

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



**Quarterly Newsletter for the EHE Group**  
July - September 2024

# the pledge

**Edition 38**



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### Front cover:

Lorraine Faulds and Judith Gordon with friends, raising EHE awareness and research funds at the Edinburgh Shine event in Scotland

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# Welcome

Welcome to our **38th edition of The Pledge**, the quarterly newsletter of the EHE Group, where different aspects of the EHE Group's activities that took place during the third quarter of the year are described.

We think the progress being made is extraordinary for such a small community, and hope that you will find the stories courageous, enlightening, uplifting and inspiring. In every edition, we sincerely thank everybody who has supported The EHE Group, whatever form that support may have taken, and this quarter is no different. Thank you.

***"Just Live"***.



# Highlights

## **Impact Statement published**

The EHE Foundation were honoured to publish their excellent and comprehensive record of progress in advancing research towards life-saving treatments and a cure for EHE.

## **New Executive Director Appointed**

Jenni Kovach, Board President of the EHE Foundation was delighted to announce the appointment of Denise Robinson as their new Executive Director.

## **Patient group in Germany launch new EHE Instagram page**

EHE patients in Germany have joined forces and opened a German Instagram page. The page is open to everyone: patients, doctors, researchers and relatives, and they hope **“people will stop by”**.

## **Researchers present exciting results**

Dr John Lamar PhD, and Dr Ajay Pobbati PhD, both recipients of research grants from the EHE Foundation, presented encouraging results from their respective drug-screening research.



## Over 2,000 turn out for Michelle Hughes

Donors, sponsors, in-kind contributions, purchases, shares, and over 2,000 runners all helped Michelle raise \$54,000 for EHE Research, which was doubled by matching from the Sarcoma Cancer Foundation of Canada.

## UK twins enjoy huge support

Twins in the UK, one with EHE, showed great bravery to share their story, and were overwhelmed by the support they received, helping to raise £10,000 for EHE research!

## Global Facebook community exceeds 3,000

October saw the membership of the EHE Patient Support Facebook page exceed 3,000. It is a long way from the 3 who started the page in 2013!

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

the **pledge** Edition 38



# 01 Patient Support and Advocacy

**In this section you will find updates on the The EHE Group's patient support and advocacy activities.**

Most of the patient support is provided by patients themselves through the different EHE social media platforms, while advocacy activities are also undertaken by the EHE Group foundations in their respective regions. In both cases, the EHE community continues to work to create greater awareness of EHE, greater focus on the research we need to defeat this disease, and all necessary support for the patients themselves.

## Rarity does not limit ambition, it drives it!

A huge focus for very small foundations and charities is delivering meaningful programmes while managing the running costs associated with them. That is why most are either largely or entirely run by volunteers and why both establishing them, but then running them thereafter, is a daily challenge. For an ultra-rare sarcoma like EHE, it has only been possible to achieve the progress we have because the EHE Support Group Facebook page connected and mobilised the global EHE community in 2013, creating a powerful global bond amongst the EHE community which continues to grow. **In October membership of the EHE Facebook page exceeded 3,000.**



It is this global community that has ensured that the rarity of EHE does not limit their ambitions, but drives them to achieve ever greater progress. This attitude was typified by the community setting up viable EHE-focused foundations to drive EHE fundraising and research. And while EHE organisations in the USA, UK and Australia were the first to be established in 2015, further groups have also been established and continue to grow and develop, in Canada, Italy, Germany and other countries.

We love to see and be able to share reports of all these organisations growing and developing. Here are a few examples for this quarter:

## EHE Canada is an excellent model

Recognising the challenges of setting up a full-blown legally-established EHE foundation in Canada, with relatively small patient numbers, the Canadian **'driving force'** that is Fiona Ross started to explore alternative models that could deliver the same outcomes. Those discussions led Fiona to the Sarcoma Cancer Foundation of Canada where she found an organisation with an equally creative mindset focused on delivering sarcoma research. The SCFC was therefore happy to assist by establishing a restricted account where Canadian citizens can donate to the SCFC and their funds are dedicated to EHE research. Not only have the SCFC provided a viable, tax-efficient structure to allow EHE patients to drive EHE-focused research, but they have also contributed towards this research through funds-matching programmes.



Fiona Ross remains at the helm of the Canadian operation, brilliantly supported by the power-house that is Michelle Hughes, other Canadian patients and their support groups, and a major private donor. Fiona has also been instrumental in establishing the significant EHE research programme that is being driven by Dr Razak at Mt. Sinai/ Princess Margaret, and which is coordinating closely with The EHE Group's European EHE research initiatives.



# 01 Patient Support and Advocacy

In fact it was Dr Razak who suggested that Fiona adopt a formal title, as Fiona explained:



“My contact information for any Canadians in the group. The title “patient advocate” was given to me by Dr. Razak. Please reach out if I can be of assistance.”

## German support grows

Patients in Germany have been in communication with each other almost from the point that the EHE global community was established. Recently they decided that they wanted to be more coordinated, establishing their own Instagram account to drive awareness and focus on EHE, as Kiara Laufs explained:

“Hello! The patients in Germany have now joined forces and opened a German Instagram page. This is of course open to everyone: patients, doctors, researchers and relatives. Feel free to stop by. All the best to you.”



We want to congratulate Germany for driving this focus and having the ambition to do more for their patient community. We will indeed “stop by”!

## EHE Italia activity grows

The newest of the EHE foundations is ‘**Associazione EHE ITALIA – Non Solo Laura ODV**’. Led by their President, Andrei Ivanescu, EHE Italia is continuing to drive forward with all its main objectives: patient support and advocacy, fundraising and research. Current activities are particularly focused on supporting the EHE Group’s European advocacy programmes and research initiatives, as more fully reported in this edition of **The Pledge**.



We think it is wonderful to see this growing engagement and activity across Europe. ■

## Impact Report is issued

In late August, The EHE Foundation published its impact report for 2023:

“We are honored to present The EHE Foundation 2023 Impact Report - a comprehensive record of our progress in advancing research toward life-saving treatments and a cure for EHE. This report highlights our ongoing commitment to empowering the EHE community with vital education and resources and spreading awareness of this rare cancer. We extend our deepest gratitude to the patients, caregivers, researchers, and clinicians whose unwavering support is instrumental in our growth and progress. Visit our website to explore the full report at <https://fightehe.org/our-impact/> and join us as we continue this critical journey.”



We want to congratulate The EHE Foundation for publishing this excellent report and we encourage everyone to read this excellent document. ■

## Dr Cote explains clinical trials

The organizations that comprise the EHE Group strive to provide information about many different aspects of EHE, and the challenges that may be faced by people living with EHE. Providing such information is at the core of The EHE Foundation's EHE 360 Connect series, a growing collection of educational webinars that are open to the global community.



One of the subjects that cancer patients realise is important but struggle to fully understand is clinical trials. The EHE community therefore eagerly anticipated the EHE 360 Connect session “**Clinical Trials for EHE**”, presented by Greg Cote, MD, PhD, medical oncologist, and early-stage clinical trialist from Mass General Cancer Center.

Held in July, Dr Cote provided an in-depth look at the drug development process and discussed the current landscape of clinical trials that include patients with EHE. This webinar was delivered for patients, families, healthcare providers, and researchers interested in the latest treatment options and advancements in EHE management. Attendees gained valuable insights into how new drugs are brought to the market and learned about opportunities to participate in ongoing clinical trials that are currently recruiting EHE patients.





# 01 Patient Support and Advocacy

Everybody who attended the webinar agreed that it was excellent, removing much of the mystique of clinical trials, and providing patients with a greater understanding of the process. Dr Cote's willingness to answer questions from those taking part provided additional education and clarity on clinical trials for EHE patients.

For those who may have been unable to attend, a recording of the webinar can be found at:

<https://youtu.be/Ybqp2NtclrM> ■

## Italian Sarcoma Group meets with Patients

During Sarcoma Awareness Month, the Italian Sarcoma Group (ISG) organized a webinar for sarcoma patients and family members. The meeting was also promoted by the sarcoma patient associations that actively collaborate with ISG, and who participated in the event.



The webinar covered a number of key topics which apply across different sarcoma histologies, and so are relevant to all sarcomas, and which offered patients useful information for different oncological settings:

- Immunotherapy in sarcomas;
- Histological reviews: when should you do them and why;
- Gene sequencing;
- Clinical trials: the significance of placebo and the importance of Quality of Life (QoL);
- Surgery: when to be radical? The role of the referral centre.



The event was a huge success, as described by Caterina Colaci, from EHE Italia:

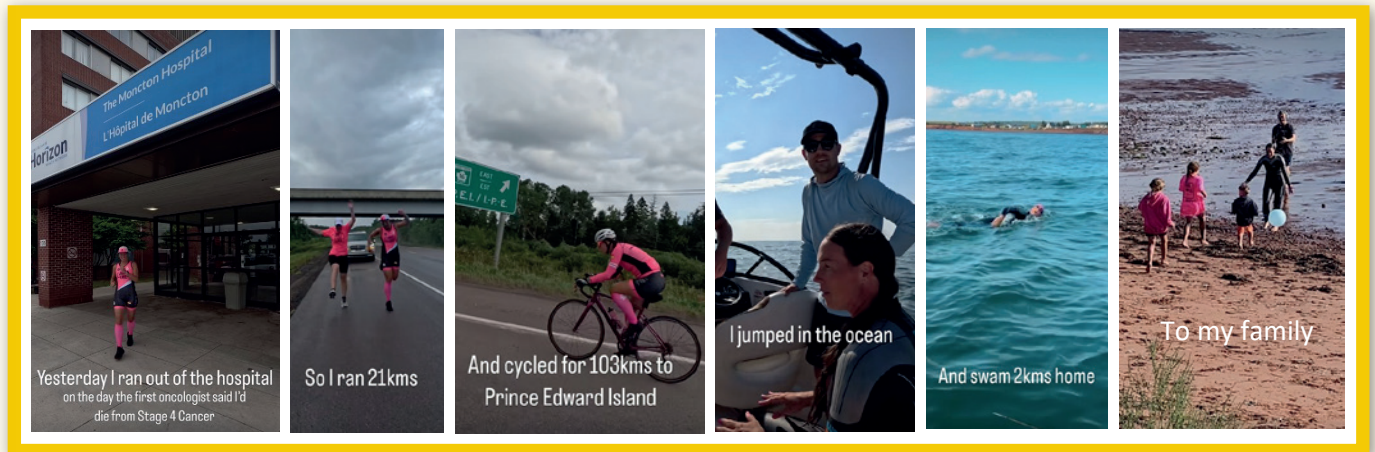
**“It was such a pleasure to be part of this ISG event and to hear about the many developments in this field and the many studies that are advancing. Several clinicians from Italian hospitals shared their experiences and thoughts on sarcomas, making the event dynamic and very interesting.”**

In addition, EHE Italia were especially proud of their President, Andrei Ivanescu, who participated as a moderator, introducing the clinicians and asking them questions submitted by sarcoma patients. They were also delighted to have received very positive feedback from EHE patients who participated in the webinar, and therefore hope that many more such meetings, addressing specific issues relevant to EHE, can be organized.

