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
April – June 2025

the pledge

Edition 41

the pledge

Edition 41

Contents

Front cover: Team Holubowski gathering for the EHE Fun Run and Walk

Welcome

Celebrating 10 years!

We are thrilled once more to issue our latest edition (edition 41) of **The Pledge,** the quarterly newsletter of the global EHE community and the EHE not-for-profit organisations that work so tirelessly to represent them.

It is a true honour to document the activities of all those involved, especially as we celebrate ten years and share so many inspirational stories. We hope you will enjoy the many stories included in the following pages.. They are shining examples of the group's mantra:

"Alone we are RARE, but TOGETHER we are STRONG!!".

Just Live!

Highlights

EHE360 is another huge success!

The 2025 EHE360 Conference, hosted by the EHE Foundation for the global patient, clinician and research communities, was once again a massive success. Details can be found in our Patient Support & Advocacy. Video recordings of all sessions are also now available.

EHE represented at iDR25 repurposing conference

Hugh Leonard attended the important iDR25 repurposing conference in Amsterdam and was delighted to be able to speak about EHE and ultra rare sarcomas generally.

EHE Italia engages with Italian clinical community

EHE Italia Non Solo Laura participated in two important webinars. The first was with the Italian Sarcoma Group focused on ultra rare sarcomas. The second with the Italian Society of Pathological Anatomy was focused on improving diagnosis of EHE.

Michelle Hughes continues to drive EHE awareness and fundraising

Michelle Hughes took part in the HYROX Race in New York with her husband Ty, sponsored by Puma. This provided great exposure for EHE, with fundraising going to fund Canadian EHE research.

2025 Research Grants funding cycle launched

The EHE Foundation were thrilled to announce that their Grant round for 2025 was officially open. See our Research section for more details.

Grass roots fundraising continues to amaze us

Grass roots fundraising in all areas continued to generate substantial funding to drive EHE research.

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

Edition 41

the pledge

Just live

01

Patient Support and Advocacy

A key area of focus for all the EHE foundations and the global EHE patient community is patient support and advocacy. Most of the patient support is provided through the established EHE social media platforms by patients themselves, while advocacy activities are also undertaken by the EHE Group entities in their respective regions. The EHE community continues to work to create greater awareness of EHE, improve patient support for all patients, and promote and fund the research we need to defeat this disease. Updates and articles on The EHE Group’s activities in these key areas can be found on the following pages. We hope you find them inspiring.

EHE 360 Global Patient Conference - celebrating progress and hope

In April, the EHE Foundation hosted the 2025 EHE 360 Global Patient Conference. This was another superb EHE conference that brought together the global EHE community for learning, collaboration, and connection. Over 200 participants from a record 25 countries were united by a common mission to drive progress in EHE research, treatment, and patient care.

Held virtually, this two-day event emphasized patient and caregiver education, empowering individuals to become informed and active partners in their care journeys. Throughout the conference, an international panel of leading clinicians, researchers, and advocates shared the latest developments in EHE science, emerging treatments, cutting-edge research, and patient experience data. Their presentations left the community energized and optimistic about the strides being made toward effective therapies for this ultra-rare vascular cancer.

Highlights of the two days included the keynote address given by Dr. Brian Rubin entitled 'Reflection on 10 years of Discovery and Future Perspectives', helping the patient community not only understand how much has been achieved in the last ten years, but also how much research is taking place, giving real hope for the future.

2025 EHE 360 Global Patient Conference Welcome & Keynote

Brian Rubin, MD, PhD
Cleveland Clinic

KEYNOTE | Reflection on 10 Years of Discovery & Future Perspectives

As in previous years, the Conference provided insight into a number of diverse areas, including EHE biology and biomarkers; clinical trials; disease monitoring, addressing what is stable and what is progression; the role of patients in driving research; and different treatment options for hepatic EHE.

Ryan Kanai, PhD Candidate
ALBANY MEDICAL COLLEGE
AMP Kinase Represses EHE Cell Growth

Jason Hanna, PhD
PURDUE UNIVERSITY
Mechanisms and Mesenchymal Plasticity of EHE

EHE Biology & Biomarkers

FIGHTEHE.ORG
RECORDED
APRIL 10, 2025

THE EHE FOUNDATION PRESENTS
EHE 360
2025 GLOBAL
PATIENT CONFERENCE

Anna Maria Frezza, MD
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI DI MILANO
How Scans & Imaging Inform Treatment Decisions

Andrea Vanzulli, MD
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI DI MILANO
Assessing EHE Growth - Why We Need a Better Tool in Our Box

EHE Tumor Monitoring: What is Stable? What is Progression?

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APRIL 11, 2025

THE EHE FOUNDATION PRESENTS
EHE 360
2025 GLOBAL
PATIENT CONFERENCE

One of the favourite sessions for patients was once again the closing 'Ask the Expert' panel discussion, where a panel of EHE clinicians address a wide range of questions. 2025 did not disappoint with Drs. D'Amato, D'Angelo, Chen and Gupta answering questions submitted by the patient and patient advocacy community.

ASK THE EXPERT PANEL

Dr. Chen
Dr. D'Amato
Dr. D'Angelo
Dr. Gupta

FIGHTEHE.ORG
RECORDED
APRIL 11, 2025

THE EHE FOUNDATION PRESENTS
EHE 360
2025 GLOBAL
PATIENT CONFERENCE

The EHE Foundation extended their heartfelt thanks to the clinicians, researchers, and industry professionals and all other speakers, who contributed their time to be part of this important event. Sincere thanks was also extended to the event sponsors, Vivace Therapeutics and SpringWorks Therapeutics, who also helped make this conference possible.

Finally, perhaps the deepest gratitude was extended to the patients, caregivers, and EHE disease advocates, as it was their presence and engagement that once again made EHE 360 such a meaningful experience.

The EHE Foundation is rightfully proud to celebrate the success of the 2025 EHE 360 Global Patient Conference. Together, they are helping to bring forward a future where people living with EHE have more answers, better treatment options, and renewed hope.

This conference not only highlighted scientific and clinical advancements but also fostered a sense of connection and shared purpose, reminding everyone that while EHE is ultra-rare, no one faces it alone. At The Pledge, we want to add our thanks to everybody who contributed to the conference, and congratulate The EHE Foundation for the delivery of yet another superb event.

Conference Recordings Now Available!

The EHE Foundation is excited to announce that recordings from the 2025 EHE 360 Global Patient Conference are now available for viewing. Whether you attended the event and want to revisit your favorite sessions or missed the live conference, you can now access these essential discussions at your convenience at www.fightehe.org/ehe-360

Doctor-Patient collaboration for a better future

EHE Italia is an enthusiastic supporter of the Italian Sarcoma Group (ISG), organised to bring Italian sarcoma specialists in multiple disciplines together and provide a platform for collaboration, communication and experience sharing. At the start of April, ISG held their 2025 Annual Meeting and EHE Italia were thrilled to be able to participate as Andrei Ivanescu, President of EHE Italia, explained:

> **We had a special moment participating in the Annual Meeting of the Italian Sarcoma Group. An event that brings together over 200 experts from different fields each year, including researchers, clinicians, surgeons, orthopedics, radiologists and anatomopathologists, all united by a common goal: to update, compare and collaborate to improve the treatment of sarcomas and make a difference in the lives of patients.**
>
> **For the last two years, this important meeting has been expanded with a fundamentally important and new element, namely the participation of sarcoma Patient Associations, This unique meeting provides an opportunity to hear advances on specific histologies and to have a direct dialogue with specialists, combining human experiences with medical expertise.**

> Our Association had the honor of being present at this meeting, both during the Patient event, but also during the specialist sessions. We would like to express our gratitude to the ISG team for making our participation possible and to the doctors who, with dedication and openness, told us about EHE and the important achievements that are improving the future for all of us.
>
> With a heart full of hope and trust, let us continue to walk together on this road to progress.

