

The EHE Foundation (USA)  
The EHE Rare Cancer Charity (UK)  
The EHE Rare Cancer Foundation (Australia)  
EHE Italia - Non solo Laura  
EHE Canada



Quarterly Newsletter for the EHE Group  
January - March 2023

# the Dledge

Edition 32



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# Welcome

**Welcome to this, the 32nd edition of The Pledge, the EHE Group quarterly newsletter covering the key activities of the EHE Group for the first quarter of 2023.**

We always take this opportunity to say a huge thank you to all our supporters for their amazing generosity, in time, energy, drive, fundraising and the many other forms of assistance that they contribute. Regardless of what type or magnitude of support and contribution they provide, they are all critical to our success and ability to manage and ultimately defeat EHE. We hope that you enjoy this edition of the newsletter, and that you are inspired by all that is happening.



# Highlights

## **EHE patients continue to drive Canadian EHE awareness and support**

The first quarter saw Michelle Lynn telling her story on Canadian TV, while Fiona Ross was lecturing MacMaster Medical College students about rare cancers, using EHE as a case study. We congratulate them both for their ongoing energy and commitment to spreading awareness of EHE.

## **The EHE Foundation launches 2023 grant cycle**

The EHE Foundation in the USA launched its 2023 grant funding cycle in late February, inviting researchers to submit applications for grant funding for EHE research that they wish to carry out.

## **Sirolimus survey results included in sirolimus label extension application**

The EHE Group 'Survey of Patient Perspectives of Sirolimus' produced excellent data and strong results that were included in the label extension application submitted to the EMA in Europe in March.

## **Researchers in Australia publish exciting results regarding sarcoma genetics**

The ISKS research team published news of distinct biological pathways that they have discovered where certain identified mutations increase the inherited risk for developing sarcoma, opening the door for better risk assessment, earlier diagnosis and better treatments for sarcoma.

## **‘Good Vibes for McKenna’ is a huge success**

‘Good Vibes for McKenna’ was set up to celebrate the life and legacy of McKenna Helm who passed away from EHE in November 2021 at the young age of 31. It not only honors her life, but it also pays tribute to every person whose life she touched. This quarter saw the first live music celebration for McKenna which did indeed celebrate her life while raising critical funds for EHE research.

## **UK/European regional research summaries show exciting progress**

This quarter you can read summary updates from all our European and UK EHE research projects where excellent progress and positive results continue to be delivered.

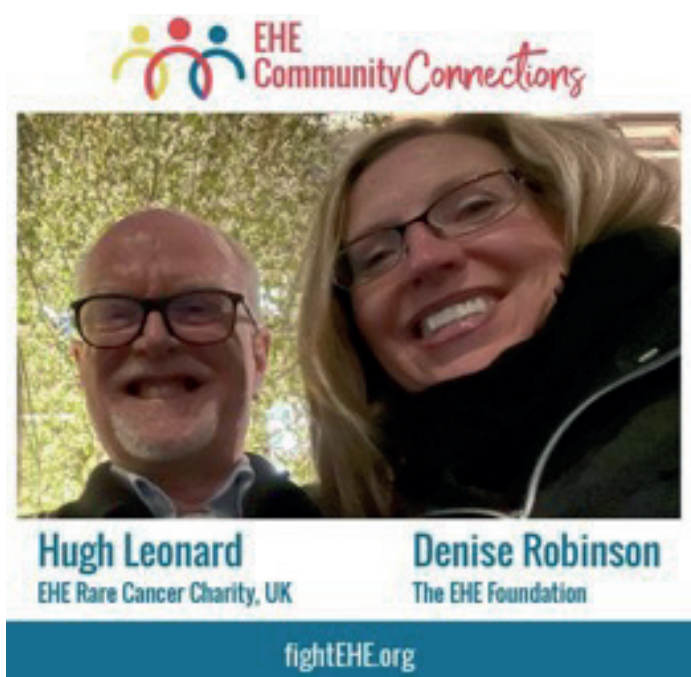
**Further details on these stories, and much more, can be found in this edition**

the **pledge** Edition 32



# 01 Patient Support and Advocacy

Patient Support and Advocacy are two critical objectives of the EHE Group and the worldwide EHE community. Patient support comes in many forms but is perhaps most powerful when advice, support and encouragement is provided to EHE patients by their fellow EHE patients in our global EHE community. Advocacy is about promoting greater awareness of EHE wherever the opportunity arises, and striving to bring about better care and better outcomes for EHE patients. The reality is that we can only achieve these objectives with the tireless energy, support and contribution provided by so many of our global EHE community. Once again this quarter saw many examples of that support being readily given, and so we again want to thank all our supporters who have contributed to our patient support and advocacy activities, examples of which are provided in this section.



## Science Saturday

On January 14th, Hugh Leonard (EHE Rare Cancer Charity, UK) and Denise Robinson (The EHE Foundation, US) highlighted EHE advancements and ongoing, worldwide research. As an ultra-rare sarcoma (cancer) community, research and awareness relies strongly on patients and advocates to keep moving forward until there are better treatments and eventually, a cure. Attendees learned about what's going on in the world of EHE research, about opportunities to participate in research, and gained knowledge to help patients and caregivers be their best advocates.

Learn more about Community Connections and watch the recording at <https://fightehe.org/community-connections/>



### Michelle continues to spread EHE awareness

Since her diagnosis in 2021, Michelle Lynn, has been one of our most active global advocates for EHE awareness. Her numerous campaigns are certainly raising awareness of EHE and in January of this year Michelle and her family were the subject of a heartfelt television news article in Canada.

We were delighted that Michelle was also able to share the report with the global EHE community on the EHE Support Group page where Michelle explained:

**“Our family was honoured to participate in a CBC Compass interview with video journalist Laura Meader. It aired over the holidays and we’ve received so much love and support from islanders, we thought we’d share with you all!”**

**“Raising Sarcoma Awareness has become a passion, a journey we didn’t expect to embark on but we are loud and proud to be alive, to share our story and to maybe provide courage, strength and hope to those who may need it. Stage 4 Needs More and I will never stop raising awareness.”**

And it’s not only raising awareness that Michelle is passionate about. A key component of her cancer strategy is her diet and fitness campaign. Michelle is often seen out running with multiple buggies, even in the sub-zero winter climate. In February she posted a wonderful video showing her getting ready (with five layers to put on!) and then going out to run in -19° temperatures.

**“Running, diet change and anti-inflammatory meds (maybe even the sirolimus) took away my cancer pain - so I can’t stop, not even in -19 degree weather! Just Live friends.”**

In March she posted news of her latest 5 km running event towing her son behind her in a 55 lb buggy, and wearing one of the EHE group’s t-shirts carrying the names of many members of our global patient community.

**“Never give up HOPE! I wore your names on my back today. I think with all our new members lately, we should do another shirt update!”**

Keep running Michelle and keep up the campaigning! We love that you are making such a difference.



# 01 Patient Support and Advocacy



## A Just Live Moment

In January, Aimee Liebert shared her Just Live moment of celebration and accomplishment. She signed up for the Run Disney Dopey challenge where she completed a 5k, 10K, half marathon, and full marathon all within four consecutive days. She signed up in May 2022 but was diagnosed with EHE on July 7th and had surgery soon after. She trained and completed the four runs with her sister, while other family members joined her on different races. She said,

**“I wasn’t sure what my EHE diagnosis meant for my race back when I signed up. This last weekend I accomplished the Dopey challenge with my EHE personalized skirt to keep me going. I hope this helps others to focus on the positive!”**

Congratulations on reaching your goal, Aimee!

## Breaking Language Barriers

EHE presentations and webinars might be challenging or “schwierig” for members who do not speak English as a first language, as they are fast paced and sometimes technical. Maeve Baechler has graciously taken the initiative to break down some of these language barriers.

On January 15th, Maeve shared, “Hier ist die endgültige Version der Übersetzung von Janes Präsentation (Immuntherapie) etwa im November 2022. Wenn Sie Fragen haben, können Sie sich gerne an mich (auf Deutsch) oder Jane (auf Englisch) wenden.” (“Here is the final version of the translation of Jane’s presentation (immunotherapy) around November 2022. If you have any questions, please feel free to contact me (in German) or Jane (in English).”

Maeve transcribed and translated two EHE presentations from English to German. First, she worked on Jane Gutkovich’s Immunotherapy Presentation from October 2022. Then, she translated the Science Saturday presentation from Jan 2023. A huge thanks not only to Maeve, but to Bettina Klöti and the Oliver Bohl family for their assistance in editing the final products. You have given our German-speaking community members a connection to this valuable information.

Translated products can be found by searching directly on the support group page <https://www.facebook.com/groups/EHEcancer>.

Global patients often find online translators, such as DeePL <https://www.deepl.com/en/translator>, helpful.





### Fundraising comes in many forms

We are always delighted when somebody posts news of a fundraising event with a new or unusual theme. Penny Wheeler in Australia did exactly that in February with news of the participation of her daughter Bec in a fundraiser for the Cancer Council SA:

**“Today was a perfect day for the 10th Marilyn Swim to raise funds for the Cancer Council SA. Over 1 million dollars have been raised since the first official event in 2013 where there were less than 50 Marilyns. We are proud of our daughter Bec who was the first South Australian to register back then. She was diagnosed with EHE in 2018 and continues to embrace the motto, Just Live! positive!”**

We love this fundraising event and thank Bec and all the other Marilyns who took part. You all look amazing.



### Community Connections Focuses on Cancer Identity

On Saturday, February 11, 2023 Doctors Vesel and Baechler concluded the fourth session on "Who am I now? Integrating the cancer identity into the self."