If you would like to watch the webinar (its in Italian), it is available on ISG's YouTube page at the following link: <https://youtu.be/xjHvQKZWvZ8?list=TLGGZWJmnZjrwT4wOTEwMjAyNA>

We want to congratulate EHE Italia on helping to organise and participating in such an excellent event that we are sure would have been hugely positive for sarcoma patients. We also want to say a huge thank you to the ISG and all the clinicians who gave so much of their precious time to participate in this patient-focused webinar. ■

## Michelle Hughes celebrates a special achievement



Michelle Hughes, based in Canada, has worked tirelessly over the last three years to promote the EHE cause, has built a huge following through her [@MyJourneyToJustLive](#) platform and brand, and has raised unbelievable sums for EHE research. But in August Michelle wanted to celebrate an important day for herself, as she explained:

“3 years ago on August 20th 2021 I heard the words EHE for the first time. I was holding my 1 month old newborn in my arms when the doctor said I had Stage 4 cancer with a poor prognosis of “**5 years, likely 3.**” My girls were 5 and 2 years old. I thought my life was over. I left that hospital, after being in the ICU from an internal bleed at the site, terrified to embark on this journey.

I am proud to share that on August 20, 2024 I was able to run out of those same hospital doors. This time, I ran 21kms, a half marathon, and hopped on my bike immediately after, cycling 103kms to meet a boat, where I swam 2kms home to my kids who were waiting for me on our beach!

I completed my own personal triathlon, in reverse, to replace that awful drive. To rewrite my story. Cancer has stolen more things from me than I'd like to admit but it has gifted me so much more. I learned to run 2 years ago; I became a runner, and in 2024 I learned to swim and bike so I could be a triathlete.

Innumerable lung tumours, innumerable liver tumours, a thigh tumour and 1 knee tumour did not define me, but it sure has redefined me. I carried you all with me, your names embedded in my suit. Thank you for being a part of this wild adventure. Let's see what we can accomplish in another 365 days living with cancer.” ■





# 01 Patient Support and Advocacy

## Patient involvement is key

Patients are the key to finding new treatments for EHE. Tumor tissue and biofluids (blood, serosal effusion, etc.) are needed by researchers to help progress research into EHE, its biology, and possible treatments. They are essential to understanding disease progression and speed up the development of new drugs and therapies.

In addition to the biospecimens, researchers and clinicians also need as much information as possible about actual patient progress and treatment to help understand the disease. Sharing your experiences with systemic therapies like sirolimus, chemotherapies, immunotherapy, or active surveillance (also called 'watch and wait'), and details of your journey—victories and setbacks—will help researchers understand EHE.



These biospecimens and patient data can only come from patients with their agreement. The EHE Group remains focused therefore on encouraging patients to donate their biospecimens to relevant EHE biobanks in their country and to also engage with and support patient databases and surveys, such as the EHE Global Patient Registry that is managed by The EHE Foundation. By joining the registry, you will add to the collective strength of our community, helping to solve the EHE puzzle, drive the discovery of effective treatments for EHE, and bring hope to others.

So if you have an upcoming medical procedure, or you wish to join the global registry, please contact your local EHE foundation or charity and seek their guidance on the best way to ensure that your contributions are properly captured.

To contribute to the EHE Global Patient Registry, please go to <https://eheregistry.iamrare.org/>

To inquire about donating your EHE tumor tissue, blood, or fluid drained in the US, please contact [biobank@fightehe.org](mailto:biobank@fightehe.org).

For biobanking in the UK, contact either:

the EHE Tissue Coordinator at the National UK EHE Biobank at the Royal Marsden Hospital at [EHEbiobank@rmh.nhs.uk](mailto:EHEbiobank@rmh.nhs.uk); or

Hugh Leonard at the EHE Rare Cancer Charity (UK) at [hleonard@ehercc.co.uk](mailto:hleonard@ehercc.co.uk).

In Australia contact the EHE-RCFA at [info@ehfoundation.com.au](mailto:info@ehfoundation.com.au).

EHE Group entities in Canada, and Italy can also advise on how to join appropriate registries and/or donate to EHE biobanks in these countries or regions. Please contact your local EHE foundation or charity to discuss any of these issues. ■

## Community Connections for Caregivers Launches

Recognizing a need to support and provide resources for EHE caregivers, The EHE Foundation launched a Community Connections series for caregivers only. Facilitated by veteran caregiving expert, Allison Breininger, M. Ed., the discussion centred around the difficult topics and emotions experienced when supporting a loved one. The first session, **“I’m part of the story too”** focused on how a loved one’s illness impacts every part of their caregiver’s life. Attendees were glad to have a safe space to discuss their feelings and the realities of caregiving.



Watch for more of these sessions in 2025. ■

## The EHE Foundation’s Scientific & Medical Advisory Board Collaborates to Improve Outcomes for People Living with EHE

On September 10, 2024, The EHE Foundation held a virtual meeting of their Scientific & Medical Advisory Board (SMAB). The meeting aimed to welcome new members, review current research projects, and discuss future needs and goals to advance EHE research.



The meeting began with a warm welcome to new members of the SMAB:

- **Tom Chen**, MD, PhD, Medical Oncology, National Taiwan University
- **Greg Cote**, MD, PhD, Medical Oncology, Massachusetts General Hospital Cancer Center
- **John Lamar**, PhD, Molecular and Cellular Physiology, Albany Medical College

Their expertise and scientific contributions will play a significant role in advancing EHE research.

The assembled group reviewed the Foundation’s mission and strategic priorities which remain focused on finding treatments and a cure for EHE by facilitating collaboration among patients, researchers, and clinicians. To accomplish this, the Foundation will prioritize:

- Aggressively funding and supporting sponsored research
- Facilitating education and collaboration across the EHE community
- Fundraising to ensure the growth and sustainability of the organization



# 01 Patient Support and Advocacy

## US EHE Biobank Progress

The EHE Biobank in the US continues to grow, with **64 consented participants** from the US and **42 specimen donations** facilitated to date. A primary goal of the EHE Biobank is to develop human-derived EHE model systems that can be used to develop treatments for patients. Currently, **four EHE extended cell cultures** are in development, and biospecimens from the Biobank have been distributed to four researchers for model development.

## Active Projects & Therapeutic Opportunities

Several exciting research initiatives were presented:

- **Dr. Silvia Stacchiotti** discussed the research program evaluating cytokines and hormones as biomarkers for EHE, a multi-center collaborative project led by the Istituto Nazionale dei Tumori (INT) in Milan, Italy.
- **Dr. John Lamar** shared his progress on pre-clinical models aimed at identifying druggable pathways.
- **Dr. Brian Rubin** updated the board on the investigation of CDK inhibitors at the Cleveland Clinic and other research initiatives in his lab.

A key discussion point was how to avoid missing potential therapeutic opportunities due to gaps in data or lack of proper measures. The board discussed the resources needed to close these gaps and ensure research progresses smoothly.

## Conclusion

The meeting underscored the importance of research collaboration and highlighted current and near-term opportunities to bring together data, resources, and key stakeholders.

This meeting marked an important step forward in advancing EHE research and clinical science. Building on patients' strong participation and passion for contributing to EHE science, the SMAB is dedicated to finding breakthroughs for this ultra-rare sarcoma. ■

## New Executive Director Appointed

In August, on behalf of the Board of Directors of The EHE Foundation, Jenni Kovach, Board President was delighted to announce the appointment of Denise Robinson as the new Executive Director and continued service as the Foundation's Director of Research.



Like many people, Denise had not heard of EHE until her friend was diagnosed in 2017 with an aggressive form of the disease. She soon began volunteering to support the Foundation's aspirations to start a study of EHE. She joined the Board of Directors in 2019 and became the Director of Research in a part-time position in 2021. Since that time, Denise has transitioned from running her own business to giving 100% of her time to EHE. She has been serving as Interim Executive Director since February.

As the Director of Research, she continues to oversee The EHE Foundation's sponsored research and Research Grants Program. Denise is the Principal Investigator of the EHE Global Patient Registry and serves as the Foundation's primary liaison with the global EHE research and clinical community.



Denise has over 20 years of clinical research experience in all phases of clinical trials in numerous rare and life-threatening diseases. Her career has been dedicated to working with patients, clinicians, and industry in drug development. She is an active volunteer in her community and enjoys spending time with her family and their dog, Jordan, gardening and running.

Jenni Kovach, EHE patient and Board President said:

“Denise has been a persistent champion for the Foundation and provides stability to this organization and guidance to the community. As an EHE patient, I am glad to have her lead our team every day.”

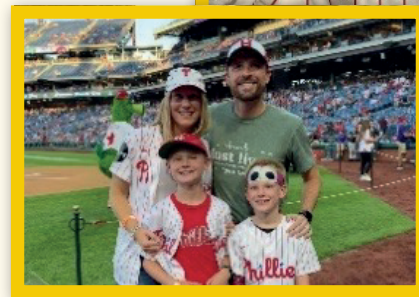
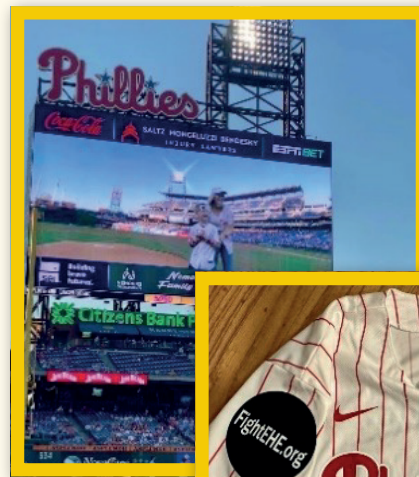
When asked about this new role, Denise commented:

“I am honored to be trusted by the community and the Board to take on this role. I feel an enormous sense of responsibility to advance our mission to find effective treatments and a cure - the most basic need that is vital to every person diagnosed with EHE. I am committed to working tirelessly to advance critical research while providing the information and resources people need to navigate their EHE journey, with the ultimate goal that everyone diagnosed can embrace the motto *‘Just Live!’*” ■

### Throwing the first pitch

Jennifer Ness was delighted to post news of an exciting day out which certainly helped raise awareness of EHE:

“I had the incredible privilege of throwing out the first pitch of the [Philadelphia] Phillies game earlier this week! I used this opportunity to bring EHE to the national stage. I added patches to my jersey and my husband wore his EHE shirt. Hoping to continue to spread awareness wherever we go!”