EHE at IDR25 Medicines Reimagined

In early May, Hugh Leonard, the Chair of the EHE Rare Cancer Charity (UK) was delighted to attend the fast growing and powerful drug repurposing conference, iDR25, in the stunning Felix Meritis, Amsterdam!

As a global event, iDR25 Medicines Reimagined attracted even more drug repurposing enthusiasts than last year, bringing together over 300 key opinion leaders, researchers and patient advocates to collectively drive innovation for repurposing in Europe and beyond.

The conference featured four pathways delivered over two days:

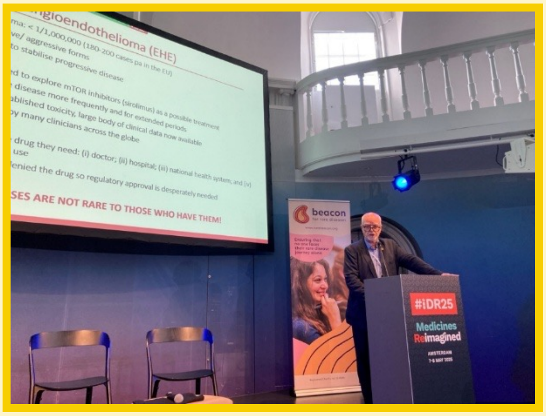
1. Repurposing for the under-served, including rare diseases, rare cancers, infectious diseases and paediatrics
2. Pathways for patient access
3. Innovative trial designs
4. AI in drug repurposing

Hugh Leonard was also delighted to have been invited to speak during the "Repurposing for the under-served, including rare diseases, rare cancers, infectious diseases and paediatrics" session on day 1.

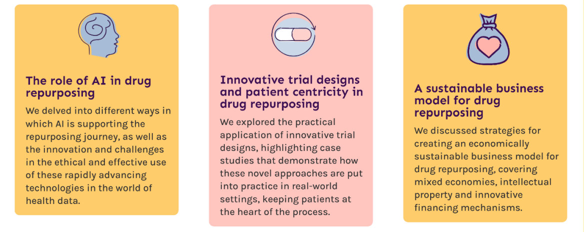
Hugh addressed a topic that he feels passionately about, namely the challenges faced by ultra-rare diseases (URDs). His talk was entitled "Repurposing for Ultra Rare Diseases – Critical but flawed". Why critical? Because of the utterly desperate unmet patient need of ultra rare diseases. And why flawed? Because repurposing is unable to progress in the required time frame; is facing many of the same barriers as twenty years ago; and is definitely not meeting the critical need!

Hugh explained:

> I wanted to lay out some of the key challenges that URDs face. We have real experience of these with EHE, through the work we have been doing over the past three years trying to make progress on the repurposing of Sirolimus for EHE. I believe that regulators are completely failing to understand the severity of the situation that is being faced by our patient community. We have to continue to break down the barriers and push regulators to change. But I also wanted to be clear that there are other players in the overall process who can also compromise and create an environment conducive to repurposing of drugs. The reality is that most new drugs for URDs will come though the repurposing route, so it has to be our primary focus.



In addition to the four key pathways, the conference explored a wide range of topics and encouraged discussion around potential solutions to various challenges. Some of the key themes covered over the two days included:



The role of AI in drug repurposing

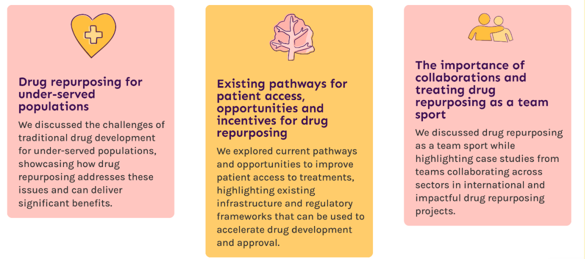
We delved into different ways in which AI is supporting the repurposing journey, as well as the innovation and challenges in the ethical and effective use of these rapidly advancing technologies in the world of health data.

Innovative trial designs and patient centricity in drug repurposing

We explored the practical application of innovative trial designs, highlighting case studies that demonstrate how these novel approaches are put into practice in real-world settings, keeping patients at the heart of the process.

A sustainable business model for drug repurposing

We discussed strategies for creating an economically sustainable business model for drug repurposing, covering mixed economies, intellectual property and innovative financing mechanisms.



Drug repurposing for under-served populations

We discussed the challenges of traditional drug development for under-served populations, showcasing how drug repurposing addresses these issues and can deliver significant benefits.

Existing pathways for patient access, opportunities and incentives for drug repurposing

We explored current pathways and opportunities to improve patient access to treatments, highlighting existing infrastructure and regulatory frameworks that can be used to accelerate drug development and approval.

The importance of collaborations and treating drug repurposing as a team sport

We discussed drug repurposing as a team sport while highlighting case studies from teams collaborating across sectors in international and impactful drug repurposing projects.

Hugh continued:

> This is a really powerful forum working so hard for so many patient groups. I hope that they can continue to both deliver and accelerate change, and of course, new drugs. They have great associations and excellent partners who are ready to contribute funding for ongoing repurposing research. I will definitely be attending iDR26, and congratulate all involved for what they are achieving".

Here at The Pledge, we want to join Hugh in congratulating everybody behind this import conference and the fast-expanding interest and delivery of such an important initiative.

Michelle pushing the boundaries

In early June, Michelle Hughes in Canada posted news and a great video of her latest challenge, the HYROX Race in New York City. Michelle was sponsored by Puma, helping to increase her profile and spread awareness of EHE. As always, our global EHE community was with Michelle throughout, as she explained:

> **I carried you all with me during our HYROX race in NYC this past weekend! My 2025 Living List goal is now complete! I've been on a slow growth journey for over a year now, so doing these fun events help remind me how very much alive I still am.**

I carried you all with me during our HYROX race in NYC this past weekend! My 2025 Living List goal is now complete! I've been on a slow growth journey for over a year now, so doing these fun events help remind me how very much alive I still am.

We love the desire and drive, Michelle, and your shear bloody-minded determination not to let EHE define you or the life you lead. Just wonderful. And congrats to Ty too for being their alongside you all the way.

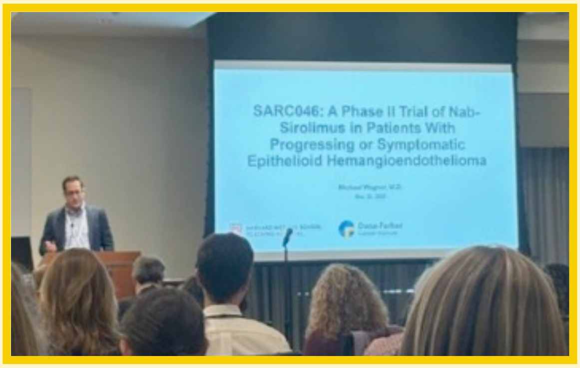
EHE represented at ASCO 2025

Denise Robinson, EHE Foundation Executive Director and Director of Research, had the privilege of representing the Foundation and the global EHE community at the 2025 ASCO Annual Meeting in Chicago, where tens of thousands of global oncology professionals gathered to share knowledge with a purposeful commitment to conquer cancer.

Aside from having the chance to speak with many sarcoma care providers who are well-loved and much appreciated by EHE patients and the community, Denise had the opportunity to attend sessions and meetings where EHE was highlighted and ultra-rare sarcoma science was emphasized. Here are several highlights:

SARC Semi-annual Meeting:

was convened just before the opening of ASCO, where, importantly, a new EHE study was announced by Dr. Michael Wagner, Dana-Farber Cancer Institute. The study, entitled ‘A Phase II Trial of Nab-Sirolimus in Patients with Progressing or Symptomatic EHE,’ should begin in late 2025. Once details are finalized, the Foundation will invite Dr. Wagner to discuss this study opportunity with our patient community. More information will follow. We are grateful to Dr. Wagner, Stephen Young, SARC CEO, and many experts who have supported this trial design.