Dr. Tamara Vesel, MD, Tufts University School of Medicine, is a palliative care physician and has extensive experience in pain management. She has become an invaluable resource to the EHE community as she helps to create safe spaces for people to meet, talk, and reflect on their identify as EHE patients. Dr. Maeve Baechler is an EHE patient and founder of LIFE Cancer Coaching. They generously give their time and talents to help EHE patients through Community Connections and other meaningful ways. These sessions were not recorded due to the personal content. The session received wonderful feedback.

We want to say a huge thank you to both Dr Vesel and Dr Baechler for their commitment and for truly making a difference.



Dr. Tamara Vesel

Dr. Maeve Baechler

fightEHE.org



# 01 Patient Support and Advocacy

## Podcast Shares a Cancer Challenging Diagnostic Journey

Jane Gutkovich was a guest on World Cancer Day in the podcast "Patient from Hell." The podcast is hosted by Manta Cares, an online global community of cancer survivors and caregivers. Jane commented:

We are grateful to Jane Gutkovich, Board Member Emeritus, for being such a passionate advocate for EHE, and a driving force for EHE research. She is a champion for more answers and never, ever gives up.

Hear Jane's story in a recent episode of the "Patient from Hell" podcast with Samira Daswani, wherever you listen to your favourite podcasts.

**"I am very thankful for this opportunity to spread EHE awareness, to talk about our challenges, and about our wonderful community!"**



## Keeping track of EHE news

One of the challenges for any cancer patient community is keeping track of developments in the research and treatment of their disease. Jane Gutkovich, Board Member Emeritus of The EHE Foundation in the USA, and a regular contributor to the EHE Support Group Facebook page, closely tracks the publication of such papers and quickly brings them to the attention of the global community. Q1 2023 was no different, with two interesting papers that both included the possible benefit of genetic analysis in identifying specific drugs that produced positive results in the treatment of the patients' EHE.

## Successful treatment of pulmonary EHE

The first paper high-lighted by Jane in January involved the successful treatment of a patient with non-operable pulmonary EHE:

**"This case report describes the successful treatment of pulmonary EHE with the combination of immunotherapy and Sirolimus. It is also a good example of how in some cases genetic analysis can help in identifying effective drugs for EHE treatment."**

To see this paper use the adjacent link:

<https://pubmed.ncbi.nlm.nih.gov/36590968/>

**Case report: Rare epithelioid hemangioendothelioma occurs in both main bronchus and lung**

Jiuyu Gong<sup>1</sup>, Fangfang Tian<sup>2</sup>, Qin Wang<sup>3</sup>, Mi Mu<sup>2</sup>, Sijia Geng<sup>2,4</sup>, Pengfei Hao<sup>2,4</sup>, Pengfei Zhong<sup>2,4</sup>, Rui Zhang<sup>2</sup>, Lin Jiang<sup>1</sup>, Rentao Wang<sup>2</sup>, Pengtao Bao<sup>2</sup>

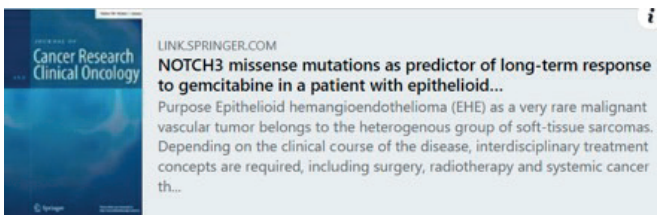
Affiliations + expand  
PMID: 36590968 PMID: PMC9799331 DOI: 10.3389/fmed.2022.1066870  
Free PMC article

### Positive treatment of an advanced EHE

In February Jane highlighted news of an interesting result relating to an EHE patient in Germany:

“Something very interesting just came out from Germany. This relates to a patient with quite advanced EHE who had a long-term (two decades) response to Gemcitabine. The authors speculate that the specific mutation( NOTCH3) found by genomic analysis might be responsible for this sensitivity to Gemcitabine.”

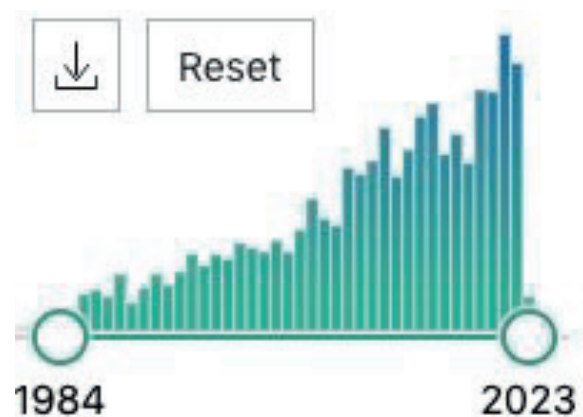
To see this paper use the adjacent link: <https://link.springer.com/article/10.1007/s00432-023-04598-1>



### Progress is being made

Jane posted some very encouraging news at the start of February, as she explained:

“I thought it would be interesting ( and good!) for you to see this graph. It shows the number of EHE publications each year since EHE was first formally identified, until now. It is such a strong visualization of the progress being made!”



# 01 Patient Support and Advocacy



## Show Your Colors for EHE

World Cancer Day was Feb 4th and Rare Disease Day was Feb 28th and the EHE Community was encouraged to show their colors.

Different ribbons are used to raise awareness and show support for those facing challenges. There are many different awareness ribbons, and the same colors often represent different cancers (or awareness campaigns).

EHE is a rare cancer, and it doesn't simply fall into one category. The EHE Foundation is often asked what ribbon best represents the EHE community.

**Sarcoma:** Since EHE is a sarcoma, many patients choose to use the yellow ribbon.

**Vascular Sarcoma:** The yellow in the ribbon still represents sarcoma, but the red is added to represent vascular. EHE is considered a vascular sarcoma because it originates in the cells that line the inside of blood vessels. This is the most popular ribbon among EHE patients. Sometimes the ribbon is

yellow with a red border or half red and half yellow (either lengthwise or crosswise).

**Rare Disease:** Zebra-patterned represents rare diseases. EHE falls into this category and sometimes patients choose to use this ribbon.

Regardless of what ribbon you decide to wear to represent EHE, we are grateful that you are creating awareness! If you are not sure what to tell others about EHE, then please direct them to one of the EHE Group websites which are shown on the back cover of this newsletter.

## Fun Telling her EHE story

Fiona Ross, based in Canada, is another of our patient members who is very focused on spreading awareness of EHE. In January, Fiona was invited to address the medical students at McMaster Medical College. Fiona immediately saw this as an opportunity to ensure that some young medics would know and understand a little more about rare cancers and particularly EHE.



**"You're one in a million", what's next?**  
A patient's journey through an ultra-rare diagnosis and the Canadian healthcare system

Fiona Ross was a high school English teacher and teacher librarian until an ultra-rare sarcoma diagnosis in November of 2017 meant that she put those communication and research skills to a very different use.

Now the leading patient advocate for Epithelioid Hemangioendothelioma in Canada, and a board member for the Sarcoma Cancer Foundation of Canada, she spends her time raising funds and awareness for this ultra rare cancer, and the issues of social justice and equity in Cancer research.

**Come and hear Fiona's story at our Zoom event on Feb 1<sup>st</sup> 2023, 11am ET**




Her excellent presentation talked about rare cancers and the challenges of dealing with them. It also focused specifically on EHE; Fiona's personal story with the disease; and important elements of finding a cure. She also talked about the imperative funding and research initiatives that were underway, with particular focus on the PRO CARE research initiative led by Dr Razak and Dr Allen which is part of a major collaboration with leading cancer research centres in Europe, and is also the largest investment in EHE research in Canada to date.

### Multi-Pronged Canadian Research in EHE (PRO CARE)

Co-Leaders: Dr. Alibruni Abdul Razak (Clinical PI), Dr. Christine Allen (Scientific PI) – Princess Margaret Cancer Center  
Collaborators: Dr. Silvia Stacchiotti, Dr. Nadia Zaffaroni – INT, Prof. Robin Jones – RMH, Dr. Paul Huang – ICR  
EHE Research Investment: \$1 Million Dollars

#### Prong 1

- ✓ Aim 1: Pan-Canadian EHE data curation with virtual tumor biobank
- ✓ Aim 2: Commitment to multi-institutional collaborations to enable EHE data curation and investigation

#### Prong 2

- ✓ Aim 1: Creation of clinically annotated EHE PDX models
- ✓ Aim 2: Pre-clinical evaluation of mTOR inhibitors using thermosensitive liposome delivery platform

Global collaborative 5-year project is the largest investment in EHE research in Canada to date.



For any of our readers who would like to watch a recording of Fiona's presentation, you can find it using the link below:

[https://drive.google.com/file/d/1cBfu9aYciSNbPdUasvrHNX1G7\\_W8qKJ/view](https://drive.google.com/file/d/1cBfu9aYciSNbPdUasvrHNX1G7_W8qKJ/view)

## EHE awareness opportunities

The EHE Group entities are always looking out for opportunities to talk about the disease, the research we are funding and the advances being made. Such opportunities often arise as part of a fundraising event, and Hugh Leonard, Chair of Trustees at The EHE Rare Cancer Charity (UK), had two such opportunities during the first quarter.

### Laptops and Lipstick Quiz Night



Kelly Denton is another of our global EHE community who is highly active and engaged in helping to deliver on all the objectives of the EHE Group. Her engagement with the EHE community, and in particular with the EHE Rare Cancer Charity UK, is driven by her daughter's EHE diagnosis. Hugh explained:

**"It was thanks to Kelly's profile that a south London based women's business network, Laptops and Lipstick, chose the EHERCC as their supported charity. As part of that support, Laptops and Lipstick organise an annual quiz night, and this year it took place in late February. It was a great night with a huge turn-out. At the meal interval I was able to explain what EHE is, why it is so important that we continue to drive research into the disease, and of course how grateful we are for their brilliant support. It was also wonderful as Kelly's whole family were there, including her teenage daughter who is another EHE superstar!"**



# 01 Patient Support and Advocacy



## The Hazel Peak Quiz Night No 2

Hazel Peak was a UK patient who was diagnosed with EHE in late 2021. Sadly Hazel had a very aggressive form of the disease and passed away very early in 2022. Her colleagues at Rolls Royce Submarines in Derby desperately wanted however to continue with their fundraising quiz night which they had planned for her in March, and which was ultimately a great but emotional success.