Wow, Jennifer, you certainly “hit that one out of the park”, which in this case seems like a very appropriate metaphor for an excellent performance. Congratulations. And what great photos! ■

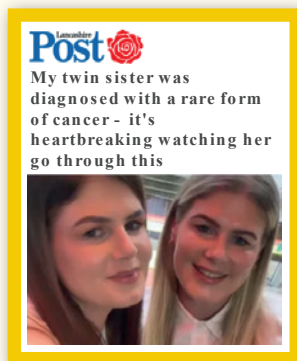


# 01 Patient Support and Advocacy

## Twins tell their story to spread awareness

One of the objectives of the EHE Group globally is to spread awareness of the disease. This can be done in several different ways, but it is generally recognised that one of the most powerful formats is when EHE patients tell their stories. That sounds easy, but to open yourself to the public in such personal circumstances is very tough and requires considerable bravery and determination from those who do it.

One such case is Kym and Emma, twins from the UK, who wanted to share their story. As twins, the sisters are facing and dealing with the disease from a particularly unique viewpoint. Their story was first picked up locally, by the Lancashire Post, and then nationally by the Mirror Group.



Emma was diagnosed with EHE earlier this year, and Kym spoke openly about how heart-breaking it is to see her sister suffering and how hard she is working to support her sister and striving to make sure she is getting the best care possible.

**“With her being my twin, it’s been so hard for me not being able to control this situation and make her better as she is literally my other half. Over the last six months Emma has shown more strength and resilience than I have ever seen in a person. Some days she is fine and others she will wake up in agony. She’s on a lot of pain relief and anti-sickness drugs. She’s fighting against this disease everyday whilst remaining the world’s best mummy to her two boys and partner.”**

Emma wanted to thank Kym for her brilliant support at such a tough time.

**“I don't know what I'd have done without Kym. From day one after getting my diagnosis she's been full into research, fundraising, gathering all sorts of different contacts to help me, whilst having her own young family to care for. She's the real superwoman.”**

The EHE Rare Cancer Charity also wanted to thank both Kym and Emma for all they have and are doing:

**“We could not be more grateful to Kym and Emma for doing so much to spread awareness and raise research funding, all at such an incredibly difficult time. Once again we are inspired and amazed by the commitment and compassion that patients and their families, like Kym and Emma, have when faced with an EHE diagnosis. On behalf of EHE patients everywhere, we want to say thank you and send Emma our heartfelt best wishes.”** ■

## Highlighting Joe for Childhood Cancer Awareness Month

September was Childhood Cancer Awareness Month. While EHE is exceedingly rare in children, there are young people who are battling this unpredictable rare cancer. Joe Mulligan in the USA was diagnosed with EHE in 2019 at the age of nine. He and his family have been incredible champions of EHE, making significant donations to The EHE Foundation through fundraisers and working with the Make-a-Wish organization to spread awareness of EHE to a wider audience. A remarkable young man, Joe inspires his family and friends by advocating for EHE and embodying our community motto to **"Just Live!"**



Researchers want to learn more about EHE in children, and parents and caregivers can help by adding their child's information to the EHE Global Patient Registry to help broaden the understanding of EHE in children and young adults. You can add your child's data by going to:

<https://eheregistry.iamrare.org/> ■

## Michael Proctor is feeling hopeful

Michael posted his latest news in September. At the end of his post was a simple message for his fellow EHE patients, concerning their well-being:

**“ Just remember we all react differently and go at your own pace. Please stay positive no matter what you may be facing because keeping your mind sharp and the right attitude will do so much for your overall recovery.”**



Thank you for the message, Michael, and we wish you and your family well. Michael's post included a photo of himself with his gorgeous daughter, which we also wanted to share. ■

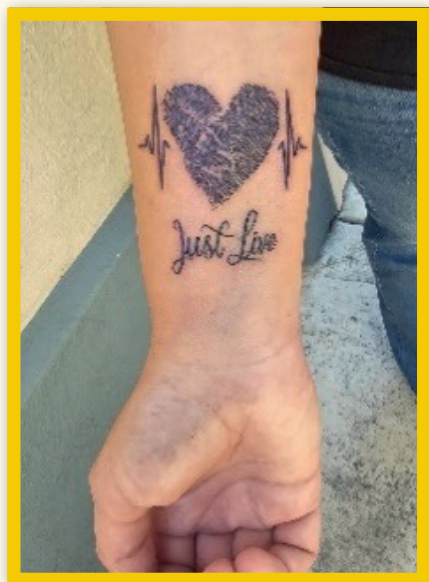


# 01 Patient Support and Advocacy

## Tattoos are once again on show

The **Just Live** logo, with the heart-beat trace, was first proposed by Georgiana Trandafir, a young patient from the USA whose EHE was already aggressive when she joined the group. It was her wish to have this logo made into a tattoo, but sadly she never had the chance.

The idea however was not forgotten, and **Just Live** tattoos have become a part of the coping mechanism for many EHE patients and their supporters, helping to make the point that their EHE will not define them, nor stop them enjoying life. We therefore always like to publish photos of the **Just Live** tattoos that members of the EHE community post, to help promote the **Just Live** philosophy.



Kristen Marotta-Paulsen posted this photo of her tattoo, which she got in support of her husband. She also included her and her husband's thumb prints in the shape of a heart...



... Bill Jardins loves his tattoo.  
***"I did this after my beautiful bride lost her battle with EHE over two years ago!"...***



...and Steve Alexander-Bird got his in support of his wife Kim. ■



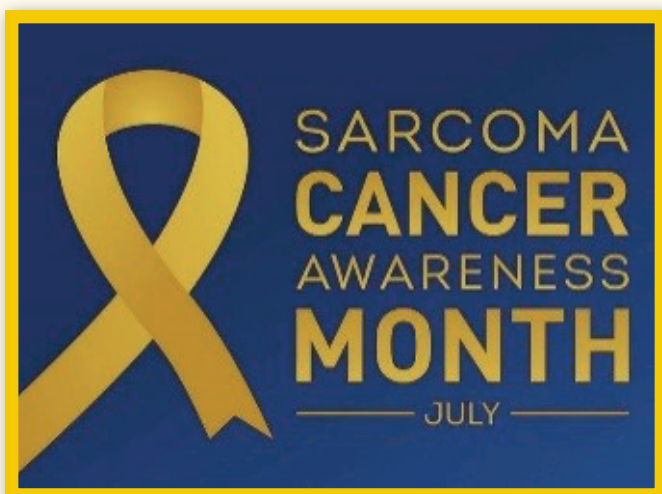
## Sarcoma Cancer Awareness Month

Sarcoma is a group name for a large number of different cancers that present in connective tissue in our bodies. All sarcomas are rare, but EHE is at the ‘ultra rare’ end within the sarcomas. The natural biology is also very heterogeneous, and has some unique characteristics. This is why the EHE patient group wanted to set up their own EHE-dedicated foundations, so that funds raised for research would be spent on a research programme targeting EHE.

BUT we never forget that we are part of the sarcoma family and so Sarcoma Awareness Month, which occurs each July, is always supported by the EHE Group, focusing on growing awareness of the challenges that sarcoma patients face; the need for funding for sarcoma research; and the desperate need to drive sarcoma research, as captured by The EHE Foundation in the US and EHE Italia in Italy:

“Sarcoma is still largely considered a “forgotten” cancer due to a lack of research & drug development. Share this post to spread sarcoma and EHE awareness. Let’s shine a light on rare cancer!”

Its not just the EHE foundations that champion the cause, but individual patients too, as seen when Tyler Davis in the UK posted his ‘Sarcoma Cancer Awareness Month’ image. ■



# 02 EHE Research

**In this section you will find stories and information relating to EHE research and understanding, most of it supported by our global patient community, and funded by the EHE Group entities.**

It is this research that will ultimately help the EHE Group find new ways to treat and manage EHE. We hope you will be inspired by the work taking place and the dedication and skill of the researchers that are delivering it.

## Exciting research explained

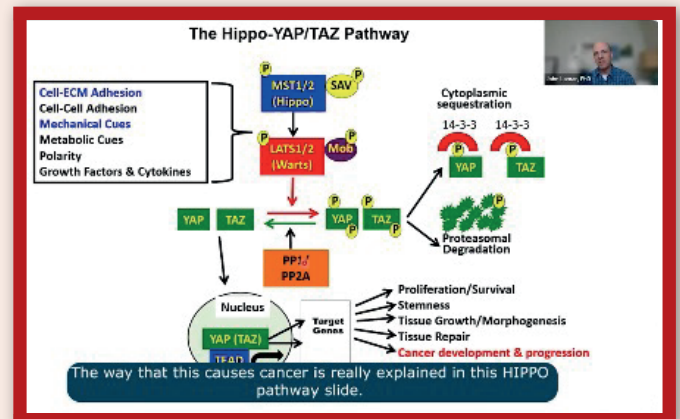
In early September, The EHE Foundation was delighted to host another **EHE 360 Connect** event with John Lamar, PhD, Associate Professor of Molecular and Cellular Physiology and Principal Investigator at the Lamar Lab, Albany Medical College.

Dr. Lamar received his first small grant from the EHE Rare Cancer Charity, which enabled him to start his research into EHE. He has subsequently been funded by The EHE Foundation as his lab and research programme have grown significantly. Dr. Lamar has been a long-time collaborator with Professor Brian Rubin, Cleveland Clinic. He also recently joined the Scientific and Medical Advisory Board of The EHE Foundation as a key EHE science contributor.

Dr. Lamar's talk, titled **"Harnessing the Therapeutic Potential of the Hippo Pathway in EHE"** provided an excellent summary of the EHE research being undertaken in his lab. He described EHE, the translocations that cause it, and the biology of the disease. Dr. Lamar then moved on to outline possible therapeutic targets, how they had used these to identify possible drugs that might have positive impacts on the disease and the exciting results that are developing from their ongoing drug screening. At the end of the talk, Dr. Lamar was able to answer questions posed by the audience which is always well received. Everybody present agreed that it was an excellent presentation and provided genuine hope for the future.