Ultra-rare Sarcomas: How Do We Move Forward?:

A number of sarcoma experts discussed the landscape and challenges of ultra-rare sarcomas in this educational session.

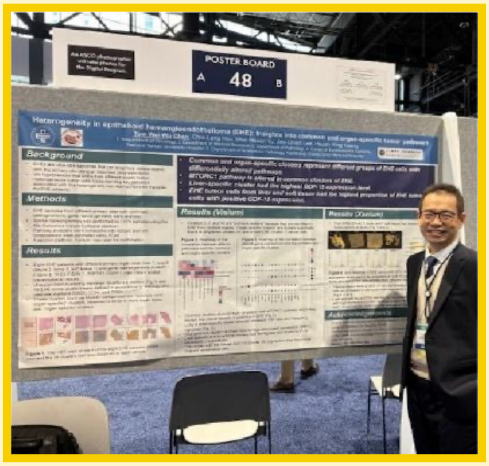
1. Dr. Stacchiotti, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, highlighted the importance of requiring disease-specific discussions in the development of treatments for ultra-rare sarcomas.

2. Dr. Kevin Jones, University of Utah, highlighted the power of preclinical models in ultra-rare sarcomas, and their reliance on tissue donation for model development

3. Dr. Mrinal Gounder, from Memorial Sloan Kettering Cancer Center, highlighted the challenges in drug development and emphasized that for ultra-rare sarcomas, it requires “out-of-the-box” thinking. Dr. Gounder shared progress in EHE science from the Rubin Lab, TEAD inhibitors in development, and encouraging results in the ongoing VT-3989 Phase I/II Study.

Heterogeneity in epithelioid hemangioendothelioma (EHE): Insights common and organ-specific tumor pathways:

Dr. Tom Wei-Wu Chen, National Taiwan University Hospital, presented this poster where Dr. Chen and his colleagues hypothesized that EHE tumors from different organs represent distinct tumor cells, and that understanding the key pathways associated with this heterogeneity could lead to the development of improved therapies. Their study found that common and organ-specific clusters represent different groups of EHE cells with differentially altered pathways. Data illustrated that common clusters showed high correlation with the mTORC1 pathway, potentially explaining the reported benefit of sirolimus in EHE.



New Drugs for Rare Sarcomas: Getting Creative:

Dr Andrew Wanger, Dana-Farber Cancer Institute, noted that ultra-rare sarcomas can and should be studied as distinct diseases, something that the EHE foundations agree with. Dr. Wagner serves on the PUSH Platform Executive Committee – a consortium of clinicians, scientists, and advocates committed to Pushing Ultra-rare Sarcomas beyond Hope (PUSH). The EHE foundations have been actively involved in the development of PUSH, with both Denise Robinson of the EHE Foundation and Hugh Leonard of The EHE Rare Cancer Charity UK also members of the PUSH Executive Committee.

The EHE foundations, and the global EHE patient community that they serve are hugely grateful for the significant efforts of all of the expert clinicians and researchers who are working to better understand EHE and so develop better treatments. There is, however, much more to be done. EHE advocacy within the clinical science community is vital to building on the incredible momentum already gained in the search to find effective treatments and to improve the lives of people diagnosed with EHE. Thanks to the wonderfully generous support of our global community, the EHE foundations will continue to work together to identify and accelerate groundbreaking EHE research projects and collaborations, and so attract interest in our disease from some of the world's leading institutions. We want to thank Denise for representing the EHE foundations at ASCO 2025.

Strengthening Global Collaboration in Sarcoma

The 15th Annual Conference of the Sarcoma Patient Advocacy Global Network (SPAGN), was held this year in early April in Washington D.C. in the United States, and was co-hosted by the National Cancer Institute (NCI), underscoring the importance of international collaboration in sarcoma advocacy. The EHE community was represented by members of the EHE Foundation. Denise Robinson, Executive Director & Director of Research for The EHE Foundation, commented:

> **As a long-time supporter and now a new member of SPAGN, alongside The EHE Rare Cancer Charity UK, we were thrilled to join with other member advocacy organizations to elevate the voice of EHE patients on a global stage.**

The conference was held over three days, with key objectives as follows:

Day 1: The Power of Collaboration

The conference began with a keynote by Dr. William Tap, Medical Oncologist at Memorial Sloan Kettering Cancer Center, emphasizing the transformative potential of collaboration between healthcare professionals and patient advocates. Subsequent sessions delved into precision oncology and the challenges of accessing research and treatment in low- and middle-income countries, featuring insights from Dr. Satish Gopal of the NCI's Center for Global Health. A panel discussion on patient-partnered research highlighted the importance of involving patients through partnership with patient advocacy organizations in the research process to drive meaningful outcomes.

Day 2: Patient Data and Clinical Trials

The second day focused on the significance of patient data in research, with educational presentations on Patient Experience Data (PED) gathered from sources like global patient registries, patient-reported outcome tools, and surveys. Patient advocate and researcher Verena Loidl, PhD, presented findings from SPAGN's Global Sarcoma Patient Diagnosis Survey, shedding light on the diagnostic experiences of sarcoma patients worldwide.

In a session exploring clinical trials, Silvia Stacchiotti, MD, shared progress of the PUSH Project (Pushing Ultra-Rare Sarcomas Beyond Hope), an important initiative supported by the EHE foundations and where Denise Robinson and Hugh Leonard are members of the PUSH Executive Committee.

Denise Robinson of The EHE Foundation, provided insight into the patients' perspective in clinical trials, highlighting how patient input should inform clinical trial planning and decision-making.

Denise also contributed to a panel discussion that included members of SPAGN, the pharmaceutical industry, and Martha Donoghue from the FDA. The discussion focused on innovative approaches and the unique challenges in conducting trials for rare sarcomas.

Day 3: Empowerment and Youth Focus

The final day explored multidisciplinary approaches to sarcoma treatment, with presentations on improving the diagnostic journey, imaging, surgery, and radiotherapy advancements. A session on empowering patients showcased advocacy projects and initiatives to strengthen patient voices. The conference concluded with a workshop addressing the unique needs of children and adolescents with sarcoma, emphasizing the importance of tailored psycho-social support and specialty resources for younger patients. Maggie Cameron, Director of Communications and Development at the EHE Foundation, and an EHE patient, who also attended the conference said:

> Participating in the SPAGN Annual Conference provided unparalleled access to engage with the global sarcoma community, the NCI, pharmaceutical representatives, and the FDA, sharing insights and strengthening collaborations aimed at improving outcomes for those affected by EHE and other rare sarcomas. As a person living with EHE, I am thrilled to have my voice heard at this meeting.

Knowing and recognising EHE

One of the key objectives of EHE Italia Non Solo Laura, the EHE foundation established in Italy, is of course to support EHE patients. As part of their work in this area, EHE Italia has been focusing on a key challenge recognised by EHE patients globally. Andrei Ivanescu for EHE Italia said:

> The main objective of our Association is to be able to support patients suffering from Epithelioid Hemangioendothelioma. In order to do that, we have been trying to identify the biggest challenges our patients face, and one of these is the diagnosis. Many of our patients have actually been diagnosed incorrectly, which in some cases has also led to treatments that are ineffective and sometimes harmful because of the myriad side effects.
>
> For this reason we are happy to present a training event of great importance from a scientific point of view, organized by our Association in collaboration with SIAPEC (Italian Society of Pathological Anatomy): Knowing and Recognizing Epithelioid Hemangioendothelioma.

EHE ITALIA
ASSOCIAZIONE NON SOLO LAURA ODV

Webinar

CONOSCERE E RICONOSCERE L'EMANGIOENDOTELIOMA EPITELIOIDE

L'obiettivo del webinar è aumentare le conoscenze sull'EHE tra gli anatomo patologi in Italia, con focus sulla diagnosi.