“Roll forward one year and Hazel’s colleagues decided they wanted to hold their second quiz night in her honour. I was invited to attend the event as I had the year before, and took the chance to speak to the guests about the research that their funds were helping to drive in the UK and Europe. People were so interested and I had the chance also to speak to some individually and answer their questions. And of course I also had the chance to thank them all for their brilliant ongoing support.”

The Rolls Royce quiz team wanted to say something to Hazel:

“Hazel, when this started, we’d hoped you would have joined us at a quiz that was for you. We didn’t anticipate this needing to be run without you. You continue to spur us on to do something where you would have played such an active part; which you would have given your energy to; and would have had a blast. Three of your close colleagues and a newbie have come together as a bit of a quiz organisation team now. We hope we can continue to impart on to the people that join us at these events a little bit of what you gave us. Your attention, your kindness, your thoughtfulness, your sense of humour (can’t believe what questions some of the quizmasters ask) and your love of people. We hope we do it justice. We miss you a lot.”

It is hard to overstate how useful and important these events are in helping to grow awareness of EHE and to help achieve many of our core objectives. We want to join Hugh in thanking Kelly's supporters and Hazel's colleagues for all that they have done to help us fight EHE.

### Tattoos Reminding us to JustLive

**Just Live** continues to be an anthem that the EHE Community stands by. Although it has a unique meaning to each individual, many people get a Just Live tattoo to honor their own EHE journey or in memory or support of a loved one.

Bill Desjardins recently got his tattoo, to honor his late wife, Tammy, who passed from EHE in February 2022. His tattoo includes a heart with both of their fingerprints, as one. Bill said,

**“For all of you warriors still fighting! This tattoo is a daily reminder to me of the battle you fight and for me to continue living.”**



Volga Vartanian also got a Just Live tattoo, which adorns a butterfly and flowers. She said,

**“This tattoo is dedicated to my angel Mother. RIP Mum.”**



# 01 Patient Support and Advocacy

## Cancer Camps and Retreats

Camps and retreats for those affected by cancer can be an amazing way for families and children to come together for an unforgettable experience while in a strong, nurturing, and fun environment. Many of these programs are low or no cost. Some programs offer family or adults events while others offer adventures for children (patients and family members) affected by cancer.

**“For many kids, cancer camp is a week that changes their outlook on life. When kids come together and see they are not alone in their situation, something magical happens. Camp week was always the week I looked forward to most every year as my sister battled EHE.”**

said Olivia Wahl. Olivia’s sister, Delaney, was only 13 when she was diagnosed with EHE. As kids, they both attended separate weeklong camps called Special Love. Now, as a college sophomore, Olivia volunteers as a counselor at Camp Kesem, a camp for kids whose parents have cancer or have passed from cancer.

To learn more about various types of camps in the US and what they offer, here’s a great starting point: <https://www.cancer.net/.../camps-and-retreats-families...>

Looking for more resources? Check out various resources used by EHE patients here:

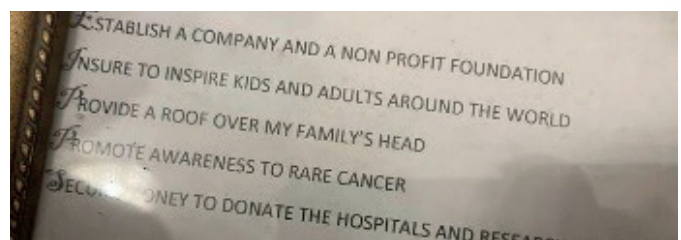
<https://fightehe.org/additional-resources/>



## When I Grow Up

Joe, who was diagnosed with EHE in Oct 2019, recently had to do a project for school. The topic was what he aspires to do growing up. Joe was diagnosed at age 9 and EHE turned his world upside down. His mom, Jennifer, said,

**“This was a proud moment when I saw this. My son is 12 and most kids want to make money playing sports, but he wants to find his own cure for EHE.”**



We are grateful for The Mulligan Family, along with their circle of supporters, for continuing to support our mission in so many ways.





## Resources for Travel Expenses

EHE is an extremely rare cancer and experts are mostly only available at a handful of major medical institutions located across the United States, which makes medical travel a necessity for many patients. This

creates a barrier to care. There are several non-profit organizations that help alleviate the financial burden of travel, so families can focus on getting diagnosed properly, a second opinion, or specialized treatment.

These are some of the organizations that offer free flights for patients who qualify: Air Charity Network, Corporate Angel Network, Miracle Flights, and Patient Airlift Services (PALS Sky Hope).

Learn more about these organizations and other helpful resources at <https://fightehe.org/additional-resources/>.

## EHE Connections

Sarah Bright said,

“I’m so happy to spend some time with Jenni Kovach! So many years of The EHE Foundation working together virtually but getting to hug and share is amazing!”



The two were recently able to meet face-to-face while Jenni was in Sarah’s part of the country for a wedding. Both are Board Members of The EHE Foundation.



## Empowering Patients

As The EHE Foundation geared up for EHE Awareness month in April, they started to announce April’s activities and invite the community to participate.

Registration opened for EHE 360: Empowering Patients – 2023 Global Patient Conference, a virtual event featuring clinicians and researchers bringing the latest information about epithelioid hemangioendothelioma (EHE) to patients and families. Learn more about the event and how to watch the recordings in the next issue of The Pledge or by visiting The EHE Foundation website at [www.fightehe.org](http://www.fightehe.org).

The EHE Group were also delighted and very grateful to the wonderful group of speakers and experts (see below) who had agreed to generously give their time to the event.

### FEATURED SPEAKERS



**Brian Rubin, MD, PhD**  
CLEVELAND CLINIC  
EHE 101: WHAT You Need to Know



**Breelyn Wilky, MD**  
UNIVERSITY OF COLORADO CANCER CENTER  
Systemic Treatment Options and Targeting EHE



**Denise Adams, MD**  
CHILDREN'S HOSPITAL OF PHILADELPHIA  
Sirotemvir as a Treatment Option for EHE



**Ajaybabu Pobbati, PhD**  
CLEVELAND CLINIC  
Why TEAD is a Convincing Target for EHE Treatment



**Hugh Leonard**  
CHAIR OF TRUSTEES (EHE BASE CANCER CHARITY UK)  
Patients' Perspectives on Sirotemvir



**Michael J. Wagner, MD**  
FRED HUTCH CANCER CENTER  
Indolent or Aggressive? EHE Outcomes and Monitoring Strategies

### ASK THE EXPERT



**William Tap, MD**  
MEMORIAL SLOAN-KETTERING CANCER CENTER  
Ask the Expert



**Vinod Ravi, MD**  
MD ANDERSON CANCER CENTER  
Ask the Expert



**Abha Gupta, MD**  
PRINCETON HENRIKSSON CANCER CENTER  
Ask the Expert



**Tamara Vesel, MD**  
TUFTS UNIVERSITY SCHOOL OF MEDICINE  
Ask the Expert



# 02 EHE Research

EHE will ultimately be defeated because the research we are funding today, which we will continue to promote and expand, will provide the answers and understanding we need to identify new treatments that will allow doctors to stabilise and ultimately cure the disease. This section of the newsletter provides an update on our research-related activities.

## A 1-in-50-year discovery!

In mid-January Jonathan Granek, Director of The EHE Rare Cancer Foundation Australia, posted exciting news that had just been published in Science:

**“This is a 1 in 50 year discovery set to change the way the world manages Sarcoma which ultimately allows the detection of the cancer earlier, and potentially improving survival and patient outcomes. This research, which included EHE patients that have enrolled, offers hope to sarcoma patients because it increases the chance of a diagnosis at an early and curable stage.”**

The breakthrough was reported from a ground-breaking, Australian-based massive, multinational genomic study involving Omico, the Garvan Institute of Medical Research and UNSW Sydney. The research team, led by Dr Mandy Ballinger and Prof David Thomas, have identified distinct biological pathways where certain identified mutations increase the inherited risk

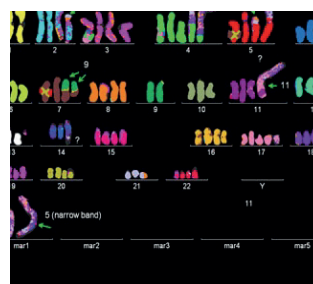


for developing sarcoma. This research has involved sarcoma professionals from across the world and



has included thousands of patients, their families also from around the world, and controls to come to this conclusion. More work is needed before these findings can lead to therapeutic advances, but the study provides much needed biological insight into sarcoma biology. The research combined data and samples from the International Sarcoma Kindred Study, or ISKS for short, and the Genetic Cancer Risk in the Young (RisC) study.

By joining ISKS, which is still ongoing, EHE patients can ensure that there is a meaningful cohort of EHE data within the project which may not only help researchers



to understand sarcoma better, but could one day lead to breakthroughs in the understanding of the genetics and risks associated with EHE itself. Jonathan Granek hopes others will join the study:

**“I’d encourage all EHE patients to consider participating in the International Sarcoma Kindred Study (ISKS) if you have not already.”**

Prof David Thomas also encourages EHE patients to get involved:

**“I encourage you to sign up to the ISKS, so we can create a unique EHE genetic database for answering questions about why EHE happens to some people and not others, and to open up new ways to better manage EHE. Research of this kind is essential to improving the lives of those affected by EHE. Contributing to the study is easy. The EHE Foundations worldwide are committed to signing up as many EHE patients to the ISKS as possible, and your participation and support is key. Please join the study if you can, and be part of the search for answers to EHE..”**

We also thought that it might be useful for us to reprint some of the explanatory information about the ISKS study that was developed for the EHE community by The Garvan ISKS research team and The EHE Rare Cancer Foundation Australia in 2019.

