which includes Dr. Razak, the research fellow hired for two years, and the pathologist. They are hoping to get 20 Canadian patients enrolled. If you want to participate in this first ever Canadian EHE study there are two criteria. Firstly you have tissue stored somewhere in Canada that can be sent to Mt. Sinai, and secondly you would be able to go to Mt. Sinai in Toronto on a clinic day to give blood and sign a consent form. Clinic days are Monday, Tuesday and Wednesday.”*

Fiona Louise also recognised that getting to Toronto may be a financial burden that patients on the East and West coasts of Canada cannot bear. She has therefore started a discussion with Air Canada regarding possible humanitarian grants to cover these costs. We wish her success with this thoughtful aspect of her campaign, and congratulate Fiona Louise on her wonderful drive and determination to raise the funds, find the research and succeed in getting EHE included in this valuable project. Dr Razak's work could have implications for EHE patients worldwide and so we thank Fiona on behalf of our EHE family for all she is achieving. *Just Live!*

Manchester PhD - Year 1 Project Summary and Year 2 Look-Forward

January 2020 marks the start of the second year of Emily's PhD project. This is a perfect time for a reflection on the past year, an overview of the progresses achieved to date and a look at what is in store for the second year.

During this first year of research, Emily performed a series of key experiments to optimize the in vitro growth of endothelial cells which are thought to be the cellular origin of EHE. To optimize these culture conditions, many parameters were tested, including the concentration of growth factors, the level of oxygenation, the duration of the culture or the type of material on which these cells are grown. Together, variations in these experimental parameters led to the establishment of a robust protocol to grow and maintain endothelial cells in culture. This is an important achievement as these newly defined culture conditions will allow testing how the fusion protein TAZ-CAMTA1, commonly found in EHE, affects the biological characteristics of endothelial cells. Preliminary experiments using this novel experimental protocol revealed that the expression of TAZ-CAMTA1 in these cultures does change the molecular identity and behaviour of endothelial cells. Together, this first year of work has laid the foundations for the next step of the project.

In this coming year, Emily will investigate in-depth the molecular changes observed upon TAZ-CAMTA1 expression in endothelial cells using state-of-the-art experimental and bioinformatics technologies. These tools allow scientists to measure all the genes that are expressed in cells and to determine which genes are changed between different cells, as there can be up to 15,000 genes expressed in a cell at any time. Emily will also further investigate the changes in cell behaviour upon TAZ-CAMTA1 expression looking at parameters such as cell movement or cell-cell interaction using the powerful microscopes available in the imaging facility of Manchester University. Together, we hope that these experiments will shed some light on how the EHE disease is initiated.

This first year was also phased with several milestones including the writing of a literature report, a first year research report and a *viva voce* that Emily passed with flying colours, allowing her to pursue her PhD studies. We want to congratulate Emily on a great first year, and look forward to seeing some exciting results next year.

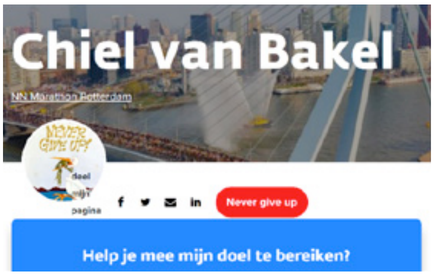
03 EHE Fundraising

We are raising funds to support critical EHE research

Today we are proud to have EHE-dedicated research being carried out in 4 different countries over three continents. The EHE Group remains totally focused on raising the critical funds needed to finance, drive and accelerate this existing EHE research programme, as well as the new and additional research that we hope will follow it. We thank all our members, their supporters and members of the public for their fundraising efforts, some of which are described below

Running the Rotterdam Marathon

Wil van Bakel's younger brother, Cas, was diagnosed with EHE in July. So the moment a friend and colleague of his proposed they participate in the Rotterdam marathon for cancer research, there was no doubt. Wil signed up immediately, even though he had promised he would never do another marathon after running two previously. Great effort Wil. We hope that the event was not too painful and you were able to raise some serious funds for cancer research and in support of Cas.