PROGRAMMA

Giovedì 8 Maggio 2025
17:30 - 19:00
GoToWebinar

Benvenuto

Introduzione Associazione Pazienti
Andrei Ivanescu
Introduzione al webinar
Prof.ssa A. Sapino

Discussione

Che cos'è l'EHE - Inquadramento clinico
Dott. G. Grignani

L'imaging dell'EHE - Inquadramento radiologico
Dott.ssa T. Robba

Inquadramento diagnostico
Diagnosi differenziale
Casi clinici
Prof. A. Dei Tos, Dott. A. Righi

SPEAKERS

Prof. Angelo Dei Tos
Università di Padova

Dott. Giovanni Grignani
IRCCS Istituto di Candiolo (TO)

Andrei Ivanescu
Presidente dell'Associazione Pazienti EHE ITALIA - Non Solo Laura ODV

Dott. Alberto Righi
IRCCS Istituto Ortopedico Rizzoli (BO)

Dott.ssa Tiziana Robba
Centro Traumatologico Ortopedico, (TO)

Prof.ssa Anna Sapino
IRCCS Istituto di Candiolo (TO)

Con il patrocinio di:

SIAPEC - IAP
ISTITUTO DI CANDIOLO - IRCCS
Università degli Studi di Padova
SERVIZIO SANITARIO REGIONALE EMILIA - ROMAGNA
Istituto Ortopedico Rizzoli di Bologna
Istituto di Ricovero e Cura a Carattere Scientifico

This important webinar took place on 9 May and aimed to increase knowledge in the medical community about EHE, with a specific focus on diagnosis. EHE Italia were delighted that high-profile figures particpated, including the prominent Prof. Angelo Dei Tos, director of pathological anatomy of Padova, and Prof. Anna Sapino, scientific director of Candiolo. The event was also supported by important sarcoma centers such as Candiolo Institute - IRCCS (TO), A.O.U. City of Health and Science of Turin (TO), IRCCS Institute of Orthopedic Rizzoli (BO) and University from the Studios of Padova.

Caterina Colaci from EHE Italia, and an EHE patient herself outlined the key objectives:

> **“This webinar was designed exclusively for the medical community. The event was also ECM accredited for Oncologists, Biologists, Technician Radiologists and Anatomist Pathologists, endorsing this important initiative for such a rare pathology. But awareness of the event was also a key factor, so we encouraged our patient community to share this event with their contacts in the medical community to help us raise greater awareness amongst specialists about the importance of knowing and recognizing EHE, so that fewer patients have to face the challenges and difficulties of misdiagnosis.**

Andrei Ivanescu was delighted to have been able to organise the event:

> **“This important event was indeed well attended. We are not naïve, however, and know that this single webinar will not simply eradicate the complex issues associated with the diagnosis of such rare sarcomas.**

> **“But here at EHE Italia we believe that this event does mean there is a greater awareness of EHE within the clinical community, and if that leads to just one patient in the future getting a correct diagnosis faster, then we will be absolutely delighted.**

We want to congratulate EHE Italia on organising such an important event and for collaborating with groups as prestigious as the Italian Society of Pathological Anatomy. This is indeed a valuable initiative, and I am sure one that will be copied in other countries in the future.

The EHE Foundation welcomes new Board members

The EHE Foundation was proud to announce the addition of two new members to their Board of Directors: Hollace D. Leppert, DO, FACOI, and Krista Sheeley, BSN, RN. Both bring extensive healthcare experience, leadership, and passion to the Foundation’s mission. Denise Robinson, Executive Director & Director of Research of The EHE Foundation said:

> **“We are honoured to welcome both Holly and Krista to the EHE Foundation Board. We look forward to working with them and benefiting from their insight, expertise, and guidance as we continue to grow in our mission and work to improve outcomes for people with epithelioid hemangioendothelioma (EHE) through education, research, and advocacy.**

Here at The Pledge we want to also warmly welcome Krista and Holly to the EHE global community. More detailed profiles are on The EHE Foundation website, with summary bios on the next page.

Krista Sheeley, BSN, RN

Krista's dedication to the EHE community began when her son, Drew, was diagnosed with EHE in 2024. Since that time, she has become a passionate advocate, raising awareness through local fundraising and education efforts and standing firmly alongside other families affected by this rare disease.

Krista joins the EHE Foundation Board of Directors with more than 23 years of clinical healthcare experience. Throughout her career, she has held a variety of nursing leadership roles within acute care settings. With a deep passion for patient safety and quality of care, Krista is dedicated to motivating healthcare professionals to prioritize patient well-being across care settings. She has extensive expertise in evaluating medical necessity, serving as a critical liaison among healthcare providers, insurance companies, and patients.

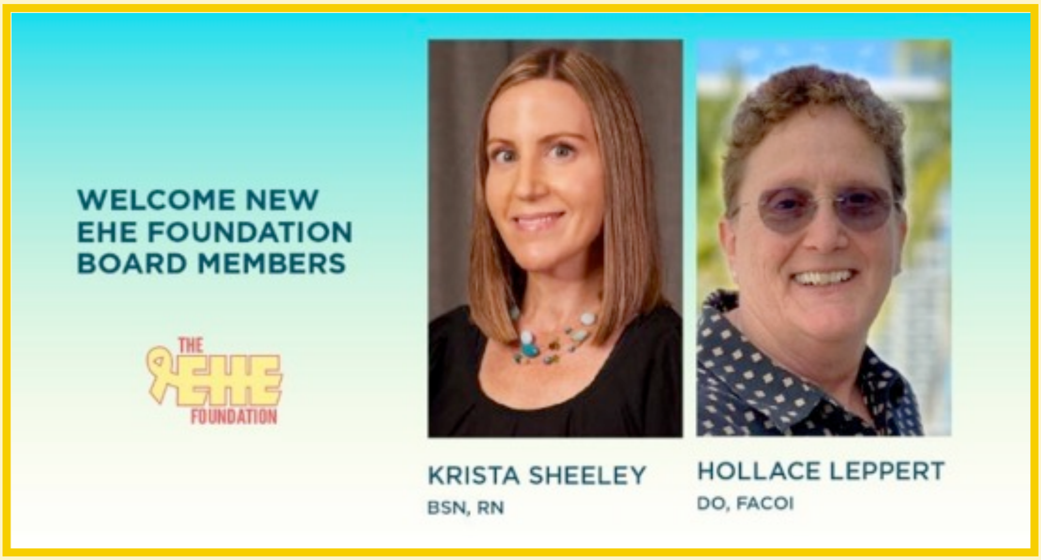
In addition, Krista has over 12 years of experience analyzing medical necessity denials and advocating for both patients and hospitals by appealing inappropriate denial decisions. Her leadership and advocacy skills are a valuable asset to The EHE Foundation's mission of improving patient outcomes and supporting the EHE community.

Hollace D. Leppert, DO, FACOI

Dr. Leppert joins the EHE Foundation Board with over 30 years of experience in internal medicine and medical education. A graduate of Eastern Michigan University, she received her Doctor of Osteopathy degree from the Philadelphia College of Osteopathic Medicine in 1989. While at Parkview Hospital, Philadelphia, she was recognized as the Most Compassionate Clinician for four consecutive years and was honored as Clinical Teacher of the Year seven times.

Dr. Leppert maintained a thriving private practice for more than a decade, moving to Florida in 2001 to become a partner at Internal Medicine Associates (IMA), where she cared for a large geriatric population. She continued practicing internal medicine until she retired in September 2024.

Her ongoing friendship with John McFadden, an EHE patient and Director of the EHE Foundation, coupled with her firsthand experience of the critical importance of early detection and the team approach to best treatment options, has fuelled her dedication to advancing research, raising awareness, and supporting the mission of the EHE Foundation.