**ISKS INTERNATIONAL SARCOMA KINDRED STUDY** Register today to receive your ISKS Test Kit: [isks@garvan.org.au](mailto:isks@garvan.org.au)

WHAT IS ISKS?	WHY WE NEED IT	HOW YOU CAN HELP
<ul style="list-style-type: none"> <li>ISKS is a free to participate global genetic, biological, epidemiological, clinical resource developed to understand the genetic basis of sarcoma in a population.</li> <li>ISKS has created a world first, one of a kind, database that is accessed by doctors, researchers and scientists across the globe.</li> <li>ISKS was developed by Australian EHE Medical Advisor David Thomas and his team at the Garvan Institute.</li> </ul>	<ul style="list-style-type: none"> <li>To create a unique global EHE resource to study genetic risk factors for EHE.</li> <li>Contribute to a growing international body of knowledge to support patients, clinicians and researchers now and into the future.</li> <li>Understand the genomic risks of EHE may lead to early detection strategies into EHE or sarcoma more broadly.</li> </ul>	<ul style="list-style-type: none"> <li>Sign up today by emailing <a href="mailto:isks@garvan.org.au">isks@garvan.org.au</a> to receive your ISKS test kit requiring you to fill in a brief questionnaire and supply a blood sample and/or hair follicle.</li> <li>Your support will contribute to EHE knowledge which may impact patients now and in the future.</li> </ul>

Logos for EHE RARE CANCER FOUNDATION AUSTRALIA and GARVAN INSTITUTE OF MEDICAL RESEARCH.

Kate Hooper, Trustee of the EHE Rare Cancer Charity (UK), also hopes that international patients will participate in ISKS. Kate noted:

**“We were delighted when we found at that there are several UK hospitals involved in the study, including the Royal Marsden and UCLH. That means a patient can provide a simple blood sample to the ISKS coordinator at the hospital when there, and know that their sample will be dispatched to the research team in Australia and be included in ISKS.”**

If any EHE patients reading this article wish to participate in the study, but are not sure of how to do that, then please contact your appropriate EHE Group representative as shown below, and they will be able to advise and assist you:

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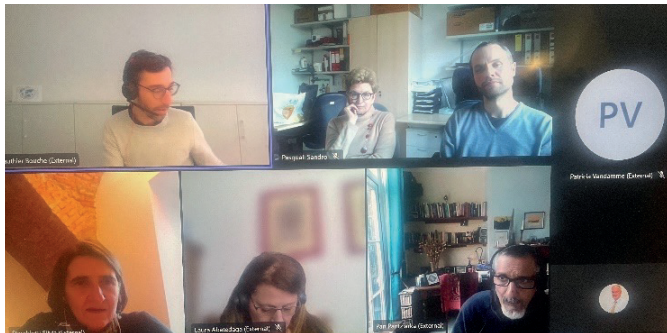
1. Australia: email Jonathan Granek at [jonathan.granek@ehfoundation.com.au](mailto:jonathan.granek@ehfoundation.com.au)
2. USA /Canada: email Denise Robinson at [deniserobinson@fightehe.org](mailto:deniserobinson@fightehe.org)
3. UK/Europe: email Hugh Leonard at [hleonard@ehercc.co.uk](mailto:hleonard@ehercc.co.uk)

If you live in any other regions of the world, please contact Jonathan Granek or any of the other EHE Group listed above.

If you want to see more about the ISKS study, or indeed some of the other studies being undertaken by team at the Garvan Institute in Australia, please go to: <https://www.garvan.org.au/research/diseases/sarcoma/research>



## 02 EHE Research



### Label extension for sirolimus & our EHE patient survey

Sirolimus is a drug that belongs to a group of compounds known as mTOR inhibitors. The drug is sold by Pfizer under its trade name Rapamune® and is used 'off label' to treat EHE as well as many other diseases. There is a growing body of evidence to demonstrate the efficacy of this drug in the treatment of some forms of EHE. The challenge we face is that the 'label' for sirolimus, which effectively lists all approved uses of the drug, does not include the treatment of EHE.

The result of sirolimus not being formally approved for the treatment of EHE means that the drug can only be prescribed 'off-label'. For many patients, that is not an impediment to accessing the drug if their doctor is able to prescribe it. However, if a patient's doctor will not or cannot prescribe off-label, or if the hospital won't allow it, or the national health system of the country won't allow or fund it, the drug will not be available to those patients. Or, if the doctor does prescribe 'off label' but the health service will not pay for sirolimus, it may be too expensive for a patient to use. In all these cases, EHE patients may be denied access to this potentially important drug.

To counter this situation, there is now a worldwide focus on seeking approval for the treatment of EHE to be added to the sirolimus label, a process known as a 'label extension'. Sadly, there is no such thing as

a global drug approval; each country or jurisdiction must approve it individually, including the UK, Europe, the US, Canada, Australia and indeed all other countries.

To gain the label extension, an application must be filed with the appropriate regulatory body, under their established procedures. This typically requires a significant body of research and clinical trial data to be produced, collated and integrated, delivering results to demonstrate the efficacy of the drug to support the label extension application.


This is an onerous process for common diseases, but for ultra-rare cancers like EHE it is particularly difficult. The bad news is that EHE will not have the patient numbers required to run large scale randomised studies or generate the quantity of data to allow for the depth of analysis and statistical significance that regulators typically see. The good news is that regulators do recognise this challenge and in most cases are prepared to work with clinicians and patient advocacy groups to try and collate different but appropriate data to allow them to approve the label extension.

The most advanced of these application processes is the one with the European Union, and specifically the EMA, the European Medicines Agency. An application document was compiled over an approximate six-month period, led by Dr Silvia Stacchiotti and her team from the Istituto Nazionale dei Tumori in Milan, Italy, and was submitted to the EMA in March.

In compiling the information for the submission, Dr Stacchiotti's team, supported by the Anti-Cancer Fund in Europe and the EHE Rare Cancer Charity (UK), undertook a worldwide search of published data involving sirolimus and EHE. This extensive data base was then reviewed and integrated into the submission document.

How do I register for the

## SIROLIMUS FOR EHE



### Survey of Patients' Perspectives

**WHO?**  
Anyone who has ever taken, considered, or talked with their doctor about the drug, sirolimus, or would like to have it as a treatment option in the future.

**WHY?**  
To advocate for sirolimus as a treatment option for all patients. Currently, sirolimus can only be prescribed as off label, which means it is not available to all patients globally. This survey aims to bring patient voices and experiences together to present to regulatory agencies.

**LINK TO SURVEY:** [https://www.research.net/r/Sirolimus?mc\\_cid=ceec37ff6d&mc\\_eid=4f2bb9a96c](https://www.research.net/r/Sirolimus?mc_cid=ceec37ff6d&mc_eid=4f2bb9a96c)  
**For more information email:** [Hleonard@eherc.co.uk](mailto:Hleonard@eherc.co.uk)

In addition to published data, the team were also very keen to include patient-curated data provided by the EHE Group. It was to provide this data that the EHE Group undertook its survey of patient perspectives and their experiences of treatment using sirolimus. The survey was targeted at our global EHE community and was strongly supported by all the individual charities and foundations that make up the EHE group.



122 patients in total from around the globe participated in the survey that ultimately provided extremely useful real-world data that we believe supports the call for a label-extension.