#EHErelayraisers Hand on the Baton for the Last Leg

On 28 October, Allana Parker was delighted to be able to update everybody with regards to her four best friends and their amazing relay that is raising funds for EHE research. This is the relay where each of the four is completing a 100 days challenge in support of Allana.

"My lovely bestie Samantha Power has finished her 100 day challenge of virtual rowing from London to Paris and back again, and raising an amazing £1,060 for EHE!! That means the girls have already raised over £3,500 to date!" That is an amazing sum and we could not be more grateful, but it is not over yet!

Allana explained. *"Now Sophie Jade Kitchen is taking up the last leg and will be swimming the distance of my house to my nearest hospital, where I receive any radiotherapy needed, and back again!! That's a total distance of 65 miles (104 kilometres) in the next 100 days."* That's 4,160 lengths of the pool! Go Sophie. We love the challenges that you, Natalie, Ellen and Samantha have all taken on to support Allana.

Not content with this marathon relay, Allana and her friends wanted to finish in style. *"The girls will have finished their 400 day relay challenge just 3 days before the Masquerade Ball on 8 February and we will be able to announce the exact amount they will have raised on the night along with the total for the Ball as well."*

We cannot thank Allana and her friends enough for their unbelievable effort, determination and organisation. That is particularly true of Samantha who through this whole process has also been dealing with the aftermath of her teenage son being hit and seriously injured by a speeding motorbike! We are glad to be able to report that he is recovering well. Keep going ladies.

You are all stars! And we'll leave the last words to Allana. *"So proud of them and their commitment".* We are too.

£750,000 - a UK Fundraising Landmark Reached

"Dear EHE Family" wrote Hugh Leonard in the UK, *"I just wanted to post a quick note to let everybody know, but particularly everybody in the UK, that the charity has gone past 3/4 million pounds raised for EHE research. We have raised over £50,000 since then also, so 1 million is on the horizon.*

But most of all I want to say congratulations and a massive thank you to all the runners, cyclists, charity-ball organisers, quiz-nighters, race-nighters, cake-sellers, Jessie Jars inventors and fillers, cancerthon dancers, employer-matchers, company sponsors, donors and every other form of fundraising and donating that has helped us raise these funds for EHE research.

Please, please don't stop, there is so much more to do. But just for tonight I want every one to feel very proud of what you have all achieved. We love you all. "

All-Oar-Nothing: the 'Oar-some' Foursome Set Off

In the last three or four editions of The Pledge we have included within the Forthcoming Events section of the news-letter information of the amazing four friends (Charlie Medwin, Lewis Matthews, Tom Whittle and Chris Slack) who would be setting out to row the Atlantic Ocean in the Talisker Whisky Challenge. Each is raising funds for their chosen charity. Charlie Medwin chose the EHERCC in support of his brother Harry who has EHE.

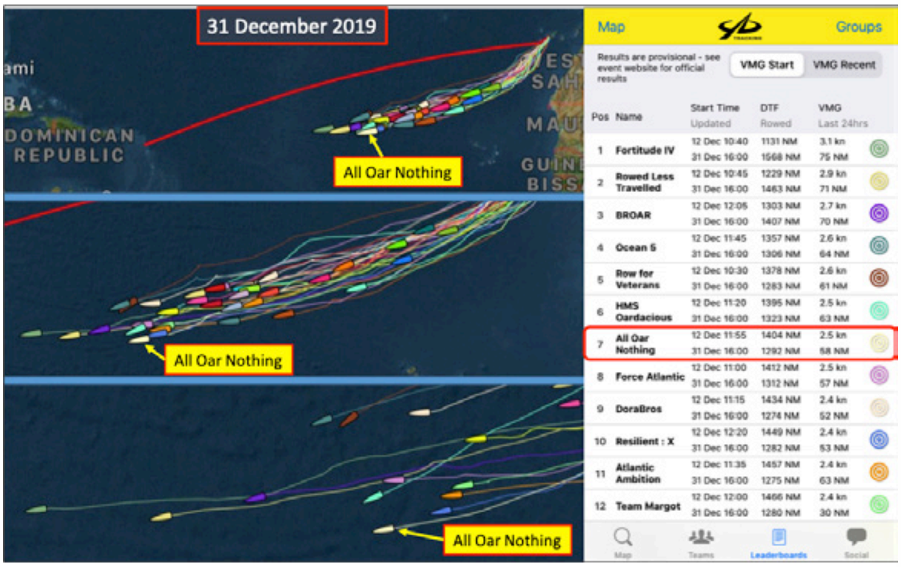
Well on December 12 the event was no longer in the future category as the boat left Gomera in the Canary Islands and the **All-Oar-Nothing** team set off on their 2,700 nm adventure. Sadly due to a severe back injury, Tom Whittle had to drop out at the last minute, but as his three friends said, he will be with them in spirit every pull on the oars.