EHE Live Stream

The EHE Rare Cancer Charity were thrilled when a group of final year students studying Television Production at Bournemouth University approached the charity and asked if they could do a Live Stream production about EHE. The charity were delighted to have been selected and of course said yes. Sally Baker, EHE patient and a trustee of the charity explained:

> Just an update on the Live Stream that the students in Bournemouth are doing on Friday 25th April. I think their preparations are going well. They did some filming at Kelly's quiz night, and tomorrow are doing some interviews/filming at the Royal Marsden in Sutton. Some of them also ran the Bournemouth 10k and have been doing some fundraising. They are an impressive group of young people.

> Hugh and I will be at the production with Kim and Sue, both fellow patients. We are all going to be interviewed which is quite scary!”

Both Hugh and Sally were amazed at how professional everything was when they turned up. Sally said:

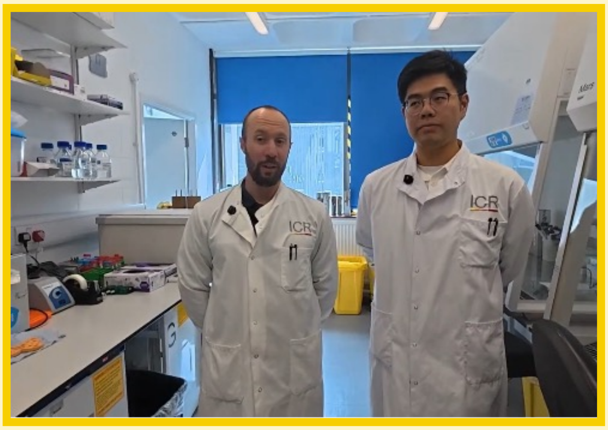
> We were amazed at how professional the whole set up was. It was a real TV studio with a huge cast of young budding TV specialists ready to go. We did several rehearsals and then went live at lunch time on the Friday. The programme was streamed on social media which was cool. We understand that it has been watched nearly 1,000 times which is fantastic in terms of spreading awareness about the disease. We could not be more grateful to the whole team.

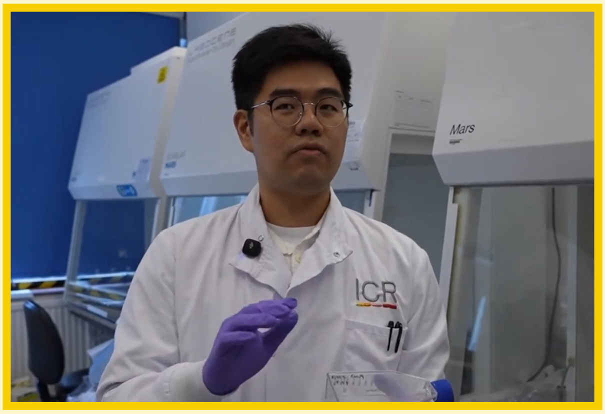
The EHE Rare Cancer Charity and the patients who took part want to thank the whole team that produced the Live Stream! They really were an amazing team, seen here.

Hugh also wanted to thank the research team from Dr Paul Huang's lab at the Institute of Cancer Research in Sutton, in south-east London, and did such an impressive job explaining what they do as they seek answers to questions about EHE and sarcomas generally.

For anybody who wants to watch the Live Stream production, it can be found at:

https://www.youtube.com/live/aaim6yPxjLY?si=sea2oEHKzrKIuOTO

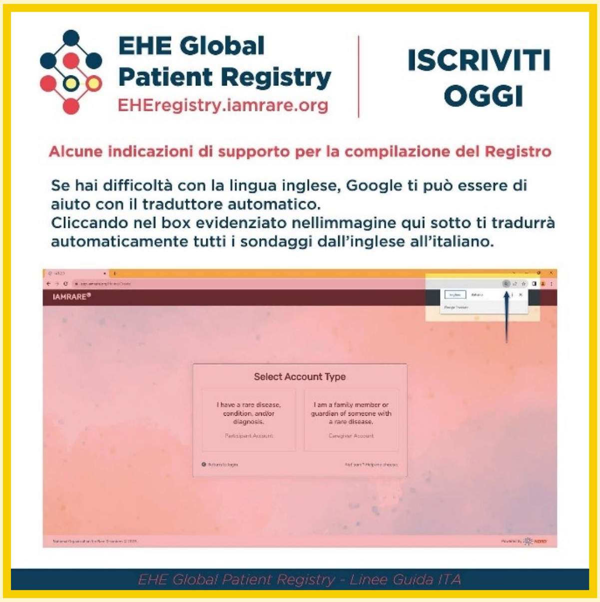




Each person makes a difference

All our readers will know that we regularly include articles about the importance of gathering patient data and experiences. This data, when collated for a large number of patients, provides a treasure trove of information that clinicians and researchers can interrogate and use to develop hypotheses about the disease and the research that might support such theories. EHE Italia also wanted to promote this important subject and the EHE Global Registry as Caterina Colaci explained to the Italian patient community:

> We need your help to better understand and characterize the journey of EHE patients. The EHE Global Patient Register is the first large-scale global effort designed to gather information from patients on diagnosis, treatment, disease progression, and symptoms. Collective data will help answer questions about the disease and support the community in developing standards of care. Patients who join the register will be asked to fill out questionnaires, with an update every 6 months of information on possible new treatments, symptoms or changes in the disease. Surveys can be completed at times that suit each patient.
>
> This registry is a powerful way for people with epithelioid hemangioendothelioma and their family members to contribute directly to research that will improve our understanding of EHE.
>
> The EHE Global Patient Registry is more than just a data collection system. The registry will empower the EHE community. Anyone anywhere in the world who has been diagnosed with epithelioid hemangioendothelioma can join the study. The information you share about your EHE journey will help inform physicians and researchers.



EHE Global Patient Registry
EHEregistry.iamrare.org

ISCRIVITI OGGI

Alcune indicazioni di supporto per la compilazione del Registro

Se hai difficoltà con la lingua inglese, Google ti può essere di aiuto con il traduttore automatico.
Cliccando nel box evidenziato nellimmagine qui sotto ti tradurrà automaticamente tutti i sondaggi dall'inglese all'italiano.

EHE Global Patient Registry - Linee Guida ITA

Here at The Pledge, we could not agree more. It is very hard to overstate the importance of this patient data. While every individual's data alone can be useful, the value of that data is increased by several orders of magnitude once it is combined with data from other patients. That is why collating the data is so important.

So, we ask every patient who is reading this, and who has not yet joined the registry, please do so if you are able to. Your support will be huge. Details of the registry and how to access it are included in this edition of The Pledge. We will be hugely grateful for every single patient who signs up because it will make a difference.

EHE Meetup in Washington, D.C.

The EHE Foundation were thrilled in April to share news of the EHE Meetup in Washington, D.C., as Maggie Cameron, Director of Development and Communication for the EHE Foundation, explained:

> Five people living with EHE, representing three countries, gathered on Sunday, April 13 for lunch and camaraderie, marking the first-ever meetup of its kind in the United States.

> **The EHE Foundation was in Washington, D.C. that same weekend to participate in the Sarcoma Patient Advocacy Global Network (SPAGN) Annual Conference, and put out the call to anyone in the area who could join us for a few hours. We were thrilled to meet this small group of people living with EHE, representing the largest EHE patient meetup held in the U.S. ever!**

The participants were Maggie herself from the Foundation, Verena from Germany, Kayla from the US, and Carlos from the Netherlands, all in town to attend the SPAGN conference. Victoria, who lives in the Washington area, joined the group for the afternoon. Maggie continued:

> **It was such a special surprise for me to be seated next to Carlos during the SPAGN meeting. Upon realizing I was there representing the EHE Foundation, Carlos exclaimed, "I have EHE!" and then explained that his subclavicular tumor was removed about five years ago. Shocked to have met another person with EHE just by chance, I insisted he join the meetup on Sunday.**

Maggie has lived with EHE for 14 years. She was stunned that meeting fellow EHE patients in person took that long. She exclaimed:

> **For me, this meetup was the most important part of the weekend. I feel more connected to the EHE community than ever! I want to encourage everybody in our global community to reach out to those who live near them who have EHE and try and spend time with them. It really is magic!**

Here's the photo of the EHE-5 meeting in Washington. We love this story and hope you can all meet up again in the near future.