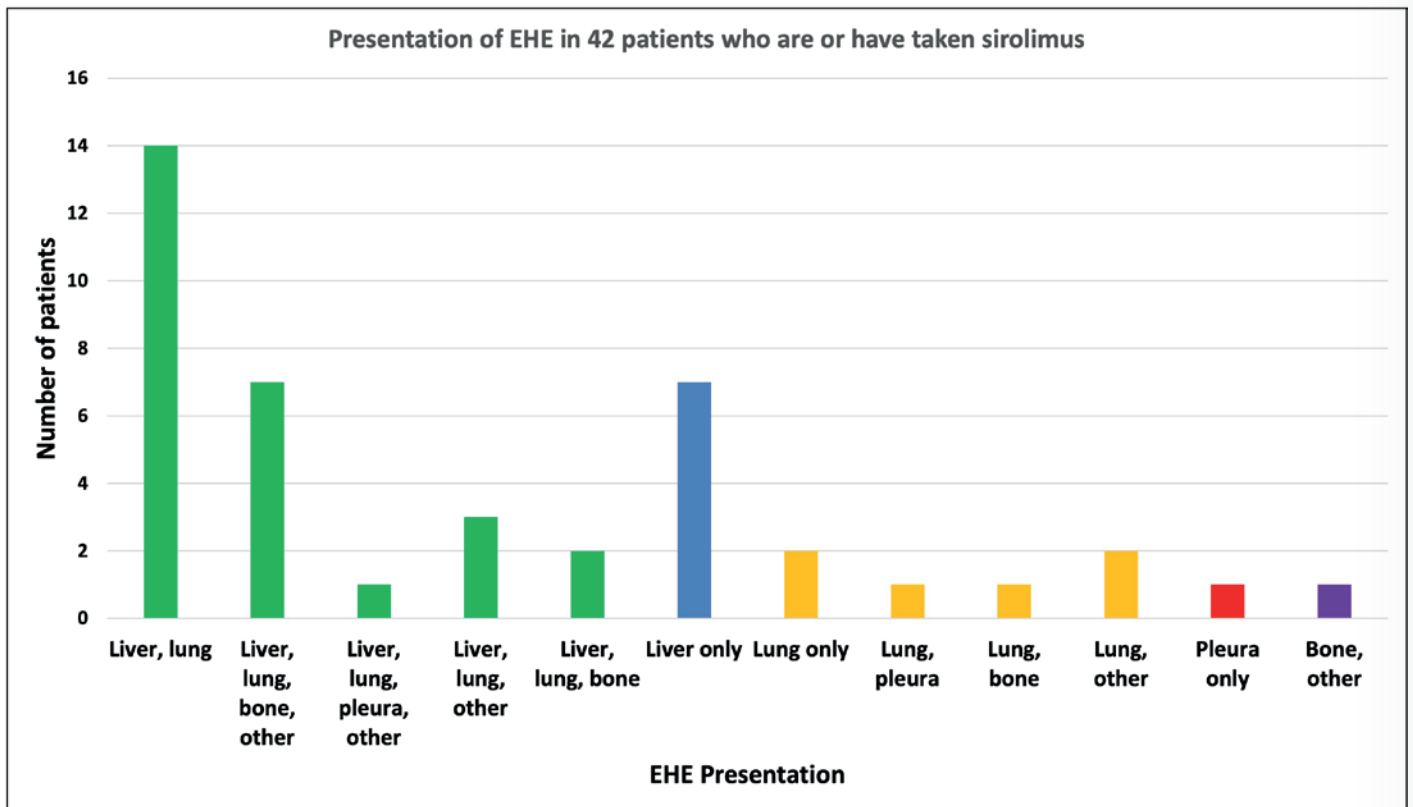
# 02 EHE Research

42 patients had had experience of taking sirolimus, of which 27 were still taking the drug. 17 of these 27 patients had not had a transplant while 10 had had liver transplants. 1 patient did not conclude their survey.

80 patients who responded had not taken sirolimus.

The EHE presentation of the 42 patients with sirolimus experience showed a distribution of the different forms of EHE reported as would be expected from global data, suggesting that this patient cohort provided a valid representation of the disease. This is important as it suggests that there has been no bias in selection of the patient community, something that regulators will be concerned about.

Key data from the patients' perspectives survey are summarised below.



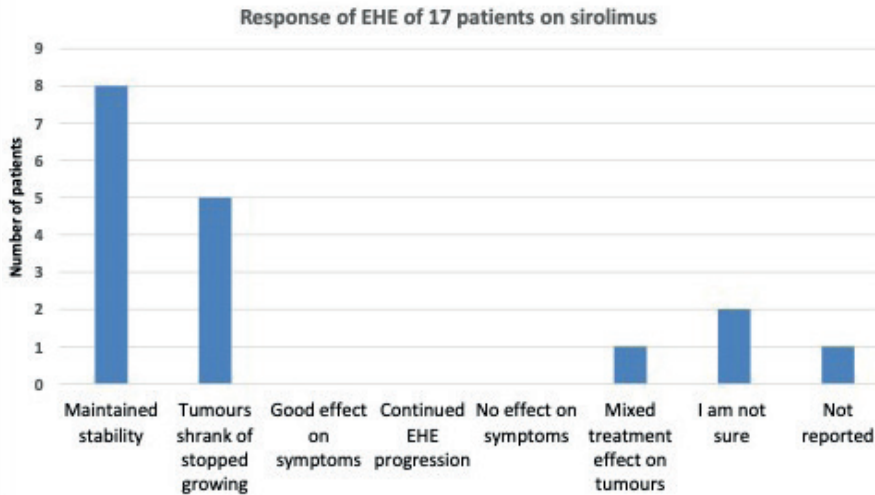
Green= liver and lung variations, Blue= liver only; Red= pleura only Gold= lung only and with variations; Purple= Bone only with variations

As you read through the following summaries, please keep in mind that the patient perspectives survey did not ask about other concurrent or prior treatments and therapies used, nor did this survey ask specifics about each respondent's disease status.

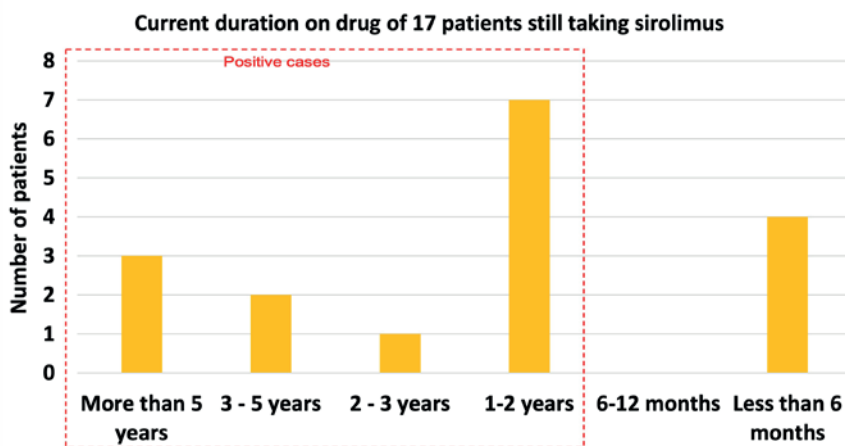
Further observational research will likely be initiated to continue to learn about how sirolimus works in different people, and presentations of EHE.

Some examples of the analysis of the survey are shown on the page opposite, looking at the effect that sirolimus had had and the duration it lasted, as well as reasons why patients stopped taking the drug.

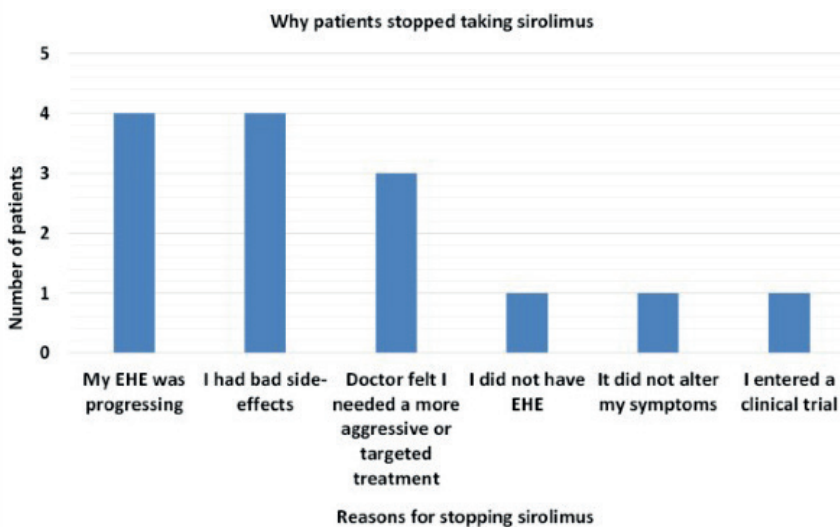
The application team are now waiting for the response of the regulator, and keeping their fingers crossed. We want to thank them for all the work they have done, and of course the 122 EHE patients who responded to the survey.



Analysis of the 17 patients still taking sirolimus showed that 13 of these 17 had seen the drug stabilise their disease, and in some cases had resulted in some tumour shrinkage. 1 patient reported a mixed response as we have seen with other drugs.



Longevity of the positive responses was also good, with the 13 patients still on the drug showing continued multi-year responses, with 3 being of more than 5 years. Patients still in the first six months of treatment are likely to still be in the evaluation phase of their treatment.



The inclusion of patients with a negative response to sirolimus is also important to demonstrate that there has been no bias in the reporting of data. Bad side effects had affected 4 of the patients while 7 (50% of the negative cases) reported that their EHE was progressing despite taking sirolimus. This demonstrates clearly that the drug does not work for all patients.

The application team are now waiting for the response of the regulator, and keeping their fingers crossed. We want to thank them for all the work they have done, and of course the 122 EHE patients who responded to the survey.



# 02 EHE Research

## Albany Medical College promoting rare cancer research!

Jane Gutkovich high-lighted the excellent EHE research being done at Albany Medical College in New York state when she posted about the Albany Med news article entitled “Research at Albany Medical College Brings Attention to Rare Cancer”. Jane posted a link to the article and said:

**“It feels really good to see EHE research, Dr Lamar's Lab, and The EHE Foundation all in the focus of New York State Medical College in Albany!”**

The Article introduced Dr John Lamar, PhD, associate professor in the Department of Molecular and Cellular Physiology at Albany College, whose lab is the focal point of the EHE research being undertaken. The article provided a good description of the disease, and the challenges that patients face living with it, even if in the indolent form.

Dr Lamar's interest was kindled from an existing broader interest in the YAP and TAZ proteins, either one of which plays a critical role in the onset of EHE. That interest led to meeting Dr Guy Weinberg and the subsequent launch and growth of the Telluride YAP/TAZ workshop where leading scientists present and discuss the latest work with these two proteins.

Then in 2019 the EHE Group funded a small proof of concept research study at Dr Lamar's Lab entitled “Identification of TAZ-CAMTA1 Regulators”. The project results were positive with the Lamar Lab developing important tools for progressing research into the biology of EHE. In 2021 the EHE Foundation (US) awarded another 3-year grant to Dr. Lamar to investigate “TAZ-CAMTA1 Regulation by the Calcium Sensor Calmodulin”. Based on ongoing positive results from the Lamar Lab EHE research, Dr Lamar

subsequently was awarded a larger 3-year grant from The EHE Foundation to enable them to continue their research on identifying molecular pathways that can be targeted with existing FDA-approved drugs. This project is entitled “Use of Pre-Clinical EHE Models to Identify Druggable Pathways to Treat EHE” which could lead to identification and testing of already approved drugs that could then be quickly repurposed to help patients living with EHE. The Lamar lab is a collaborator with Dr Brian Rubin's Lab at the Cleveland Clinic. Dr Lamar and Albany Medical College PhD student Ryan Kanai have also been engaged in a number of presentations of their work, expanding awareness and interest in EHE, at both scientific conferences and as invited speakers at other academic institutions.