For those who may have been unable to attend, a recording of the webinar can be found at:

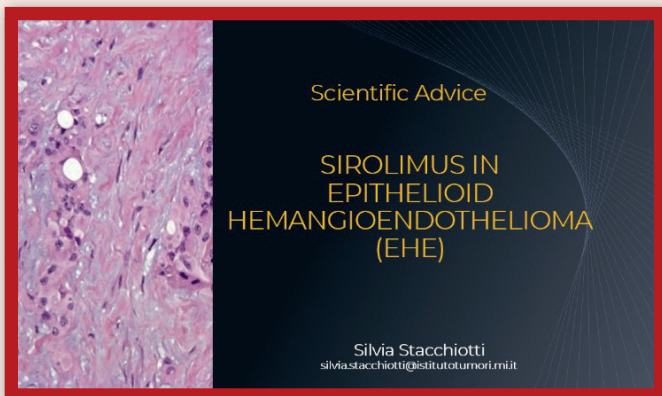
<https://youtu.be/O8I6J4WR4R4> ■



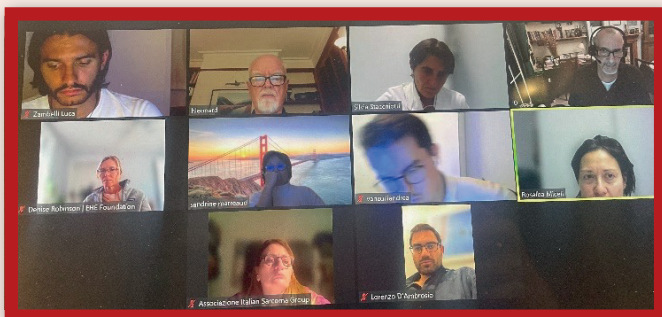
# 02 EHE Research

## Sirolimus approval discussions are progressing

As many of our readers will know, the EHE Group are working with the EMA in Europe and the FDA in the US to try and obtain a label extension for sirolimus for the treatment of EHE, so that many more EHE patients can have equitable access to this important drug. This is necessary as sirolimus is not currently approved for the treatment of EHE, or indeed any sarcomas, and so is only available to patients if their doctor, hospital, health system, and/or insurance companies will allow off-label use. Many of our patient community can access sirolimus, but due to this off-label limitation many cannot, often because they cannot afford to self-fund the drug.



One of the key issues under discussion with the regulators is how efficacy of the drug is measured, because the traditional methodology, using a process called RECIST v1.1, does not work well for EHE. The EMA and FDA are receptive to looking at other measures, and the team at Istituto Nazionale dei Tumori (INT) in Milan have been doing some amazing work, developing these new ideas.



There is still a lot of work to do, but everybody was thrilled when it was announced this quarter that the team at INT have had their submission accepted for ORAL PRESENTATION at the prestigious CTOS 2024 Annual Meeting which will be held in San Diego, California, in November. Their paper is entitled: REDEFINING RADIOLOGIC RESPONSE IN EPITHELIOID HEMANGIOENDOTHELIOMA: BEYOND RECIST?

It really is wonderful to see EHE being the focus of a presentation at this prestigious gathering of many of the world's top sarcoma experts. EHE is definitely "on the map", and that is very largely due to the hard work and support of so many people on the EHE Support Groups Facebook page and our EHE Group foundations. It's your data, your energy, your drive, and your commitment to the creation of a global research-ready EHE patient community that is being noticed and driving change and progress in EHE.

The EHE patient community has also been able to add important data to this discussion, with its survey of EH patients globally helping to provide further evidence of the beneficial effects of sirolimus, as explained by Hugh Leonard:

**“The EHE Group survey of our global patient community collated the experiences from 129 patients, 32 of whom were non-liver-transplant patients that had experience of treatment with sirolimus. This enabled us to present important results confirming that at the time of the survey, 20 of the 32 patients (63%) were still on the drug. Of these 32 patients, 21 of the 32 (66%) had been on the drug for one year or longer (one had subsequently stopped taking the drug), with notably 5 of the 32 (16%) having been on the drug for 5 or more years. These results were all included in a paper published on 26th February in Frontiers in Oncology, a prestigious, peer-reviewed scientific journal, and entitled **The patient perspective on sirolimus for epithelioid hemangioendothelioma (EHE): results of a community survey highlighting the importance of equitable access to treatments.**”**

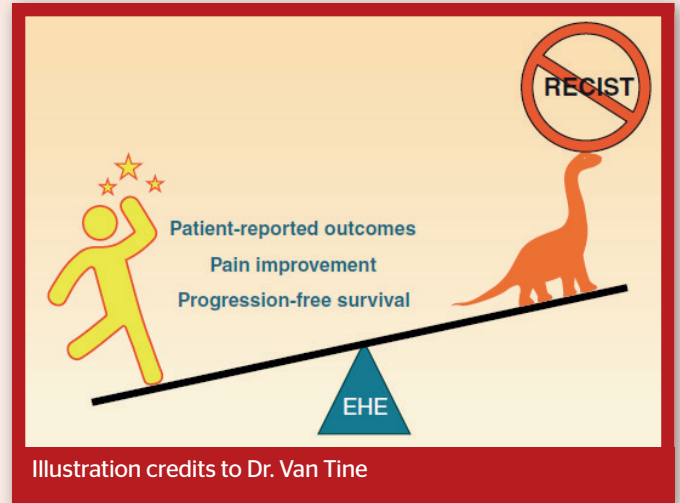


The discourse with the EMA, who have been clear that additional data will be required, is ongoing, and it was agreed that a further round of Scientific Advice had been approved, allowing the applicant group led by Dr Stacchiotti to modify and update its Scientific Advice submission, including revised data generation plans. This was submitted in early July, and at the end of the third quarter, the EMA had provided a list of further questions that needed to be addressed. Discussions with the EMA are ongoing after which the final application for Scientific Advice will be submitted later in the year.

The EHE applicant group hope that reasonable progress can be made and that they will be able to provide a positive update in early 2025.

Here at **The Pledge**, we also want to thank the INT team for their hard work and dedication, and CTOS for accepting their submission. Progress also needs the energy and commitment of these clinical and research experts to produce the results that are taking us forward, so we could not be more grateful for their unbelievable work. ■

## Thank you, Dr. Van Tine!



The challenges of using RECIST to assess drug efficacy in rare sarcomas, like EHE, has been previously described in past editions of **The Pledge**. The EHE Group were grateful therefore to Dr. Brian Van Tine, MD, PhD, Washington University, for sharing his commentary on the same subject in his paper ‘**Is It Time to Resist Using RECIST as a Primary Endpoint for Rare Tumor Trials?**’ Dr Van Tine appropriately cited the recently published Phase 2 trial of Trametinib (Schuetze, et. al. Clin. Cancer Research 2024) where the investigation of Trametinib failed to meet its endpoint which relied on RECIST. Bravo, Dr. Van Tine for highlighting this challenge.

To see a highlight of Dr. Van Tine’s publication please go to:

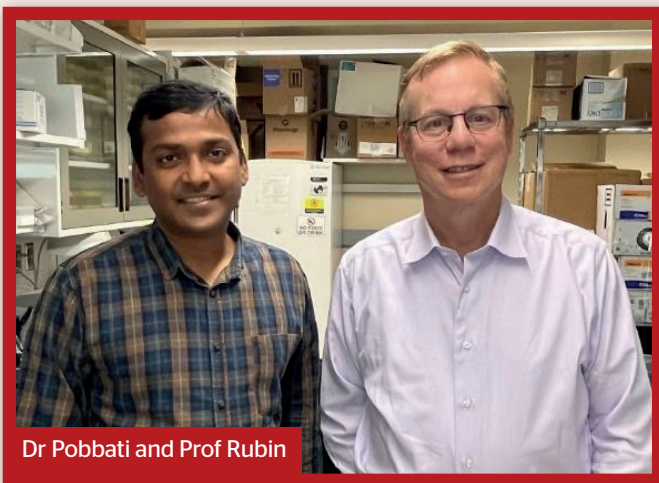
<https://aacrjournals.org/clincancerres/article-abstract/30/20/4552/748819/Is-It-Time-to-Resist-Using-RECIST-as-a-Primary?redirectedFrom=fulltext>



# 02 EHE Research

## CDK Inhibitors look exciting!

Ajay Pobbati, PhD, Brian Rubin, MD, PhD, and colleagues at the Cleveland Clinic were delighted to see their findings from the study whose thesis was “**CDK9 inhibition by dinaciclib is a therapeutic vulnerability in epithelioid hemangioendothelioma**” published in *Clinical Cancer Research* in September. This study, funded in part by a grant from The EHE Foundation, set out to evaluate the harnessing of cyclin-dependent kinase inhibitors to gain mechanistic insight into the regulation of the TAZ-CAMTA1 fusion protein. Results provide a strong rationale for investigating dinaciclib, a cyclin-dependent kinase (CDK) inhibitor, as a potential therapeutic candidate for the treatment of aggressive EHE.



Dr Pobbati and Prof Rubin

The publication discusses the anti-tumorigenic properties of dinaciclib demonstrated in *in vitro* and *in vivo* EHE models. Findings from the study include the following:

1. Dinaciclib facilitates TAZ-CAMTA1 (TC) degradation by inhibiting CDK9, a transcriptional CDK.
2. Dinaciclib treatment mobilizes TC, which allows it to shuttle between the nucleus and cytoplasm and is eventually degraded by proteasomes.
3. This process suppresses the levels of TC-regulated transcripts and cell viability, promotes apoptosis, and reduces the area of metastatic lesions.

Dinaciclib is already FDA-approved for use in combination therapy to treat hormone-receptor-positive breast cancer and has been granted orphan drug status for chronic lymphoblastic leukemia (CLL). It is currently being studied in clinical trials for other various cancers.

Denise Robinson, Executive and Research Director of the EHE Foundation said:

**“This study and these findings importantly build on a small seed grant given from The EHE Foundation in 2022 for a study that aimed to identify FDA-approved drugs for the treatment of EHE. This study identified CDK inhibitors as regulators of TC location and stability and has identified a potentially exciting therapeutic target. The EHE Foundation is grateful to Dr. Pobbati, Dr. Rubin, Dr. Nancy Wang, and colleagues in the Rubin Lab at the Cleveland Clinic for their commitment to EHE research and for publishing these findings.”**

The Pledge would also like to thank the Cleveland Clinic team for their ongoing work and focus on EHE, and to wish them ongoing success with all aspects of their EHE research. ■

## Quality of Life Study

To better support drug development and improve overall outcomes for people diagnosed with EHE, the European Organization for Research and Treatment of Cancer (EORTC) has been conducting an international study on Quality of Life (QoL) in people with rare cancers, including EHE. The EHE Foundation, on behalf of the EHE Group, engaged with EORTC to enrol EHE patients in this study, as Denise Robinson explained:

**“The EHE Foundation has been working to enrol people with EHE in this quality-of-life study. This is an easy way for patients to help with EHE research from the comfort of their own homes! The overall objective of the study is to develop a document that can be used to help measure the quality of life in EHE patients, and which can then be used also to assess the impact of a specific drug on such patients. While QoL assessment will never be sufficient on its own to justify drug approvals, the reality with ultra-rare diseases is that all evidence is important, and for this reason, this study is important, and one that the Foundation wanted to support. As always, the EHE patient community was keen to help, and were able to provide EORTC with the EHE participants they needed, another excellent example of how patient involvement is so important to our overall EHE objectives. We want therefore to thank all those who took part in this important study.”**

This is an important effort and collaboration of the EHE Group aligning with ongoing efforts to work with regulators to look at repurposing drugs, specifically sirolimus for the treatment of EHE, as well as novel drugs for ultra-rare sarcomas. In repurposing drugs or efforts to get a new investigational drug into review, the issue of establishing the efficacy of a drug has arisen because standard forms of measuring drug impact in cancers, importantly EHE, are inadequate.



Regulators rely on a standard named RECTIST v1.1, which often does not show disease control by a drug in EHE.