03 EHE Fundraising

On 11 December Hugh Leonard posted best wishes from everybody in the EHE group worldwide. *"Tomorrow I will get up and catch the train up to London. Charlie Medwin however will get up and start a slightly more challenging journey because tomorrow is when Charlie and two very close friends start their epic challenge to row the Atlantic. I wanted to post this to thank them for what they are about to do, but most of all to wish them Godspeed and a safe passage. I don't know what form of deity everybody worships, but whatever God or higher presence you believe in, please take a few minutes tonight to ask them to look after these three very brave men."*

Progress of the All-Oar-Nothing team has been possible using social media and the event app. On Christmas day they had completed 900 nm, with 1,800 still to go. And by News Year Eve they had completed a further 392 nm. We all found it hard to imagine what it would be like sitting in such a small vessel in the middle of such a vast expanse of water.

Hugh again posted *"I just wanted to wish our three rowers who are mid-Atlantic a very happy and SAFE new year. When we are all old, none of us will remember with absolute clarity where we spent a particular New Year, but these three guys will never forget New Year's Eve 2019. Sarah Medwin please send all our thanks and best wishes to the three lads. Just Live".*



Results are provisional - see event website for official results

Pos	Name	Start Time Updated	DTF Rowed	VMG Last 24hrs
1	Fortitude IV	12 Dec 10:40 31 Dec 16:00	1131 NM 1568 NM	3.1 kn 75 NM
2	Rowed Less Travelled	12 Dec 10:45 31 Dec 16:00	1229 NM 1463 NM	2.9 kn 71 NM
3	BROAR	12 Dec 12:05 31 Dec 16:00	1303 NM 1407 NM	2.7 kn 70 NM
4	Ocean 5	12 Dec 11:45 31 Dec 16:00	1357 NM 1306 NM	2.6 kn 64 NM
5	Row for Veterans	12 Dec 10:30 31 Dec 16:00	1378 NM 1283 NM	2.6 kn 61 NM
6	HMS Oardacious	12 Dec 11:20 31 Dec 16:00	1395 NM 1323 NM	2.5 kn 63 NM
7	All Oar Nothing	12 Dec 11:55 31 Dec 16:00	1404 NM 1292 NM	2.5 kn 58 NM
8	Force Atlantic	12 Dec 11:00 31 Dec 16:00	1412 NM 1312 NM	2.5 kn 57 NM
9	DoraBros	12 Dec 11:15 31 Dec 16:00	1434 NM 1274 NM	2.4 kn 52 NM
10	Resilient : X	12 Dec 12:20 31 Dec 16:00	1449 NM 1282 NM	2.4 kn 53 NM
11	Atlantic Ambition	12 Dec 11:35 31 Dec 16:00	1457 NM 1275 NM	2.4 kn 63 NM
12	Team Margot	12 Dec 12:00 31 Dec 16:00	1466 NM 1280 NM	2.4 kn 30 NM

And here is the snap shot of their position as we all began to get ready to see in the New Year.

As we go to print Charlie, Chris and Lewis are still making great progress as they enter the latter stages of the event.

All-Oar-Nothing Mums are also Raising Funds

On 21 December Sarah Medwin, mother of Charlie Medwin on the All-Oar-Nothing boat rowing the Atlantic, was delighted to host 45 ladies for lunch, supported by Chris and Lewis's mothers too. In fact the mothers stood side by side in the same order as their sons.