Dr Lamar remains excited by the progress being made, and said:

**“While there is still a lot of work to be done, the progress that has been made in the EHE field in the past few years is remarkable. I believe that if we can sustain this momentum, more effective EHE treatments are within our reach.”**

### Dr Lamar's update on his research TAZ-CAMTA1 Regulation by the Calcium Sensor Calmodulin

At the end of the year Dr Lamar was delighted to be able to provide an update on his lab's EHE research, against major objectives of their work.

**Objective 1:** Test if activation of Calmodulin (CaM) represses TAZ-CAMTA1-dependent oncogenic activity.

EHE cell lines (EHE cell populations that are grown and maintained in cultures, typically in petri dishes) are now available for these studies so most of the experiments in this Objective will be performed in these EHE cells.



We can now regulate the expression of CaM in cells and we are in the process of stably expressing this in the EHE cells and testing if CaM can repress TC activity as hypothesized. Additional experiments are ongoing.

**Objective 2:** Determine the mechanism of Calmodulin regulation of TAZ-CAMTA1.

Work on this Objective 2 will occur once key experiments in Objective 1 are completed.

**Objective 3:** Investigate the role of Calmodulin in EHE.

As noted above, we and our collaborators in the Rubin lab have each confirmed that the EHE cell lines can be transplanted into mice to study EHE tumor formation and growth. The Rubin lab found that these cells form EHE-like tumors when injected subcutaneously and form lung tumors when injected into venous circulation. We found that when the cells are injected into arterial circulation, they form tumors in the lung, pleura, liver, bone, and several other soft tissue sites. These exciting results demonstrate that we have multiple transplant models that can be used to study pathways that influence EHE formation and growth in mice and to test potential treatments.

#### **Other progress on EHE projects:**

We have also focused some significant time on the project that the EHE Group initially funded. This work identified 6 regulators of TAZ-CAMTA1 and has focused on AMPK, which we found can repress TC activity and function in NIH3T3 and HEK293 cells. Recent work has revealed that activation of AMPK (via an available compound) can repress EHE cell viability. However, we need to confirm that the effects of this treatment are due to AMPK and to determine if AMPK represses TC function in the EHE cells as it did in the other cell types.

## **EHE Foundation 2023 Research Grants Funding Cycle is Open!**

The EHE Foundation in the USA launched its 2023 grant funding cycle in late February. This is an annual process whereby The EHE Foundation invites researchers to submit applications for grant funding for EHE research that they wish to carry out. Denise Robinson, Director of Research at The EHE foundation explained:

**“One of the key objectives of The EHE Foundation is to support and fund the most promising basic, translational and clinical EHE research in order to expand the understanding of EHE and accelerate the development of treatments. So each year we invite researchers to submit an application and to join in our commitment to promoting collaboration, information, and resource sharing among the global EHE community including patients, clinicians and researchers. The EHE Foundation aims to award several research grants annually. The availability of awards is of course subject to the availability of funding, but due to the wonderful energy and generosity of our patient community, their supporters, and several corporate sponsors, we are able to launch this, our third call for grants. It is hard to overstate the importance and benefit to our patient community of being able to run these annual grant cycles, so we could not be more grateful to all those who have worked so hard and been so generous in their support.”**

We look forward to being able to update our readers in future editions about the results of the 2023 grant cycle.



# 02 EHE Research



## **EHE Biobank (US) Working to Advance Research**

Denise Robinson, Director of Research at the EHE Foundation (US) reiterated the importance of patients taking part in EHE-specific biobank opportunities in

the UK, Australia, and in the US. Denise explained:

“Only people who have EHE can donate EHE tissues, fluid or blood samples to advance EHE research, and since this is an ultra-rare cancer, it is important to know that if you are willing to contribute a biospecimen to any research - it is most useful if it is donated to EHE-specific research. EHE cell lines and other model development is essential to finding effective treatments, and without fresh surgical tissue it becomes nearly impossible to develop models of this disease.”

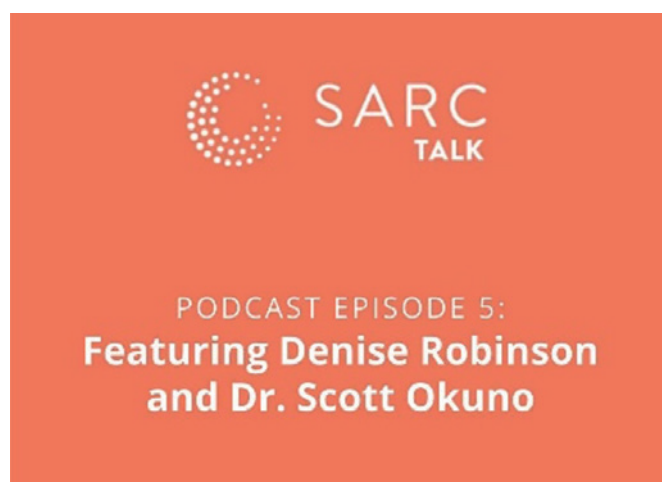
Denise continued:

“Please consider pro-actively contacting the EHE Biobank if you are thinking about any type of surgery or an organ transplant in the future. Early correspondence with the Biobank is helpful and once you have made the initial contact, and if you decide to join, the remainder of the process is very simple - patients do not have to worry about any of the logistics of coordinating with their doctor.”

The Biobank Coordinator, Patty Cogswell, in the US can be contacted by emailing [biobank@fightehe.org](mailto:biobank@fightehe.org).

## **SARC Talk Podcast Featuring EHE Advocacy & Research**

During March Denise Robinson, Director of Research at the EHE Foundation (US) joined Dr. Scott Okuno, Chief Medical Officer, SARC (Sarcoma Alliance for Research through Collaboration) to talk about EHE research and patient advocacy. You can listen to the SARC Talk Episode 5 podcast on YouTube, Spotify, and Apple Podcasts.



## Regional updates: Europe and the UK

One of the great challenges we face at The Pledge is to adequately cover all the EHE research that is now in progress, whether the EHE Group is providing funding, patient data, and/or biobank samples or not. In previous editions we have provided updates that are available and usually where significant progress is being made.

We have decided this year to also take a more targeted view of our research reporting, and so will be dedicating each edition of The Pledge to a specific region. The first quarter (Q1 - this edition) will focus on the UK.

We also wanted to provide these updates in the words of the researchers themselves. So we reached out and asked them to provide a summary report of their projects for inclusion in The Pledge. We are excited about the updates that we will be reporting, and hope that you enjoy them too, starting this quarter with Europe and the UK.

### Dr Valerie Kouskoff at the University of Manchester

The aim of our research is to develop a model of EHE, which can then be used to investigate various aspects of EHE biology. This model utilises mouse embryonic stem cells, which are differentiated into endothelial cells. TAZ-CAMTA1 expression is induced in these endothelial cells, allowing its function to be investigated in the same cell-of-origin as EHE tumours. It is hoped that studies using this model will uncover previously unexplored mechanisms of EHE development, which may lead to novel treatment options for EHE patients.

To date, our investigations using the stem cell-based model have revealed that TAZ-CAMTA1-expression causes a large amount of DNA damage in endothelial cells. DNA damage often occurs in cells, and is usually repaired without consequence by one of multiple DNA repair pathways. In TAZ-CAMTA1 expressing endothelial cells, the large amount of damage overwhelms these repair mechanisms, and often goes unrepaired. We discovered that, in many TAZ-CAMTA1 expressing cells, this causes cells to enter a state of senescence. This is a state in which the cells are dormant, and cannot divide but also do not die. Senescent cells can accumulate in a tumour, and our data suggest that this could represent the indolent, slow-growing tumours many EHE patients develop.

The other consequence to overwhelming DNA damage is that a more error-prone pathway attempts to repair the damage. This leaves cells vulnerable to a genetic mutation occurring, which may allow cells to bypass the barrier of senescence and induce uncontrollable proliferation. This could be the reason some EHE tumours suddenly become more aggressive and metastasise. Currently, we are investigating if using drugs to inhibit some of the proteins involved in the onset of DNA damage or senescence-bypass can induce the death of TAZ-CAMTA1 expressing endothelial cells. Some of these inhibitors are already used or in clinical trial for treating other types of cancer. If any of these prove successful, these drugs could become available for EHE patients in the future after further testing.



## 02 EHE Research



Dr Valerie Kouskoff (left) has led her laboratory at the School of Medical Sciences at the University of Manchester since 2016. Interest in the Hippo pathway effectors YAP and TAZ in normal regulation and their chromosomal translocations leading to vascular tumours led to her interest in EHE.



Emily Neil (left) joined Dr Kouskoff's lab at the start of 2019 to begin her PhD studies, developing a stem-cell based model for investigating EHE development and the consequences of TAZ-CAMTA1 expression. She was awarded her PhD in March 2023. She is currently continuing this work on EHE in Manchester, prior to beginning a postdoctoral position at the University of Oxford, where she will be studying childhood leukaemia development.

### **Dr Fredericus van Eeden, The Bateson Centre, University of Sheffield**

The zebrafish is an animal that just like mice, can be used to “recreate” human diseases. Such models can then be used to understand the disease better, and perhaps identify and test treatments. The zebrafish has unique advantages, as its embryo develops rapidly; within 5 days a complete larval fish is formed that can feed independently and do everything needed to survive and grow up. In addition, it develops outside the mother and is transparent. Therefore, many processes can be followed in minute detail, for instance blood vessel formation and maintenance, which is highly relevant for EHE.