We are grateful to the EORTC for undertaking the development of a standardised instrument that can be used to objectively assess the change in symptoms experienced by the patient, measuring the effect on the QoL of those taking a drug, or during active surveillance. QoL assessment is an established and recognised process in the clinical and research world. The EHE Group completed such a survey of QoL for EHE patients in 2019, led by Dr. Marije Weidema from the Rebound University in Holland, but this assessment was of the disease generally, and not undertaken with specific reference to treatment outcomes or a specific drug. (The published paper for this assessment can be found in the EHE Library on The EHE Foundation website or at <https://www.tandfonline.com/doi/full/10.1080/0284186X.2020.1766696> ). ■





# 02 EHE Research

## GDF results published

The EHE Group were thrilled to see the excellent research paper entitled "**GDF-15 predicts epithelioid hemangioendothelioma aggressiveness and is down-regulated by sirolimus through ATF4/ATF5 suppression**" published in Clinical Cancer Research. This research, undertaken by Sandro Pasquali, MD, Nadia Zaffaroni, PhD, and colleagues at Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, and Dr Paul Huang and colleagues at the Institute of Cancer Research (ICR) was part of the broader EHE research collaboration between INT and the (ICR) in London, funded by The EHE Rare Cancer Charity UK and The EHE Foundation. Dr Silvia Stacchiotti (INT) and Professor Robin Joines (Royal Marsden Hospital) were reciprocal PIs for this research.



Dr Pasquali and Dr Zaffaroni reviewing research results with the EHE Group

This groundbreaking research demonstrates that EHE cells produce and secrete GDF-15 and that sirolimus modulates the secretion. In patients, GDF-15 can potentially serve as a predictive marker for EHE progression and holds implications for monitoring the effectiveness of treatment with sirolimus. Questions have also been raised as to whether GDF-15 may also be playing an active role in the ongoing progression of EHE and its symptoms, something that both The EHE Rare Cancer Charity and The EHE Foundation hope will be the subject of new GDF-15 research in the new year.

If you want to read the paper, you can find it at <https://pubmed.ncbi.nlm.nih.gov/39283723/> or in the EHE Library on The EHE Foundation website at <https://fightehe.org/ehe-library/>. ■

## Push Platform continues to grow



Earlier this year, we reported on new infrastructure called the PUSH Platform (**P**ushing **U**ltra-rare **S**arcomas beyond **H**ope). This platform is being developed to help address the significant challenges that patients, clinicians and researchers of ultra-rare sarcomas face, such as:

- Having minimal data on the natural history of their disease;
- An acute lack of research funding to comprehensively study ultra-rare diseases;
- Few if any defined treatment options; in EHE there are no disease-specific approved systemic treatments
- Major hurdles to, and in most cases the impossibility of, designing and performing large, randomised clinical trials within a reasonable timeframe and cost due to the extreme rarity of patient populations
- Difficulties in drug development and access due to low interest from commercial drug developers and their perception of high costs and risk of failure when engaging with regulators.

As previously reported, it is ultimately hoped that a significant number of institutes and academic centres across the globe will join the project, forming the PUSH Consortium, giving the PUSH Platform real momentum and an ability to change the landscape for ultra-rare sarcomas. This will include collating relevant prospective and retrospective data from substantial numbers of patients from around the world, including real-world data from patient registries such as the EHE Global Patient Registry.

PUSH will incorporate data from a large range of different sources that will in turn be used, with regulatory involvement and input, to define and undertake appropriate new prospective studies and associated analyses to help deliver new treatments for patients in faster, lower-risk, well understood and defined processes. PUSH is designed to also include prospective clinical trials.

The first two sarcomas to be included were EHE and Chordoma. Two additional multi-centred disease studies have now been added this year: for Low Grade Fibromyxoid Sarcoma/Sclerosing Epithelioid Fibrosarcoma (LGFMS/ SEF); and for Adult-type Rhabdomyosarcoma (RMS).

The PUSH Platform is also a component of the ongoing discussions with the EMA and the FDA concerning the processes and procedures relating to drug approvals for ultra-rare sarcomas, as a template for many ultra-rare diseases. There is recognition that changes need to be made to reduce the time, risk and costs of such processes, and so encourage pharma involvement in the development of such drugs.

There is also a recognition that many patients of such diseases face very significant unmet needs in terms of the availability of effective treatments. This is particularly important when considering cases of repurposing of drugs, where traditionally preferred evidence such as randomised trials may not be available or feasible in ultra-rare diseases, yet significant bodies of data of other forms may exist supporting the approval of the drug.

So a huge amount of work is ongoing, as Hugh Leonard from the EHE Rare Cancer Charity and Denise Robinson from the EHE Foundation, both of whom are members of the PUSH Executive Committee, explained:

**“Establishing major new infrastructure like PUSH takes a huge amount of work, focus and determination. Multiple working groups have been established looking at a wide range of relevant issues, such as data collection, legal issues, operational management, trial protocols, translational research and regulatory/pharma liaison. Right at the moment a key area of focus is how we resource and run PUSH to ensure that the daily operation and administration of the platform is fully covered, effective and efficient. Exciting discussions are underway and we hope we can report further on these in the coming months.”**

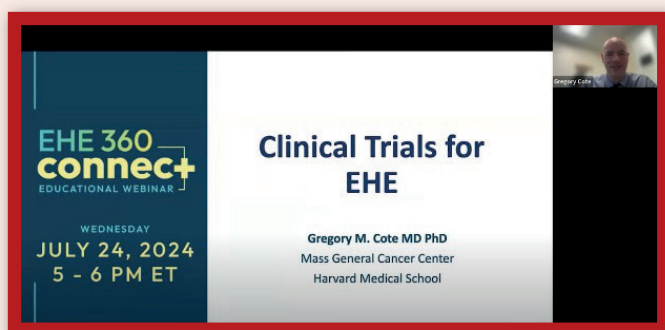
We look forward to further updates in the future and will make sure these are included in future editions of **The Pledge**. For those who want to read more about the objectives of the PUSH Platform, please go to the PUSH website at <http://www.push-platform.org/> ■



# 02 EHE Research

## Clinical Trials for EHE

An ongoing challenge for our patient community is keeping abreast of the clinical trials that are investigating treatments for EHE, the locations where these trials are being conducted, and the entry criteria. This was recognised by Dr. Cote as a significant challenge for patients during the **EHE 360 Connect** webinar given by Dr. Cote on the subject of clinical trials, and as reported in the Patient Support and Advocacy section of this edition of **The Pledge**.



The EHE Foundation works with each of the trial sponsors to ensure the EHE community is actively involved in drug development, and it maintains a list of clinical trials for EHE on its website at <https://fightehe.org/ehe-clinical-trials/>. The list continues to be updated including new TEAD inhibitors entering first-in-human trials. As more information is made available by drug companies, The EHE Foundation will keep patients updated through all communication channels.

To reiterate a key goal of the EHE Global Patient Registry, this valuable resource is intended to be used to help identify clinical trial participants if patients join and are interested in learning about relevant research opportunities. Join here if you haven't already: <https://eheregistry.iamrare.org/>.

We are grateful to all patients and the doctors who participate in these trials, which ultimately aim to provide better treatments of EHE. ■

## New Clinical Trial Open for EHE

The EHE Foundation posted news that Vivace Therapeutics, Inc. is expanding its Phase I study of VT3989, a first-in-class TEAD Inhibitor, to include patients with EHE. This development brings a new therapeutic opportunity to EHE patients where no proven systemic drugs exist. Patients are encouraged to review the clinical trial information and consult with their care team, or other trusted partners in their care journey, regarding this trial.

The study is open at multiple US locations and in Australia; however, not all locations include EHE participants. The sites currently open to EHE patients include:

- Memorial Sloan Kettering, New York, NY
- MD Anderson Cancer Center, Houston, TX
- Dana Farber Cancer Center, Boston, MA
- Mass General Hospital, Boston, MA

Denise Robinson explained:

**“This is an exciting development for a potential new treatment for EHE. Patient participation is limited in Phase I studies, which primarily tests safety of a new drug, and may also help understand the drug’s side effects and determine the best dose. To learn more about clinical trials please visit The EHE Foundation website <https://fightehe.org/ehe-clinical-trials/> where you can find an updated list of clinical trials. In addition, for those who are interested, you will also find on the EHE Foundation’s website a recording of Dr. Greg Cote’s excellent EHE 360 Connect presentation about clinical trials and will be able to listen to the excellent question and answer session that followed his presentation.”**

More information about this Vivace study can be found at:

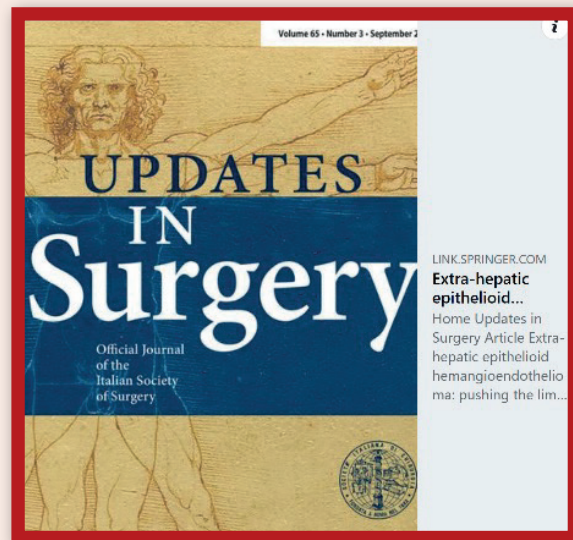
<https://clinicaltrials.gov/study/NCT04665206>:

while information about Vivace Therapeutics' initial phase 1 trial can be seen at:

<https://www.prnewswire.com/news-releases/researchers-report-clinical-proof-of-concept-data-for-vivace-therapeutics-vt3989-a-first-for-a-cancer-drug-targeting-the-hippo-pathway-in-oral-presentation-at-aacr-2023-301798333.html> ■

## An important paper!

Jane Gutkovich, Board Member Emeritus of The EHE Foundation, posted news of an important new paper concerning the use of sirolimus by patients with an upcoming liver transplant. Jane explained:



“Here is the first published paper discussing the utilization of Sirolimus PRIOR to liver transplantation, especially in patients with extra hepatic EHE involvement. This question comes up all the time: **‘Should EHE patients waiting for a liver transplant start sirolimus PRIOR to receiving their new liver?’** The clinical rationale behind using the drug, before the transplant, is to keep EHE under control while waiting and possibly to prevent recurrence (or progression in other organs) after the transplant. This is a rather small study demonstrating that this approach CAN be used. Many doctors have been hesitant because there is no published evidence. So here is the first such publication!”