The event was a huge success and raised an amazing £1,183 for the All-Oar-Nothing Team. Sarah Medwin posted *"Thank you to all involved, the boys really appreciate your efforts!"*. Charlie's chosen charity is the EHERCC. This is every personal to Sarah, and the whole Medwin family, with her youngest son (and Charlie's brother) suffering from it. *"There is currently no cure and it is very underfunded, so every bit of your money really goes a long way @eherccuk."*

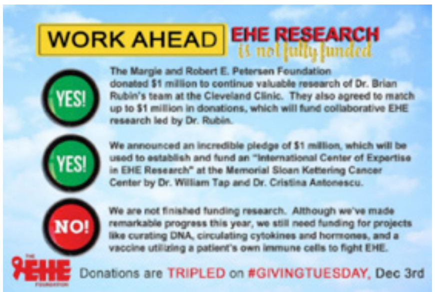
If anybody wishes to sponsor the team, it is not too late. Please go to www.alloarnothing.co.uk and click on sponsor.

#GivingTuesday a Huge Success

In late November the EHE Foundation launched its #GivingTuesday fundraising campaign. The campaign featured stories and informational posts about the Foundations accomplishments and goals. Some of our *'EHE warriors'* shared their personal stories through the Foundation's inspiring "Faces behind EHE" campaign to help shed light on some personal struggles and feelings about this rare cancer. The awareness this brought was astounding

The Foundation was also thrilled to announce that all donations received by the campaign were DOUBLED and up to $50,000 were also TRIPLED on #GivingTuesday (Tuesday, December 3rd) by the Foundation's generous supporters. There was even a chance that donations were QUADRUPLED

03 EHE Fundraising



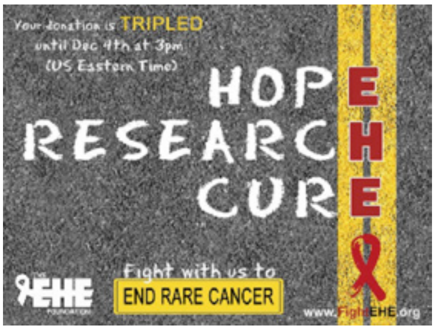
WORK AHEAD EHE RESEARCH *is not fully funded*

YES! The Margie and Robert E. Petersen Foundation donated $1 million to continue valuable research of Dr. Brian Rubin's team at the Cleveland Clinic. They also agreed to match up to $1 million in donations, which will fund collaborative EHE research led by Dr. Rubin.

YES! We announced an incredible pledge of $1 million, which will be used to establish and fund an "International Center of Expertise in EHE Research" at the Memorial Sloan Kettering Cancer Center by Dr. William Tap and Dr. Cristina Antonescu.

NO! We are not finished funding research. Although we've made remarkable progress this year, we still need funding for projects like curating DNA, circulating cytokines and hormones, and a vaccine utilizing a patient's own immune cells to fight EHE.

Donations are TRIPLED on #GIVINGTUESDAY, Dec 3rd



by Facebook matching or QUINTUPLED if a donor's employer matched the donation.

#GivingTuesday is a global movement to celebrate and encourage giving after Thanksgiving, Black Friday, and Cyber Monday. This is our members' chance to ask their friends and family to multiply the impact in helping everyone affected by this extremely rare cancer by donating mostly through the Foundation's Facebook Page.

We are now excited to confirm that the Foundation's 2019 #GivingTuesday was a fantastic success, and all we can say is THANK YOU. We shattered our #GivingTuesday donations from 2018! After donations were multiplied by our generous donors, our total is $200,139!

The entire EHE community was in awe of this wonderful success, and we want to join The EHE Foundation in saying a huge thank you to the generous donors who matched funds raised; to our compassionate supporters for giving hope to those suffering from EHE; to our EHE family who, while cancer is affecting their own lives, found the spirit to rally their friends, families, and communities to help others on #GivingTuesday; and to our volunteers for standing alongside all of us in this fight against EHE. We are grateful to those that took the time to share their stories and stories of their loved ones. Their stories reached tens of thousands of people, which is amazing. Thanks to the Harrison Pluta's family, Amanda Holland, Michael Proctor, Melissa McPherson, and Sarah Bright Yaneza.