Stronger Together

The EHE Foundation announced the start of 'EHE Support Groups' as part of its broad objective to support, connect and empower EHE patients. The meetings are intended to help EHE patients to connect, reflect, and heal together under a strong headline – "You are not alone" – providing a supportive space for people affected by EHE to connect with one another. The first EHE Support Group meeting took place in late April, with further sessions in late May and June.

These sessions are led by Dr. Maeve Baechler. Maeve is an EHE patient, life coach, and psychiatry resident. Originally from Washington State, she earned her medical degree there before continuing her training in psychiatry abroad. With a deep commitment to the EHE community, Maeve has dedicated countless hours to coaching fellow patients and caregivers, helping people navigate life with this rare cancer.

These free virtual meetings explore various topics that help and support people newly affected by EHE, as well as those who have lived with EHE for a longer time, all within a closed, supportive environment. If you wish to know more about the future meetings, please go the EHE Foundation website at https://fightehe.org/ehe-support-groups/

Here at The Pledge, we want to thank Maeve for all she does to support EHE patients everywhere through these sessions, combining her unique blend of medical expertise and lived experience to offer compassionate guidance to others.

How long have you lived with EHE?

April is EHE Awareness month, and the EHE Foundation ran their 'How long have lived with EHE?' campaign to help raise awareness of the disease. Once again, it was a simple idea that delivered real impact. EHE patients used a printable template to fill in their details and share with the EHE community.

Maggie Cameron from the EHE Foundation said:

> **Spreading awareness of EHE is a core objective for the EHE foundations and the EHE global community. We were delighted to provide these simple tools and want to say a huge thank you to all those in the US who took up the challenge and helped spread awareness.**

Here are just three of the EHE patients that supported the campaign. The Pledge wants to join Maggie and the EHE Foundation in thanking everybody who took part for being such great patient advocates.

Meet Eddie Opichka, EHE Library Volunteer

Eddie Opichka's connection to EHE began at just five years old, when his mother, Jenny Opichka, was diagnosed with EHE in her liver. Despite enduring three liver transplants, she passed away just three months after her diagnosis, shortly after her 34th birthday. As Eddie reflects, "When you're five, it doesn't really matter what cancer your mom had—just that she's gone."

Motivated by the grief of losing his mother at such a young age, Eddie grew up with a powerful sense of purpose: to help prevent others from experiencing the same loss. That commitment has shaped his future. Eddie will begin medical school later this year, with the goal of becoming an oncologist specializing in rare sarcomas.

Over the past year, Eddie has generously volunteered his time to assist with the archiving of publications and case studies in The EHE Foundation's EHE Library, as well as summarizing content for their newsletters. An ever-growing resource of more than 200 peer-reviewed publications and case studies, the EHE Library was created as a supportive tool for patients, clinicians, and researchers. With Eddie's help, this resource will also support the development of an adaptive prioritized research agenda for The EHE foundations, the broader EHE scientific community, and most importantly, for the global EHE community.

The EHE Foundation are deeply grateful to Eddie for sharing his time and talents with them, particularly during the rigors of school, and we are inspired by his passion to make a difference—for his mother's legacy, and for all those affected by EHE. Here at The Pledge we also want to thank Eddie for all that he is contributing to the fight against EHE. We also know that the global EHE community would want us to express their deep gratitude too. Thank you, Eddie, and we also want to wish you every success for your medical training.

For anybody who wants to access the EHE Library, this can be found at https://fightehe.org/ehe-library/ . If you have questions relating to ongoing EHE publications, or indeed EHE research, please contact your local EHE foundation or email Denise Robinson at research@fightehe.org .

Italy are supporting EHE Awareness Month

EHE Italia Non Solo Laura celebrated EHE Awareness Month with the Italian patient community.

> April is EHE Awareness Month! Let's help spread knowledge. Awareness is a fundamental pillar of progress for EHE, which can help advance diagnosis and treatments, increase funding for research, and widen support networks for patients with this ultra-rare cancer.
> Here are some simple ways to participate:
>
> 1. Share our posts: look for patient stories and facts about EHE to share with your community.
> 2. Share a message about EHE that you want others to know: tell us your story!
> 3. Invite friends and family to support EHE ITALIA: https://www.ehe-italia.it/sostienici
>
> THANK YOU

Supporting the EHE Biobanks

One of the most important aspects of what the EHE foundations have achieved globally is to establish EHE biobanks in their respective countries and regions so that ultra-rare tissue and fluid samples can be collected and saved for use in EHE research. For example, tumour tissue donated by patients from their surgery has led to the exciting development of both PDX mouse models in Europe and even more importantly, actual EHE cell lines in the US. These are huge steps forward in terms of EHE research and have only been possible because patients donated their tissue. Here are just two examples from this quarter.

Sarah Bright shared her decision to donate to the EHE Biobank in the United States saying:

> **I travelled from Virginia to New York to have a mass in my right elbow removed which had been causing pain for over a year. I had this elbow tumor looked at by other physicians and centers many times before and it was not considered cancerous or worrisome, but the pathology after its removal confirmed it is EHE. I am incredibly grateful that I coordinated ahead of time to have the tissue biobanked with the EHE Foundation as a precaution, because now I will have a better chance of having treatments tested and targeted on my tumor tissue.**

In the UK, patients from South Wales and Liverpool contacted the EHE Rare Cancer Charity wanting to know how they could contact the UK National EHE Biobank to ensure their data was captured. Introductions were made, and patients' consents were completed where necessary. From that point onwards, the Biobank Tissue Manager at the Royal Marsden coordinated and made all arrangements to ensure the samples were captured.

The EHE community could not be more grateful to these patients who donated their tissue. EHE biospecimens are so rare and therefore unbelievably valuable and critical for EHE research. We would encourage everybody who has surgery to please contact your nearest EHE foundation to explore how your tissue can be donated to EHE research. Here are links for the US, UK and Australia:

US Biobanking

1. EHE Foundation biobank team at biobank@fightehe.org
2. Details about the biobanking process can be found at https://fightehe.org/ehe-biobank/

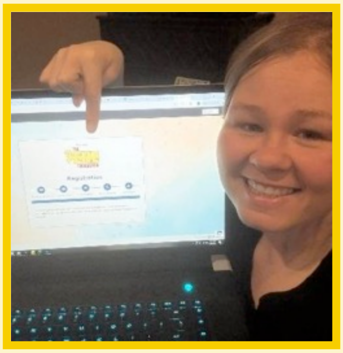
UK Biobanking

1. The EHE Tissue Coordinator at the National UK EHE Biobank at the Royal Marsden Hospital at EHEbiobank@rmh.nhs.uk ; or
2. Hugh Leonard at the EHE Rare Cancer Charity (UK) at hleonard@ehercc.co.uk
3. Details about biobanking can be found at https://ehercc.org.uk/uk-national-ehe-biobank/

Australian biobanking

1. The EHE-RCFA at info@ehefoundation.com.au

Call to Action: Join the EHE Global Patient Registry



Ashley Wibbenmeyer from the US posted a simple message to the global community, encouraging all patients to join the EHE Global Patient Registry and make sure their data is included:

> Don't be like me. Please. I've been part of this group since I was diagnosed with EHE back in November, and only today did I finally register for the EHE patient registry. Why did it take me so long? Honestly... life; emotions; overwhelmed; I just kept putting it off. But if we want a treatment, a cure, hope, this is one thing we can do that directly helps researchers. This is how they understand our rare disease. This is how they see patterns, symptoms, outcomes. This is how they fight for us.
>
> It took me maybe 15-20 minutes to enter my data. That's it. And yet I know there are others in our community just like me, overwhelmed, tired, hesitant — who haven't done it yet either. But if you're reading this, please don't wait any longer! Please make today the day you do it. You can access the registry at https://eheregistry.iamrare.org/ where you will find all you need to participate.