Our primary research goal is to develop a zebrafish model of EHE. We are working to express TAZ-CAMTA1 and YAP-TFE3, which are fundamental to the onset of EHE, in the blood vessels of the zebrafish. This has so far been difficult; however, we have recently made clear progress using a molecular switch system. Using a technology that analyses gene expression of all genes across the genome (RNAseq), we have seen activation of an EHE signature (“the Sealy signature”) in our fish.

Although this is only a first step, and we think further work on increasing TAZ-CAMTA1 expression levels needs to be done, we have started raising fish which will have TAZ-CAMTA1 activated in their blood vessels. In addition, we have targeted another gene, CDKN2a/b, in some of these fish, which has been shown to promote tumour progression in humans. In the coming year we hope to analyse these fish for the formation of EHE-like tumours. If this is successful, we can start using our fish as an accessible model to study the behaviour of these tumours and in the future as a way to do preclinical testing of treatments.



Dr Fredericus van Eeden (left) is the joint PI of our zebrafish project, and is a Senior Lecturer at the School of Biosciences of the University of Sheffield. The other PI is Dr Robin Young, clinical oncologist based at Weston Park Hospital in Sheffield and a member of the Charity's Advisory Board.

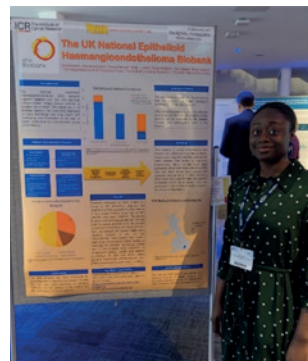
Eleanor Markham (above) is the MPhil student who has been undertaking this painstaking research over the past four plus years.

### The UK Biobank, The Royal Marsden Hospital, London

The role of the UK national EHE Biobank is to collate as many tissue samples from EHE patients as possible. This is because there are a limited number of EHE blood and tumour samples available for researchers to access within the UK. The rarity of this cancer means that researchers do not readily have access to these rare samples, hence why the collection of these materials is so important. The EHE Biobank aims to facilitate research into EHE including improving the diagnostic accuracy of EHE, the identification of new drug targets and the development of new biomarkers.

The EHE Biobank has been quite successful as we have 28 patients that have given consent for their tissue to be stored within the biobank. As this sarcoma arises in any area of the body, we have a range of tissue types that are currently stored in the biobank, primarily consisting of biopsies of the:

lung, bone, liver and neck. Another recent success was the opportunity to present the biobank at the annual British Sarcoma Group (BSG) Conference 2023 which was held on 22nd and 23rd March. This was a very exciting opportunity for the biobank because there were many sarcoma clinicians and professionals present during the conference. Everyone that attended was given the chance to read about the EHE Biobank and we can only hope that this exposure helped spread awareness of the UK EHE Biobank.



Eniola Ayeni, Tissue Manager at the Sarcoma Unity, Royal Marsden Hospital

This photograph shows Eniola Ayeni, Tissue Manager at The Royal Marsden NHS Foundation Trust, presenting at the British Sarcoma Group (BSG) Conference 2023 in March, where she was promoting the EHE Biobank, with pamphlets and the associated poster shown in the photo. 'Eniola explained:'

**“The best part of the biobank, undisputedly, is the interaction we have had with the patients who make this biobank possible. Talking and meeting with these patients face to face has been very eye-opening, especially when hearing about their experiences before they got their EHE diagnosis. All of the progress that we have made is truly incredible and we would like to thank all of those that have reached out to the EHE Biobank so far. We hope that with our continued efforts that the EHE Biobank will aid future research and will improve the outcomes for EHE patients.”**



# 03 EHE Fundraising

The EHE Group continues to remain focused on raising the funds needed to finance, drive and accelerate the existing critical EHE research programme, highlights of which can be found in the previous section of this newsletter. We thank all our members, their supporters and members of the public for their fundraising efforts, some of which are described below.



## Hazel remembered

Just over a year ago the EHE UK patient community lost the lovely Hazel Peak. Her colleagues at Rolls Royce Submarines in Derby in the UK were understandably shattered, but continued with their quiz night that Hugh Leonard from the EHE Rare Cancer Charity had the honour to attend and speak about EHE.

As the anniversary of Hazel leaving us approached, those same lovely colleagues decided that they wanted to continue to support the charity, in memory of Hazel.

Paul Phillips from Rolls Royce, a close friend of Hazel and one of the event organisers said:

**“It is fantastic how engaged the Womens Hub volunteers are in these quiz events. It’s something Hazel would have been skipping about and something which feels extra special for us. We would also like to thank Hugh Leonard for joining us on both quiz nights. As volunteers working with our communities to fundraise, we also are very passionate about raising awareness about causes that most people don’t get to hear about.”**

Hugh was again able to attend:

**“When Hazel explained her cancer to me, my first thought was ‘this just doesn’t sound possible’, but sadly it is. Thanks Hugh for representing the charity. Your ability to join us helped make this more impactful than just the quiz. And, we would like to thank Hazel. It’s in her memory we are continuing our quiz nights and using them as a force for good. Andy Peake (Hazel’s Husband) and Emily Peake (Hazel’s daughter) have joined us at both quiz nights (and this time were on the winning team) which is another wonderful aspect of the evening.”**

The event also raised over £3,000 for EHE research on the night thanks to the great organisation and the unbelievable generosity of all who took part. This sum was also matched by a kind donor taking the total raised to over £6,000.

We want to join Hugh in sending Hazel’s colleagues and Rolls Royce Submarines our thanks for all they have done. We are also delighted to be able to share some photos of the evening.



## Laptops & Lipstick

'Laptops & Lipstick' is a business networking group for women which meets in Beckenham, Kent in South London. Each year this group chooses a charity with a local connection to support, including providing them with a free membership to Laptops & Lipstick. In late 2021, following an invitation to present her pitch for why the EHE Rare Cancer Charity should be considered, Kelly Denton who lives in the area and whose teenage daughter has EHE, was delighted to hear that she, on behalf of EHERCC, had been selected as the charity they would support in 2022. That membership was extended for a further year, and in February they held their second annual Quiz Night to raise funds for EHE research.

The Quiz Night packed out the Bridgehouse pub. Kelly and the Laptops & Lipstick group had also collected some wonderful raffle prizes which added to the fundraising. Kelly explained:

**“Last night my local community all came together for a quiz night in support of EHE research. Amazingly we raised over £2000. Hugh Leonard made a guest appearance and gave a fantastic speech explaining why these kind of fundraisers are so important. It was truly over whelming to see how many people care.”**

Hugh was also hugely grateful:

**“It was lovely to meet Kelly’s family, their supporters, and some of the Laptops & Lipstick members who have been brilliant. I was able to personally thank them for their ongoing support and explain more about EHE. With EHE being a predominantly female cancer, I think it is wonderful when we have a female-focused group that wants to help and support our work. It was also a very noisy and vibrant evening with the pub packed. Every table was full. Kelly also asked me to speak about EHE and what we are doing to defeat this cancer. That gave me a wonderful opportunity to spread awareness and understanding of EHE with Kelly’s support group.”**

We want to congratulate Kelly and Laptops & Lipstick for organising such a positive event, and join Kelly and Hugh in thanking them for their ongoing support. We are also delighted to be able to share some photos of the evening.



# 03 EHE Fundraising



## Good Vibes for McKenna are rocking!

Thanks to “Good Vibes for McKenna, A Celebration Benefiting Cancer Research” for hosting an EXTRAORDINARY two-day event held on January 21st and 22nd in Fort Myers, Florida. We truly appreciate their \$25,000 donation to The EHE Foundation to support EHE research and for creating much needed EHE awareness! The event featured a fine dining experience and acoustic performance at Colleoni’s Ristorante Italiano on Saturday and an epic all-day concert at The Ranch Concert Hall and Saloon on Sunday.

“ Good Vibes for McKenna,” is a non-profit formed in memory of McKenna Helm who passed away from EHE on November 17, 2021 at the young age of 31. McKenna Helm was a fun, caring, empathetic, and poised young woman that brightened the life of everyone she touched. After her EHE diagnosis, McKenna focused on making the most of each day and turned to her next love, live music, for hope and encouragement.”

The event included Cody Canada & The Departed, Ian Moore, Them Dirty Roses, and Ross Mead.

Bob Hebdon, President of Good Vibes for McKenna Inc. said:

“ Good Vibes for McKenna allows us to carry on McKenna’s legacy and spirit of loving and caring. It not only honors her life, but it also pays tribute to every person whose life she touched. Thanks to those who joined us in Fort Myers that weekend. We are already looking ahead to future events. We are incredibly grateful to the bands and sponsors for helping us support The EHE Foundation. Together, we are supporting research for those who are fighting the same rare cancer as McKenna.”

LeeAnn Conner and Julie Wahl are both Board Members of The EHE Foundation and accepted a \$25,000 check on behalf of The EHE Foundation at the event.

“ We are very thankful for “Good Vibes for McKenna” and everyone who came together in McKenna’s memory to make this a truly remarkable event. This donation is dedicated to EHE research and will have a direct impact on those affected by this one-in-a-million cancer.”

The EHE Foundation is hugely appreciative to the event’s sponsors for their dedication to rare cancer research! Sponsors include Sam Galloway Ford, School of Rock Fort Myers, Luminary Hotel & Co., Colleoni’s Ristorante Italiano, Cozza Investment Group Inc., and Taco Works.

Good Vibes for McKenna is planning to host another event in Florida to benefit EHE research in early 2023. Stay tuned for details!



## London Landmarks pre-race fundraising

The 2023 London Landmarks Half Marathon involves running 13 miles on closed roads around central London, running past many of London's most famous landmarks. The EHE Rare Cancer Charity has 50 runners taking part. Some of those taking part have been running events through the first quarter, using the half marathon as a catalyst for fundraising.