We also want to express a special THANK YOU to The Margie and Robert E. Petersen Foundation for matching all donations. Thanks also to Team Jenni Kovach, Jane Gutkovich, and other donors, who also matched a portion of donations. Without matching, we raised a total of $63,069.62.

‘Easy Money’ from Amazon Smile

It’s not often we can refer to any fundraising as easy money. Perhaps the closest we get to it is from shopping sites like Amazon Smile. John Lamb in Arkansas wanted to remind everybody that if you shop with Amazon through Amazon Smile you can select your favourite charity and they will make a donation based on a small percentage of every purchase. John supports the EHE Foundation. Thankyou John for the reminder and we hope everybody will use Amazon Smile when buying on line. Amazon Smile has already donated over $4,600 to EHE research, a really fantastic effort

Funds-Matching Announced in Canada

Canada was delighted to be able to report two major funding opportunities over the December 2019 to February 2020 time frame. Fiona Louise explained “Firstly, the Sarcoma Cancer Foundation of Canada have been so pleased with our EHE fundraising efforts that they have offered to do a donation match, up to $50,000, for the next three months. In addition, we have a generous and amazing patron (who is also an EHE patient) who has offered to match this matching, so another $50,000!”

We cannot express enough how rare, how generous and how amazing these matching offers are. It basically means that every dollar raised will be trebled. However, as Fiona explained, the offer is time limited. *“Time is important. Our window for matching is for funds raised between December 1st and February 28th.”*

So this opportunity is live now, as we go to press. Every dollar donated will be trebled. Please do all you can to support this brilliant Canadian drive.

Cupcakes, Pizzas and Samosas

Not all fundraising has to include massive challenges, miles run or cycled, mountains and oceans conquered. Large amounts of our funding have been raised through small but valuable events. One such example of this was a cupcake - pizza - samosa sale held just before Christmas. Fiona posted *“Sadly I didn’t get pictures but a group of students ran a cupcake - pizza - samosa sale today and we raised $372 for the Sarcoma Foundation (EHE) Canada”.*

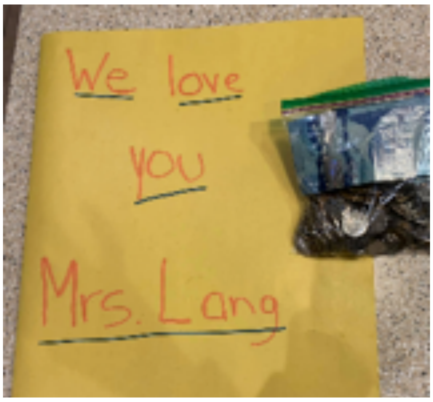
We love the simplicity of this idea. Imagine if 1,000 of our supporters each ran one event like this. That would be nearly half a million dollars for research. So never under estimate the value of these smaller fundraisers. They are critical to our success. Fiona, please pass our thanks and congratulations to everybody involved.

We Love you too Mrs Lang

Support for EHE research can come from many different sources. Some can be surprising, and are often very touching when delivered with genuine love and affection. Karen Starr-Lang posted a lovely story in December involving some young students.

“I am always amazed at the generosity of others. Over the past week many family and friends reached out to donate to the Sarcoma Cancer Foundation of Canada in support of EHE and Dr Razak’s research in Canada. Today I was surprised and deeply touched by the kindness of some Grade 7 students at my school who raised their own money to donate to EHE research. I feel very blessed.”

Karen, we can totally understand why you feel blessed. What a lovely, heart-felt gesture. And the fact is that no matter how old we get we all have special memories of the fantastic teachers and staff who looked after us at school.