Thank you, Ashley, for this great 'call-to-arms'. Here at The Pledge, we also want to add our voice to Ashley's important request.

Denise Robinson, Executive Director and Director of Research at The EHE Foundation, who is also the Principle Investigator for the registry, explained:

> Participation in the EHE registry is vital to improve our understanding of the disease, treatments used and how they work, and what long-term living with this ultra-rare sarcoma really looks like.

Denise gives an example of why patient participation in the registry is so important, citing that early registry data indicate that about 15% of participants enrolled have lived with EHE for 10 years or more.

> We want to record as many long-lived EHE patient journeys as possible. We think there are more patients who have lived with EHE, and their experiences are important. This type of data and experience sharing will inform doctors and patients, and it could give hope to many people newly diagnosed with this disease.

If you've been living with EHE — whether recently diagnosed or for decades — your experience is key. By joining, you can help provide hope and real-world answers for those newly diagnosed, and your voice can shape the future of EHE care.

To join the EHE Global Patient Registry please go to https://eheregistry.iamrare.org/

02 Research

This is the section of The Pledge where we included information relating to EHE research and our understanding of the disease. Much of the work reported here is supported by our global patient community and funded by the EHE Group entities, thanks to your generosity. It is this research that will ultimately help the EHE Group find new ways to treat and manage EHE. We also include information and updates on clinical treatment and advances in disease management. As always, we are inspired by the work taking place and the dedication and skill of the researchers and clinicians that are delivering it. We hope you will be too.

Tyler Davis's case is front and centre

Tyler Davis is a UK EHE patient with EHE in his liver. His oncology team at UCLH have been very proactive in treating his multiple liver tumours over a significant period with IRE ablation. So, Tyler was excited when his case was presented, as Tyler explained:

> “
>
> The annual British Society of Interventional Radiology took place in June in London over two days, Chaired by Dr Praveen Peddu from King's College Hospital in London. A case study was presented by Dr Jason Yeung at the conference and was in fact my case history.


British Society of Interventional Radiology

BSIR IOUK Annual Meeting Programme

19th - 20th June 2025

Leonardo Royal Hotel,
Tower Bridge, London

The case summarised the following key learning points for those in attendance:

- Interventional oncology can provide durable disease control in select patients with hepatic metastases from rare tumours like EHE, especially when systemic options are limited.
- The proximity of lesions to the diaphragm requires careful procedural planning and consideration of technique (e.g., IRE vs MWA).
- Patient-centred care includes listening, even when patients challenge standard pathways. Their priorities can shape decisions in a meaningful and ethical way.

Tyler continued:

> “
>
> UCLH wish to follow up on my case and submit a full patient study to a research journal, to provide an evidence base in support of continued use of Microwave ablation and IRE to treat multifocal disease and slow disease progression.
>
> For context, I have now had 9 separate ablation procedures using a combination of Microwave and IRE, on a total of 18 liver tumours (a record for any patient at UCLH or Kings). This has acted as a bridge to allow me to also have a SIRT (selective internal radiation therapy) procedure under compassionate access on the NHS in March on segments 5 - 8 of the liver, with the last two scans showing no new tumours and disease stability in the treated areas.
>
> In the interim I hope the case retrospective on me can be helpful to someone with multiple liver lesions who has been denied Microwave or IRE.


Dr Praveen Peddu

Hugh Leonard, from the EHERCC, was also excited:

> **It is so good to hear that Tyler's treatment is working. It is also great to see oncologists and IRs working together to use these different treatments for hepatic EHE tumours, being proactive on how extensively these ablations can be used, and involving the patient at the centre of their thinking. We have already progressed a long way from the days when a tumour of more than 2cms in size was considered too large to ablate. So a huge thank you to Tyler and his medical team for sharing this information and for wanting to move to a full paper. Only by sharing these sorts of experiences can we continue to expand the use of these important treatments for other patients.**

For the EHE community it was also exciting to see Dr Praveen Peddu and Professor Govindarajan Narayanan presenting together. Dr Narayanan has been one of the leading proponents of IRE ablation in the USA from its early introduction, and it has been his work that has widened the boundaries of this treatment for EHE.

Prof Govindarajan Narayanan

2025 EHE Research Grants funding cycle is open !

The EHE Foundation is dedicated to finding treatments and a cure for epithelioid hemangioendothelioma (EHE) and is committed to funding innovative and transformative research that will improve outcomes for individuals diagnosed with EHE. At The Foundation, their Research Grants Program is a cornerstone of their mission, representing the single-largest funding source dedicated to advancing EHE science. The Foundation has committed over $2,000,000.00 to advance EHE research globally, supporting transformative and collaborative research efforts.

The EHE Foundation were therefore thrilled to announce that "The 2025 EHE Research Grants funding cycle is open". The Foundation invites researchers to submit an application and join the global commitment to promoting collaboration, information sharing, and resource sharing among the EHE community, including patients, clinicians, and researchers. For more information or to apply for a grant, please go to https://fightehe.org/ehe-research-grants/ .

Areas of Interest

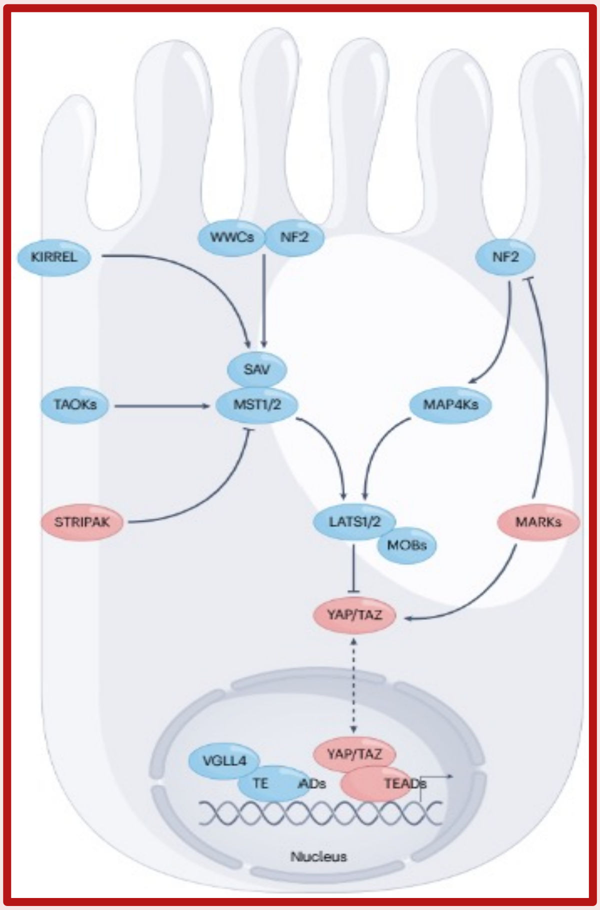
The EHE Foundation is interested in promising basic, translational, and clinical proposals that have the potential to advance scientific knowledge in EHE, improve our understanding of disease presentation, and accelerate the development of therapeutic options. Areas of interest are focused on:

- Identification and development of biomarkers for EHE
- Translational science that has the potential to identify and advance a new treatment, including novel and repurposed drugs
- Development of essential in vivo and in vitro resources and models
- Clinical trials with a strong rationale that bring an opportunity for treatment investigation to EHE patients

‘Targeting the Hippo pathway in cancer’

The Hippo pathway is a significant potential therapeutic target for EHE, as well as for other cancers and heart disease. In a newly published article, "Targeting the Hippo pathway in cancer," published online in Nature Reviews Drug Discovery, authors Kieran Harvey, PhD, Peter McCallum Cancer Centre, and Tracy Tang, PhD, Vivace Therapeutics, provide an in-depth review of the scientific progress and drugs in development, some of which are being investigated in EHE.