The publication has a limited access. Please contact your local EHE foundation if you want information about how to access the paper. ■



# 02 EHE Research

## How you can help find a cure for EHE Registries!

A critical component of the overall research program for any cancer is gathering data from patients about all aspects of their cancer journey. By collating, analysing and presenting this data, patients, clinicians and researchers can begin to understand the biology of the disease, and through that process, begin to identify possible strategies for delivering better and more effective treatments

**If you are an EHE patient, please, please join the EHE Global Registry and make sure your information is helping to find a cure.**

**You can find the registry at:  
<https://eheregistry.iamrare.org>**





**Biobanking!**

Access to biological samples is also a critical component of EHE research initiatives. Tissue, fluid and blood samples provide researchers with critical access to actual EHE biological specimens that allow researchers to investigate and understand the natural history and development of EHE; investigate new hypotheses; and develop and test both new and existing drugs to see if they will help combat the disease. The EHE Group has established dedicated EHE biobanks in both the USA and the UK, and has agreed biobanking capabilities in Australia and Canada.

Today, EHE biospecimens donated by the EHE patient community are helping drive critical research:

1. EHE tumor samples are being used to deliver EHE human cell lines that will assist in the evaluation of drugs to combat EHE;
2. Tissue and blood samples have helped to identify and validate a likely biomarker of EHE.

**If you are an EHE patient, please, please support EHE biobanking and make sure your samples are helping to drive EHE research.**

If you need help or further information on the EHE Global Patient Registry or on how to access biobanking for your samples, please contact any member of the EHE Group or visit any of the EHE Group websites. ■



# 03 EHE Fundraising

**Fundraising is the lifeblood of all not-for-profit organisations without which other activities could not take place.**

It is for this reason that we are especially grateful for the amazing effort, organisation and generosity that have all been required to enable us to raise the funds needed to drive EHE research. Here are highlights of some of the fundraising undertaken by our supporters this quarter. Whether you are a fundraiser, a donor, or a supporter, we want you to know that we are deeply grateful for all you have done.



## Michelle Hughes hosts another huge event



Michelle Hughes celebrated the third year of her 'thrivership' on 25th August 2025. To celebrate properly Michelle wanted to raise funds for EHE research, and so set about organising her **Just Live** Fun Run. Michelle explained:

“Hey everyone! My **Just Live** Fun Run has close to 1,500 people registered and I'm super excited to see our **Just Live** motto being shared around the world! We have race kits going to Australia, Africa, Europe, across the US and Canada! We are mailing out Virtual Kits which include race bib and medals, Race shirts are extra. All proceeds are going to the Sarcoma Cancer Foundation of Canada where they are being matched and allocated to the PRO care EHE Research Team here in Canada!”

Michelle posted photos of her brilliantly vibrant shirts, medals and bibs! She has also signed a deal with Asics who would be giving everyone registered a free running program with their Run Keeper app.

Michelle continued:

“We receive direct donations on the race site and already \$20k has been donated to Research before the event even starts!! Our big day here in Prince Edwards Island, Canada is Aug 25th to celebrate my 3 year thrivership living with EHE.”



# 03 EHE Fundraising

And what an event it was, as Michelle explained:

“Donors, sponsors, in-kind contributions, purchases, shares, and a simple like of a post. It all mattered. Each and every one of you contributed, and I’m so darn grateful. Together we raised \$54,000 for the Sarcoma Cancer Foundation of Canada which was allocated to the Pro Care EHE Research team at the Princess Margaret Cancer Center. But what makes it even more special, is the Sarcoma Foundation of Canada matched it! Every dollar. So incredible. I never expected this. We had race kits sent all around the world! Wow, over 2,000 people who came out to participate. Thank you. Truly, thank you!”



We want to congratulate Michelle on organising such an amazing event, and also thank every single person who participated or donated funds to this fabulous cause, helping to deliver such a huge result. ■

## Erika and Gianluca's Wonderful Gesture

On July 19, 2024, Erika and Gianluca celebrated their wedding, a wonderful day that marked their love for each other.



On this special occasion, they also decided to think of EHE ITALIA, donating the expense of the wedding favors to the association with a generous donation of €600.

EHE ITALIA were thrilled, as Caterina Colaci explained:

“We were thrilled to know that Erika and Gianluca were getting married, and when they informed us that they wanted to make this gesture, we were deeply moved by their generosity and support for our cause. We are immensely grateful that Erika and Gianluca have made us a part of their great love. We wish them a life full of love and happiness!”

We at **The Pledge** want to add our voices to Caterina’s sentiments and wishes of love and happiness, and to thank Erika and Gianluca for such a lovely and thoughtful gesture. **Just Live.** ■

## ‘Make an Impact’ with a ‘Circle of Friends’

The EHE Group, including all the EHE foundations and the global EHE Facebook community, has at the core of its activities the ultimate goal of finding a cure for EHE, and if not a cure, the therapeutic means to stabilise and manage the disease on a long term basis. Research being funded by the EHE Group is producing exciting results in a number of areas, with an understanding of EHE biology continuing to develop. Progress for such a rare sarcoma has been extraordinary, but there is still a huge amount that needs to be done, as each successful piece of research leads to several new questions and a resultant need for further research and funding to answer them. This lies at the centre of the group’s battle cry, often quoted in this newsletter:

### Raise the Funds; Drive the Research; Find the Cure!

Raising this critically-needed EHE research funding is also a core objective of the EHE Group, and was at the centre of two powerful fundraising campaigns launched by The EHE Foundation in the USA.

The first of these is the ‘**Make an Impact**’ campaign, encouraging supporters to make a donation, and thus an impact on The EHE Foundation’s ability to deliver EHE research. This was amplified in the message from Jenni Kovach, President of The EHE Foundation:

“For people diagnosed with EHE, an ultra-rare cancer, there is an urgent need to find effective treatments. The EHE Foundation is advancing scientific research to accelerate the development of treatments and improve outcomes for everyone living with EHE. Help us keep our foot on the gas! Make an impact with your gift today.”



The second initiative is The EHE Foundation’s ‘**Circle of Friends**’ campaign. It is recognised that regular giving, usually monthly, is one of the best ways for foundations and charities to receive donations, providing a steady and predictable income for their ongoing fundraising and activities.





# 03 EHE Fundraising

## MONTHLY GIFTS ARE SUSTAINING

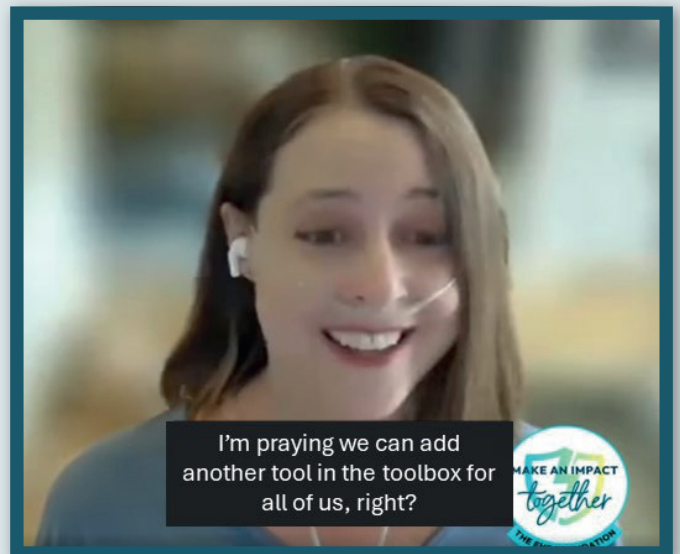
Monthly gifts sustain the work it takes to facilitate critical research, develop impactful patient educational programming, and advocate for people living with EHE.

Julie Wahl, Board Member Emeritus & Finance Manager of the Foundation explained:

“Recurring gifts, providing reliable and sustained income that we know will be there, help us to deliver ground-breaking research, strengthen patient advocacy, and inspire educational programs. This funding ensures that we can continue to provide hope for people living with EHE. We call this our EHE ‘Circle of Friends’ and hope that more of our supporters will make recurring donations, and if they can, encourage someone else to give too.”

Of course, fundraising campaigns such as these need to be promoted and the background and context of the cause need to be explained. The most powerful way to do this is for EHE patients themselves to tell their stories, although this can be very difficult indeed for individuals, for obvious reasons. The global EHE community could not be more grateful therefore when patients agree to openly and honestly share their stories, especially when this is in the form of a video recording.

The EHE Foundation’s ‘Make an Impact’ and ‘Circle of Friends’ campaigns were both supported and hugely enhanced by Amy Baghdadi’s recording of her EHE journey to date. We know we speak for the global community in thanking Amy for having the bravery and the compassion to tell her story with such eloquence and honesty. Thank you, Amy.



And the need for this support is hard to overstate, as Denise Robinson, Executive Director and Director of Research at the EHE Foundation explains:

**“There is real momentum in the science of epithelioid hemangioendothelioma (EHE)! And, patients like Amy are looking for another tool in the EHE toolbox. To achieve the breakthroughs that patients need, we need to harness the momentum we see in the scientific community by funding critical research projects that pave the way to approved treatments for EHE. Please help us.”**

If you want to support The EHE Foundation’s campaigns, you can do so using the links below. These are of course US-based campaigns. However, the benefit of such campaigns also applies to the EHE entities in Canada, UK, Italy, and Australia. If you would like to make such donations to these entities, with the associated tax benefits, please contact the EHE entity that is most local to your country of residence.

And here are the links if you want to support either of The EHE Foundation’s campaigns;

**Make an Impact:**

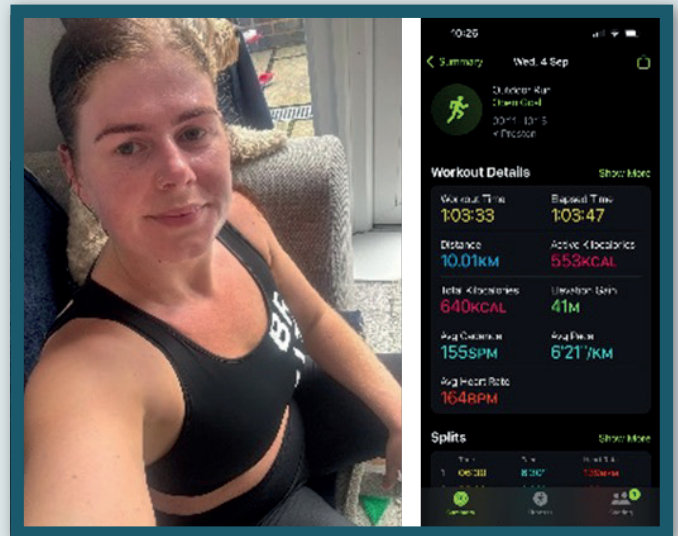
<https://bit.ly/make-an-impact-together>

**Circle of Friends:**

<https://fightehe.org/circle-of-friends/> ■

## Running for Emma

In the Patient Support and Advocacy section of this edition of **The Pledge**, we reported on how twin sisters, Kym and Emma, had used Emma’s story to raise awareness of EHE following Emma’s diagnosis with EHE.