04 Upcoming events...

EHE Charity Masquerade Ball

As reported earlier in this edition, Allana, Nathalie, Ellen, Samantha and Sophie will be holding their EHE Masquerade Ball on 8 February in Skegness. We hope that they have a fantastic evening and wish them every success with this amazing event

MASQUERADE

Charity Ball

Saturday 8th February 2020

AT

Butlins - Skegness

7.30pm - Late

3 Course Meal • Live Entertainment

Magician • Raffle & Auction

All proceeds go to the EHE Cancer foundation

EHE RARE CANCER CHARITY (UK)

Tickets are £45 per person

Tables of 10 or individual tickets available

Available from Natalie on **07908917583**

or email **eherelayraisers@gmail.com**

London Landmarks Half Marathon looms

The EHERCC will have a team of 41 runners taking part in the London Landmarks Half Marathon on 29 March in central London. Support has once again been fantastic, with Team Henderson again providing the core of the group. This year Hugh Leonard, Chair of Trustees is also hoping to run, assuming the physios can keep him going!

The First EHE Concert

Following her wonderful participation in the Courage on the Catwalk event held in Aberdeen at the start of the year, Adrianna Glennie wanted to do something to raise funds for EHE research. She decided to combine that cause and her 40th Birthday with her love of music and will be holding the first ever EHE concert in Stonehaven, south of Aberdeen, on Saturday 15th February.

"It's booked!!! . EHE fundraiser / my 40th Birthday / Music Festival on Sat 15th Feb 2020. Would love to see you if you can make it to Stonehaven (home of Dunnottar Castle) just south of Aberdeen, UK."

We want to wish Adrianna every success with this brilliant event, and hope that everybody who can, will get there and support her. Go Adrianna, our first EHE impresario!

THE CHANDELIERS
FULL FAT
CEILIDH
COLIN CLYNE
MORE ACTS TO BE
ANNOUNCED

FUNDRAISING GAMES
RAFFLE
AUCTION

SAT 15 FEB 2020
3PM–MIDNIGHT
STATION HOTEL,
STONEHAVEN

Music
Festival
Fundraiser
& Ad's 40th Birthday

PROCEEDS TO
RARE CANCER
EHE
CHARITY (UK)
&
CLAN

PRIVATE EVENT (TO ALLOW UNDER 18s)
TICKETS FROM :
PAYPAL SEARCH: PAYPAL.ME/EHE20
OR BY BANK TRANSFER
EMAIL: EHE2020@OUTLOOK.COM
TEXT: 07432640090
ADULT TICKETS FROM £23
FURTHER DETAILS ON FACEBOOK

05 And in other news…

Getting Together!

Sally Baker and Tina Biehl Nielander together in London in October. *"Had a lovely coffee at the Natural History Museum in London with Tina Biehl Nielander this morning. It's so rare to meet fellow EHE patients, which makes it all the more special, particularly when they've come all the way from Denmark. Great to meet Tina's family too. Thank you for the hugs, chat, coffee, and muffin. Come back to London soon, Tina."*

Nobody likes clinical consultations, but they do sometimes present chances for our EHE community to meet in person, such as in November. Sally Baker posted *"Lovely EHE meet-up in London yesterday with Adrianna Glennie, Mariana Coutinho, Anna Wydro, Artur Rozwalak and Mariana's Mum. So good to see everyone. Oh, and ignore the man photo-bombing in the background."*

And again in December when Allana Parker posted news of her meet up in London with Anna Wydro and Mariana Coutinho. *"The best bit of the day was meeting up with these two wonderful friends. Anna had been keeping Mariana a surprise. I thought she had already flown home and I had missed her so how wonderful when she turned up for lunch with us, having changed her plans just to be there. EHE might bring us lots of horrors but it's also brought me some wonderful new friends for life."*

Raija Hirschi and Liz Barrett Schick meet up in Bern.

Jenni Kovach, newly elected President of The EHE Foundation (USA) meeting in New York with Jane Gutkovich, Director of Research.

Photo Therapy

We know from many previous posts and past editions of The Pledge that photography can offer real peace and inspiration to the group.

Michelle Benedettini Chmelko posted her *'Just Live'* photo of her and her youngest child celebrating her latest scan results in November. Keep those handstands going guys.

Robinson Ortiz Jr. shared another wonderful photo with the group with a simple message: *"Never Forget how you kept moving forward one courageous step at a time."*

Carl Dickson posted some stunning photos from his night walk in light snow and darkness, which for Carl equates to peace of mind. We love the photos Carl.

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