### Team Dean are all in

Paul Dean's brilliant supporters are one group that have organised a pre-race fundraising event, as Paul explained:

**“ Just a few days before the run, at the end of March, Lucy Calrow organised a pre-run EHE quiz and bingo night which Simon and Lesley Calrow hosted at the Fordhouses Cricket Club to raise funds for EHE research. Around 100 people took part and raised £520 for EHE research. It reminded me once again that I have some truly awesome support, but to be honest, I never ever forget that!”**

Paul provided us with these great photos of the night. We want to join Paul in thanking everybody who took part and of course all those who will be running. We also look forward to posting photos of the run itself in our next edition of The Pledge.



## Ginger's Fitness including cakes



Ginger's Fitness is an outdoor fitness group based in south London who will also have a team of runners in the London Landmarks Half Marathon in April in support of Kelly Denton whose teenage daughter has EHE. As part of their campaign the group organised a cake sale in their local park on a Sunday. Paul Preston who runs Ginger's Fitness explained:

**“ We held the cake sale in the park immediately after our Ginger's Fitness class to boost our fundraising for the London Landmarks Half Marathon on 2nd April. 20 of the Ginger's Fitness Community are running for the EHE Rare Cancer Charity. Cakes were available from 9.30 am. We had soft drinks, coffee, prosecco and bucks fizz all available for a donation of the person's choice. We asked people to tell their friends and family and to bring lots of cash to donate. It was great fun and we raised over £700 from this one event which was wonderful!”**

Paul wanted to say a huge thank you to Anja Workman, from Anja's Gingerbread, for baking so many brilliant cakes and gingerbread men for the sale. We loved the EHE Gingerbread Men runners so much that we had to put them on the front cover of this edition. We want to thank everybody in the Ginger's fitness team and their supporters for their brilliant support, and look forward to posting pictures of the run itself in our next edition.



# 03 EHE Fundraising



### An Easter Basket

Adam Patrick ran the LLHM with Jessica Rawdon and Adam and Jayne Sausby-Gallimore in memory of their dear friend Allana

Parker who many of our EHE family knew well. They decided to boost fundraising by raffling an Easter chocolate basket. We thought that was a great idea. And of course we want to thank all four, and Steph Scott for their ongoing brilliant support.

### Farewell to Amazon Smile

As many of you may already know, Amazon has decided to discontinue its charitable program known as AmazonSmile as of Feb 20, 2023.

For years, non-profit organizations like The EHE Foundation have come to appreciate the funds this program allowed our supporters to generate. We thank you for supporting the EHE community through AmazonSmile and we are grateful to AmazonSmile for donating a total of almost \$14,000 to The EHE Foundation over the years.

### Upcoming events

#### The London Landmarks Half Marathon

The end of the quarter was accompanied by much excitement in the UK as the London Landmarks Half Marathon, one of two major events in which the EHERCC directly funds places, was only a few days away. The event involves running a half marathon on closed roads around central London, running past many of London's most famous landmarks.



This year the Charity had 50 places filled by their brilliant supporters. Sally Baker, Trustee of the UK Charity and herself an EHE patient was excited:

**“ This is the fourth time we have had a team running, and it’s the biggest group yet. 20 of the runners are all from south London and are running to support Kelly Denton whose daughter has EHE. They are all part of fitness group called Ginger’s Fitness. Another 20 are all running to support Paul Dean, another EHE patient who is also running in the race.”**

The EHERCC charity running shirts arrived in March and were distributed to all the runners. This means that all 50 runners will participate wearing an EHE Rare Cancer Charity shirt. The charity also hopes that runners will wear these when running in the future as they train and participate in recreational events, and so raise awareness of EHE.



## EHERCC Riders are out training again

The second event that the EHE Rare Cancer Charity participate in each year is the Ride London 100 cycling sportive, now called the Ford Ride London. This is where participants will ride on closed roads for 100 miles, starting and finishing in Central London. The Charity has 20 places in the race that will be taking place at the end of May.

**“It’s wonderful to have such great support, including Hugh, Sam and Oliver taking part. They are all out training hard. Obviously we don’t have any photos yet, but here is a montage from last year to wet the appetite. Just Live and Just Ride!”**

This year, Hugh Leonard, Chair of Trustees will be riding again but this time accompanied by his son Sam. Dr Oliver Pearce, a Trustee of the charity and a member of the EHERCC Research and Medical Advisory Board will also be riding to raise funds for EHE research. Sally Baker said:

## The EHE Foundation 2023 Fun Run & Walk is on!

Every year, the EHE Foundation organises its Fun Run & Walk event to bring EHE patients and their families and supporters together, to shine a light on EHE, and at the same time raise critically-needed funding for EHE research.

At the end of the first quarter registration opened for the annual EHE Fun Run and Walk. The 2023 theme is Shine a Light on Rare Cancer. Check out top teams, learn about sponsors, and more at <https://fightehe.org/2023-fun-run/>



Registration starts at \$30 and includes a t-shirt (in various youth and adult sizes), bracelet, temporary tattoo, and shipping (US only). Simply register by April 30th and you’ll receive your packet in the mail after May 15th.

This family fun event is for all ages and abilities. It is virtual, which means it can be done anywhere you are. Many supporters choose to skip the run/walk altogether and wear the shirt to show support year-round. Thanks to Kim Young for the amazing shirt design!

We love reporting on this event every year and look forward to sharing photos and stories from this year’s event in future editions.



# 03 EHE Fundraising



## Exciting collaboration with Truly Yours Holidays

During the first quarter the EHE Rare Cancer Charity was excited to announce a collaboration with Truly Yours Holidays @ Not Just Travel. Hugh Leonard explained what this means:

“For all holidays and travel needs of EHERCC supporters that are booked through Truly Yours Holidays, the EHE Rare Cancer Charity will earn a commission from those bookings to go towards the charity funds. So we just need to spread the word. There are two simple ways that we can all help raise funds for EHE research. Firstly, book your holidays through Truly Yours Holidays; and secondly, tell everyone you know to book through Truly Yours Holidays. Don't forget to let them know you are an EHERCC supporter!”

Truly Yours Holidays is run by Julia Onslow-Cole. She became aware of the charity through her membership of Laptops and Lipstick, the women's business support group that adopted

the EHERCC as their 2022 and 2023 charity to support, as reported in this and previous editions of The Pledge. Julia wanted to help and suggested this collaboration. Julia explained:

“Hello, my name is Julia and I am a 'Not Just Travel' franchise owner. My part of the business is called Truly Yours Holidays. I have over 20 years' experience in the business and run it from my home in Godstone, Surrey, just south of London. I am protected by ATOL and ABTA. Booking holidays for people is my passion and it makes me very happy to find the holiday that my customers are looking for. I can book holidays for passengers travelling from any part of the UK, whether it be Gatwick, East Midlands, Manchester to name a few. There is no extra charge for my service, it's just like going to your high street agency but I will also check you in for your flights and send your boarding passes to you, I have access to hotels direct for any requests and questions, I can also book airport parking and lounges, car hire, excursions in resort and travel insurance”

“ My prices are very competitive whether its a standard package or a bespoke holiday. The service I offer is a personal concierge travel service and I am excited to book your holidays and help towards raising money for this important charity.”

Sally Baker, a Trustee of the Charity wanted to express thanks for this great support:

“ We are so grateful to Julia for setting the charity up to benefit in this way from holidays booked through Truly Yours Travel. It’s just another sign of the wonderful support and generosity that the charity receives from so many people. So a huge thank you to Julia from our global EHE family.”

We at The Pledge also want to thank Julia for this wonderful collaboration, and think it is lovely that something as enjoyable as holidays can help raise funds for rare cancer research. As we say so often, **Just Live**, and maybe **Just Holiday** too.

TrulyYours Travel please contact Julia directly using the contacts below:

**Email:**

[sales@trulyyoursholidays.co.uk](mailto:sales@trulyyoursholidays.co.uk)

**Phone:**

03330 113388 (local rate)

To see offers and ideas being promoted by Truly Yours Travel, go to:

**Facebook:**

<https://www.facebook.com/TrulyYoursHols>

**Insta:**

@trulyyourshols

**Website:**

<https://trulyyoursholidays.notjusttravel.com>



# 04 And in other news...

Every quarter we include messages that have been posted by our EHE community that are not necessarily related to EHE, as we think they reflect the spirit of this wonderful group, namely that they will not let EHE control or dictate how they lead their lives. They will “Just Live”! Here are the contributions for this quarter.



## **Our newest arrival**

We always love news of new arrivals, and were even more thrilled to welcome Adam and Steph's new daughter, Hattie, into the London Landmarks Half Marathon Support Team. At six weeks old she is also the youngest person to ever wear an EHERCC running shirt. Just wonderful. Congratulations to the whole family.





**Photo therapy**

As is usually the case, Carl Dickson posted some great photos and accompanying messages of encouragement for the EHE family. Here are just two.

“Cancer sucks. I wouldn’t wish it on anyone but as I always say you must focus on the good in life. This is what I am seeing this morning on my way to another surgery. I might have just been sitting here and miss this great gift by Mother Nature. Hope you like it as much as I did.”



“Remember we all have each other, if you feel too alone just turn to our Facebook page and we are all here to help.”



Fiona Louise also sent a wonderful winter picture from Canada taken in the morning following a particular heavy snow storm. “Quite the storm last night!”





**The EHE Foundation (USA)**  
[www.fightehe.org](http://www.fightehe.org)

**The EHE Rare Cancer Charity (UK)**  
[www.ehercc.org.uk](http://www.ehercc.org.uk)

**The EHE Rare Cancer Foundation (Australia)**  
[www.ehefoundation.com.au](http://www.ehefoundation.com.au)

**EHE Italia - Non solo Laura**  
website not yet available

**EHE Canada**  
website not yet available