But raising awareness was not all Kym was determined to do. In addition to all she is doing to help Emma, Kym will also be taking on the Lancashire Loop Trail Run in late November, to help raise funds for EHE research, by supporting the EHE Rare Cancer Charity UK. Her Go-Fun-Me page has raised more than £10,000 which is an extraordinary achievement. Emma and Kym are so grateful for the tremendous support they have received, as Emma explained:

**“It’s been so wonderfully overwhelming how generous and kind people have been, everyone just wants to help, my work, small businesses, family and friends. People really have come together for me.”**





## 03 EHE Fundraising

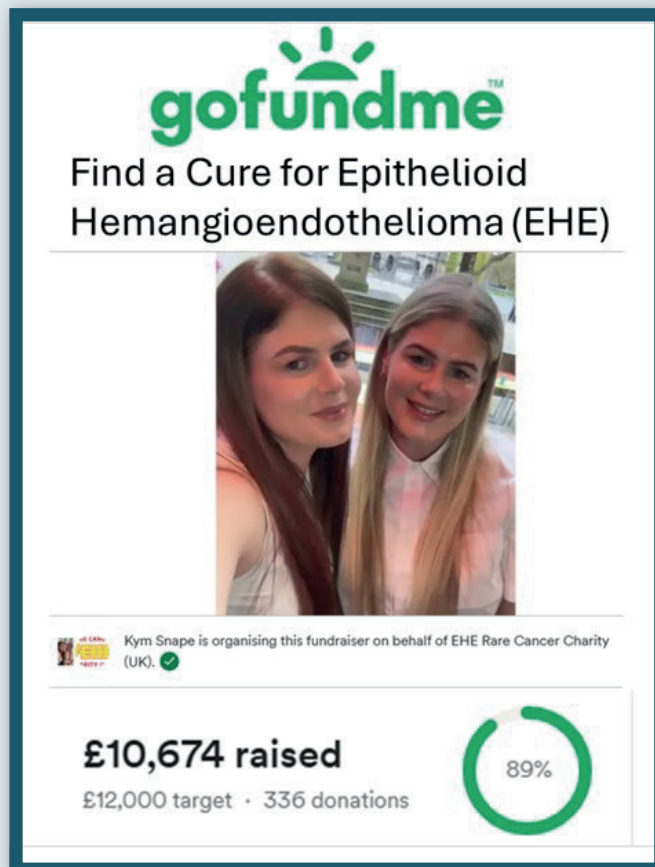
For Kym, of course, it is all about supporting her sister:

“This morning I ran my first 10km since before I had my two boys! I’m happy with the time considering I only started running a few weeks ago. Anyway, it’s not about my timings, it’s about raising money in support of my wonderful sister.

So far, together we’ve raised nearly £10,000!! And here is what this money can fund:

1. Cover all costs in collecting samples in the biobank for over 12 months; or
2. Cover 8 months of the costs of the EHE tissue manager at the Royal Marsden Hospital (specialist hospital for cancer); or
3. The testing of GDF 15 biomarker levels in multiple EHE patient blood samples.

All funds we raise will contribute to ongoing EHE research, and because the charity is entirely run by volunteers, with their charity costs funded by a single donor, every penny they receive from us will be spent on research! The EHE charity and support groups have supported me so much since Emma’s diagnosis. Everything I’ve learned from them I’ve been able to use to help Emma in some way. Thank you to all those who’ve donated and supported the cause thus far. Please continue to share and support where possible. Emma may be one person, but to us she’s our world.”



Hugh Leonard from the Charity wanted to thank both Kym and Emma for all they have and are doing:

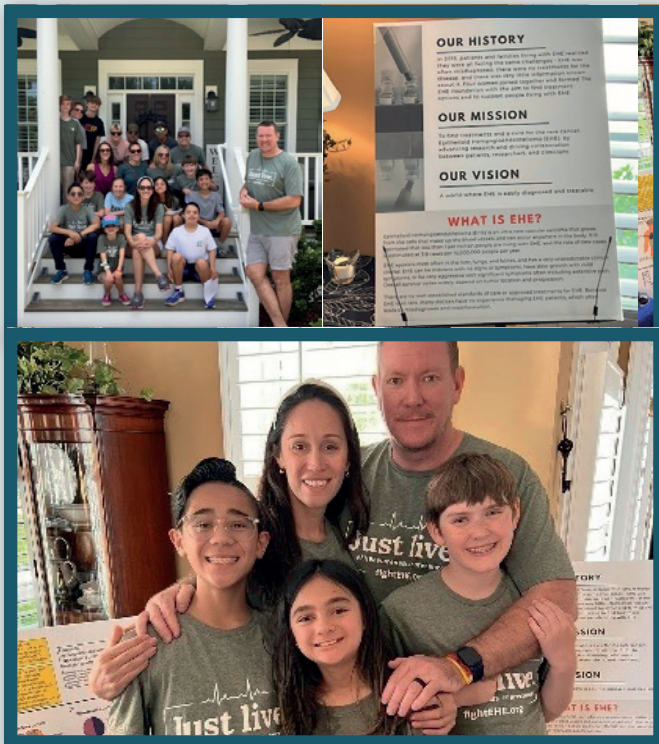
“We could not be more grateful to Kym and Emma for doing so much to raise research funding, on top of everything else that Emma, in particular, is facing. 100% of the funds that Kym has raised will go to fund EHE research.”

If any of our readers want to support Kym’s Go Fund Me page, you can find it at:

<https://www.gofundme.com/f/find-a-cure-for-epithelioid-hemangioendothelioma-ehe> ■

## Bright by name and Bright by nature

One of the frequent contributors to the EHE Patient Support Facebook page, and Treasurer for The EHE Foundation, is Sarah Bright. Her posts are inspiring and often full of great photos of herself, her family, and the activities they are undertaking to support the EHE cause. There are always lots of smiles! July was no different with Sarah posting news and photos of her ‘mini’ walk supporting the Foundation’s 2025 Fun Run and Walk.



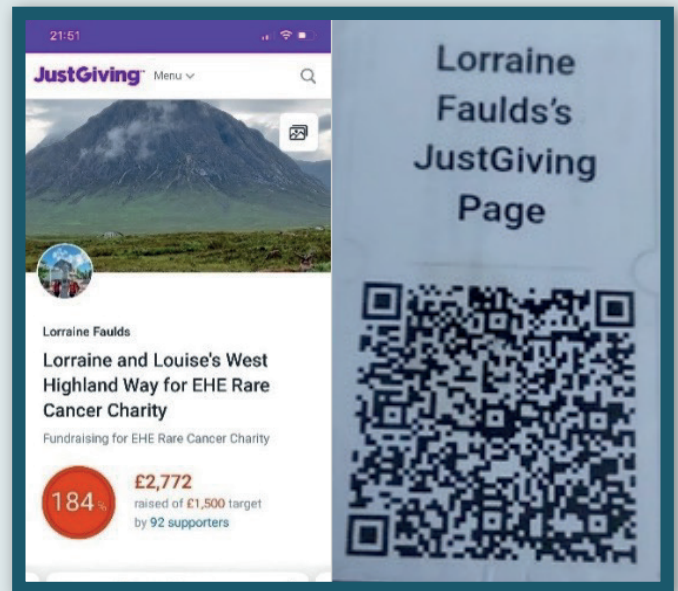
“Hello EHE Warriors! I don’t believe I posted pictures of our little mini walk we did in our neighborhood back in June. Gathering folks together like this makes me feel hopeful for research and so very loved in living with this disease. May each one of you feel love from your people and from this community. This disease can discourage and isolate us as so few understand, but we are not alone. We are ALL in this together!”

We love your words, Sarah. Thank you for your continued contributions and positive energy for this community. ■

## Lorraine goes high tech

In our last edition of **The Pledge**, we reported on Lorraine, and her daughter Louise, wanting to help, and so they decided to get walking, taking on a 96 mile trek from Milngavie, Glasgow to Fort William. Lorraine wanted to raise funds for EHE research as her mother, an EHE patient, sadly passed away.

Lorraine explained:



“Raising awareness and money for EHE was something we felt we could and wanted to do to help combat this horrible disease. I know that my wonderful mother would want us to do this, and she would have been cheering us on.”





# 03 EHE Fundraising



In describing their walk, Lorraine also explained how they had used technology to help raise funds:

“We wanted to try and collect funds during our walk, as we felt we would have the chance to meet many other walkers and with our EHERCC t-shirts on, we felt there might be interest in, and an opportunity to talk about, EHE. We also are aware that a lot of people don't carry cash around these days, so we decided to set up and carry a QR code so that if people asked we could show them the code and link them straight to our fundraising page. And it did work, helping us raise £2,772 for EHE research!”

We love this idea, Lorraine, and the fact that lots of walkers between Milngavie and Fort William started their walk having never heard of EHE and finished with just a little more awareness of the challenges faced by patients with ultra-rare diseases. ■

## Judith organises participation at Edinburgh Shine



Judith Gordon and friends participated in the Edinburgh Shine night in September, and were joined by Lorraine Foulds, as Judith explained:

“Here we are having a ball doing the Edinburgh Shine night, raising funds and attention for EHE and enjoying the clear night and good vibes while doing that.”



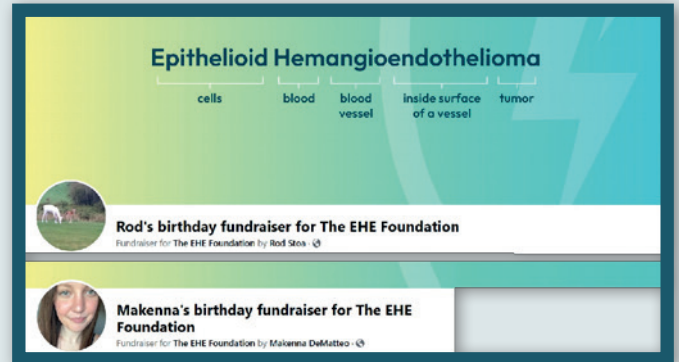


Lorraine echoed Judith's comments:

**“Our attendance was all instigated by Judith. It was good to catch up with her and hear her good news.”**

It appears it was a great night, and we loved the fact that Lorraine and Judith got together. Huge thanks to them for spreading awareness and for raising funds for EHE research. ■

## Birthday Fundraisers for The EHE Foundation



The EHE Foundation was thrilled to see some of its supporters running **‘Birthday Fundraisers’** to help raise funds for EHE research during the third quarter. Rod Stoa and Makenna DeMatteo were just two examples. Maggie Cameron, Director of Development & Communications at The EHE Foundation, wanted to express The Foundation’s gratitude to both Rod and Makenna, for their wonderful support:

**“Thank you to Rod and McKenna for supporting The EHE Foundation with your Facebook birthday fundraisers! Your generosity and compassion are helping fund crucial research and bring hope to those living with EHE. We are so grateful for your kindness and commitment to the EHE community. Happy Birthday to you both.”** ■

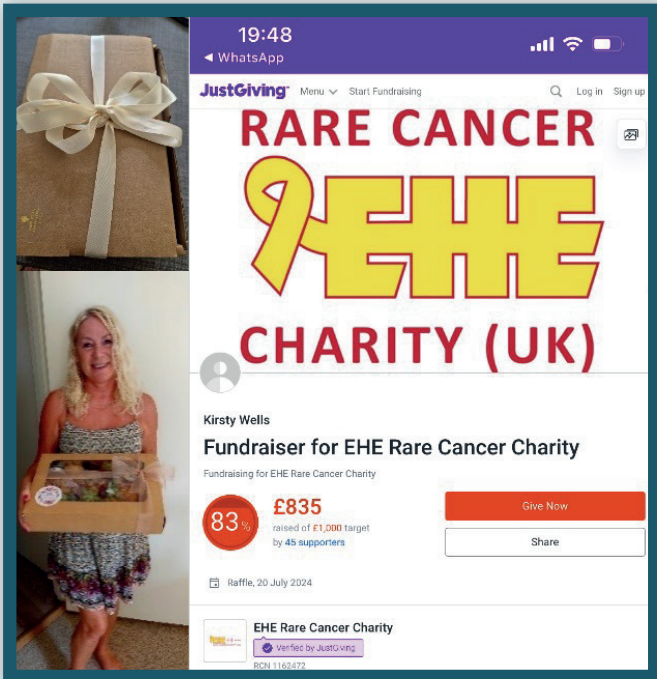


# 03 EHE Fundraising

## The Payne family raffle

Isolde (Issy) Payne is an EHE patient who lives in the UK. Issy and her two children, James and Kirsty, wanted to help raise funds for EHE research, and came up with the idea of holding an online raffle. As is often the case, the family were amazed at the generosity of so many people, both donating the prizes and buying raffle tickets. Issy said:

“We were so grateful that people helped us raise over £800. Prize donations were fabulous and we could not have hoped for more in terms of people buying the raffle tickets. We also got to say thank you personally to those who picked up their prizes, as you can see in this photo.”



We love this story. Huge thanks to Issy, James and Kirsty for such a great event, and of course a huge thanks to the donors of the prizes and everybody who bought a ticket. ■

## Grant Award for The EHE Foundation



The EHE Foundation was honored to announce that they had been selected as a Global Advocate Grant Recipient of the 2024 #RAREis program from @Amgen. Denise Robinson explained:

“With the #RAREis Grant, we plan to build upon and expand our efforts in EHE patient education and advocacy as we work to address the needs of all those impacted by this disease.”

We want to congratulate The EHE Foundation for securing this prestigious award which is a testament to the dedication and effort of all those at The EHE Foundation. ■



## EHE ITALIA focuses on Sarcoma Awareness Month

EHE ITALIA wanted to remind everybody that July is recognised as Sarcoma Awareness Month. Sarcomas are a category of rare cancers that occur in connecting tissue and affect soft tissue and bone. While all sarcomas are rare, Epithelioid Hemangioendothelioma (EHE) is one of these that is ultra-rare, annually affecting about 4 people in every 10 million. Sarcoma Awareness Month is critical to encourage research given the reduced knowledge about these diseases.

One of the Italian EHE patients wanted to help and opened a fundraising campaign using PayPal, and managed to raise €300. Andrei Ivanescu, President of EHE ITALIA, was very grateful:

“We want to say a huge thankyou to the EHE patient who raised these funds. Sharing information through events and fundraising campaigns can make a big difference. These efforts not only provide financial support for research, but also an opportunity to engage the community and create a support network for patients and their families. With your support, we can change the lives of so many people!” ■

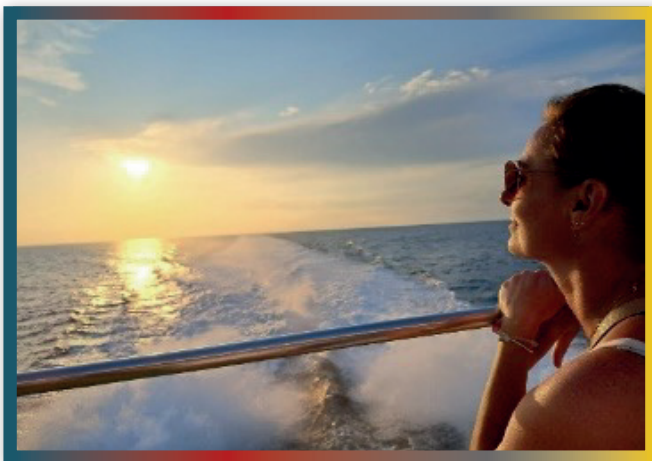


# 04 And in other news...

We love sharing a few examples of stories which we feel amplify the group's motto - ***Just Live*** - even if they don't relate to one of the main activity areas of the **EHE Group**. We hope you enjoy them too.

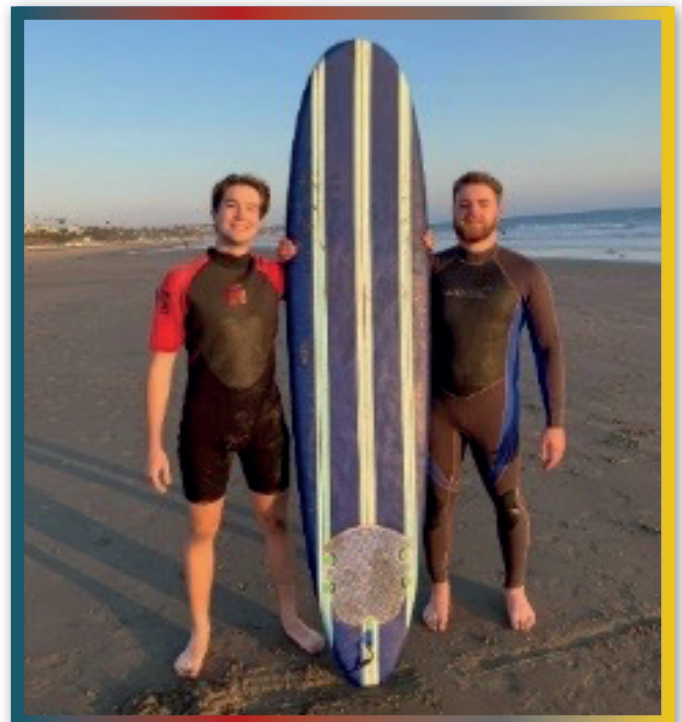
**Kim Delannoy** shared this photograph with the simple words:

“Enjoying the good life. #justlive” ■



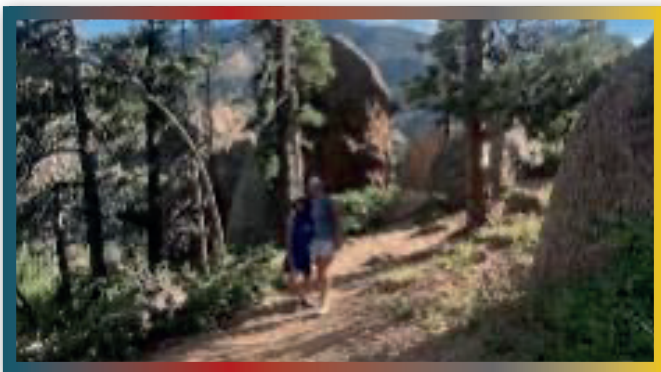
**Lael Bellamy** posted a photograph of her son, Foster, in California:

“Well, having not been feeling well, look who rebounded?! Foster is on the left. ***Just live!P***” ■



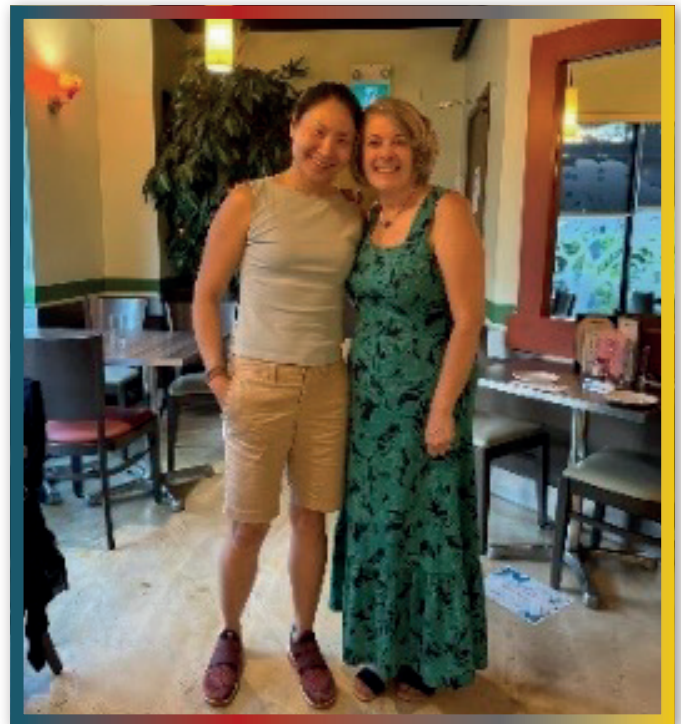
**Carl Dixon** was proving the medics wrong!

“Once again I had to prove the doctors and the statistics they have are not always correct. As I stated in a previous text last July 28th according to the statistics they had on hand I had a 13% chance of making it to this July so yesterday we celebrated once again how stubborn we are and how my family likes to go against the odds and ascended the Manitou Incline. It was a gorgeous day for the climb and here are some photos so you all can see the beauty we experienced firsthand.” ■



**Getting together.** We always love photos and stories of when members of the EHE patient community get together, Fiona Ross posted news of such an occasion:

“It is so special when we get to meet in person. Best wishes for your meeting tomorrow Ida Liu.” ■





# 04 And in other news...

**Kym Snape shares a poignant message.** Kym's twin sister is battling with EHE, so when this memory appeared in her social media, Kym wanted to share it with other patients:

“This popped into my memories today. It's never been more relevant for my sister and I imagine most of you guys!” ■

*for you*

This is for the ones who are struggling right now. This is for the ones who have been having a rough day or week or even year. The ones who feel like this storm will never end.

Keep fighting for *you*. Not for your friends, not for your family, but for *you*. Keep fighting because deep down you hold a tiny voice that knows you were meant for far more than this sadness and pain you are feeling. Keep fighting because the person you will be on the other side of all this is cheering for you so much. Keep fighting because you *will* get there. *And it will be worth it.*

- Nikki Banas | *Walk the Earth*

**Thank you to everybody  
for these lovely messages  
and photos.**

**It is wonderful to see  
members of our patient  
community living  
life to the full.**

**And always  
remember:**







**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-Associazione Non Solo Laura ODV**  
[www.ehe-italia.it](http://www.ehe-italia.it)

**EHE Canada**  
website not yet available