Read more at: https://rdcu.be/et2NL



Simplified depiction of the human Hippo pathway. Kieran F. Harvey and Tracy T. Tang; Nature Reviews Drug Discovery 2025

Here at The Pledge we want to congratulate Drs. Harvey and Tang for this publication, and we are grateful for their continued research on the Hippo pathway and EHE.

A new EHE review published on EHE Treatments and Innovations

Jane Gutkovich posted news of a new paper published in May, in the journal Current Treatment Options in Oncology, of EHE treatments:

> **A new review of EHE treatments entitled ‘Epithelioid Hemangioendothelioma: Treatment Landscape and Innovations for an Ultra-Rare Sarcoma’ just came out from Dana-Farber Cancer Institute and Brigham and Women’s Hospital, Harvard Medical School.**

The authors, Drs. Erica Pimenta, Michael J. Wagner (a well-known EHE expert), and colleagues share their opinions and observations on the progress and unmet needs in the EHE treatment landscape.
Jane highlights that the paper gives a description of current and emerging treatments for EHE, exploring systemic therapies, local treatment options, and investigation and advancements in the YAP/TAZ/TEAD signaling pathway as a therapeutic target in EHE. VEGF pathway inhibition, mTOR inhibition, and MEK inhibition are also discussed. The authors also mention histotripsy, a new non-invasive therapy for liver tumors, and their plans to further examine its use and outcomes for selected sarcoma patients.

This publication is important for patients and translational and clinical scientists because it highlights that additional work is needed to make progress in the management of EHE.

Many factors about EHE and how different treatments work in which patients are unknown. Importantly, the authors highlight the need for novel biomarker discovery—a priority need that can improve treatment decisions, treatment response, and ultimately, patients' lives.

There are a few important points to note about this publication:

1. There are still many unknown factors influencing the outcome of treatments (or no treatment, active surveillance). These factors probably hide deep in EHE biology and in our body's variables.
2. This means more data collection, more lab research, and more tissue collection are the ONLY ways to solve these puzzles.
3. There is early excitement about newly-developed targeted therapies which are currently in clinical trials, but results are still very preliminary in nature.

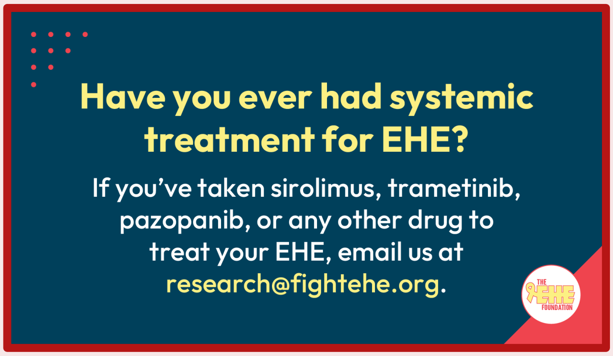
We appreciate the work these authors dedicated to highlighting treatments and progress in EHE.

Thank you, Jane, for this post and for continuing to keep the EHE patient community updated. The article itself is not freely available but details of how to access it can be found on the Springer website using this link: https://link.springer.com/article/10.1007/s11864-025-01328-2

Visit the EHE Library for more EHE publications and case studies at https://fightehe.org/ehe-library/ .

Have you ever had systemic treatment for EHE?

In its ongoing quest to continually improve treatments for EHE patients everywhere, the EHE Foundation posted a call to all patients who have ever been prescribed systemic treatment for their EHE.



Have you ever had systemic treatment for EHE?

If you've taken sirolimus, trametinib, pazopanib, or any other drug to treat your EHE, email us at research@fightehe.org.

> **If you have ever been treated with systemic therapy for EHE, please contact the EHE Foundation's research desk using our email research@fightehe.org . Every patient experience brings new knowledge to the clinical science community and can improve care for others with EHE. Chemotherapy, targeted therapy, immunotherapy, immune suppressants, or hormone therapy - did you have a good or not-so-good response? We need to know! Your experience helps us learn how treatments work in different people. Together, we can improve outcomes for people diagnosed with EHE.**

The Pledge strongly endorses this call for patient engagement and sharing information about your experiences of systemic treatments. You may think that your data won't make a difference, but it might just be the missing piece of a critical jigsaw puzzle. So your data is key. Please don't leave it to others to provide data. The EHE Foundation needs your help now.

Vivace continues to enrol EHE patients

The EHE Foundation and The EHE Rare Cancer Foundation Australia are pleased to share the news that Vivace Therapeutics are continuing to enrol EHE patients in their Phase I study of its TEAD inhibitor, VT3989 in the US and in Australia.

Clinical trials evaluate the safety and effectiveness of new potential treatments. VT3989 is a first-in-class TEAD inhibitor, a new class of drugs that could represent a possible breakthrough in the treatment of EHE. This trial is an open-label, dose escalation and expansion study to evaluate the safety, tolerability, pharmacokinetics and biological activity of VT3989 administered, alone or in combination, once daily in patients with mesothelioma and/or metastatic solid tumors that are resistant to standard therapy or for which no effective standard therapy is available. This included EHE.

If you are considering treatment—or your current treatment is no longer effective—clinical trials such as this one should be considered when developing your care plan. We encourage you to review the study details and speak with your care team. Questions about this study or for support navigating the clinical trial process can be directed to:

1. The EHE Foundation in the US using the email research@fightehe.org , and
2. The EHE Rare Cancer Foundation Australia using the email info@ehefoundation.com.au .

For further information, you can go to:

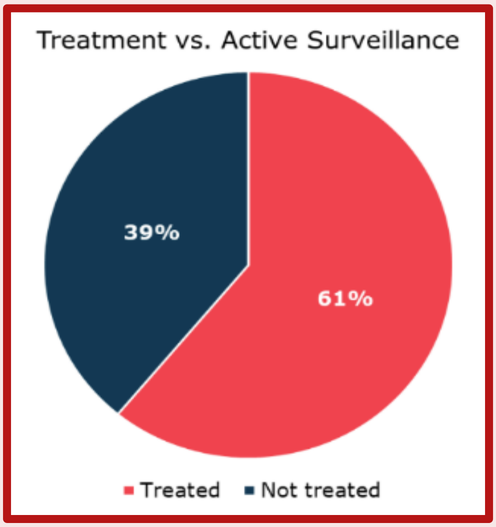
1. For Clinical Trials for EHE: https://FightEHE.org/ehe-clinical-trials/ , and
2. For the VT3989 trial specifically : https://clinicaltrials.gov/study/NCT04665206

EHE Global Patient Registry is Patient-Powered Research

In an ultra-rare disease, every patient's journey is an opportunity to learn and help someone else who will be diagnosed in the future. The EHE Global Patient Registry (EHEGPR) harnesses the power of each patient, telling their journey from diagnosis through treatments. By counting every person's EHE experience, we can better understand this complex disease. As of early 2025, the registry included over 230 EHE patients from 29 countries—an amazing patient collaboration for an ultra-rare, one-in-a-million disease.

By capturing structured data, this initiative of the EHE Foundation (US) aims to find answers to the questions like–Do people have tumors in multiple organs and not have treatment? Do other people have EHE like mine? How are different people managing their EHE and related symptoms?

One of the most common questions patients ask is "What treatments work?" Honestly, no doctor or researcher can easily answer that question because each person's EHE may behave differently due to a huge range of issues resulting from the combination of their EHE and their own biology. Without data from patients who have similar disease presentations and are also treated similarly, it is impossible to really know the answer. We are learning from early analysis, but currently have too few patients reporting treatments of any type to learn about treatment outcomes.



Current data shows that 61% of patients in the registry report having had some form of treatment, while 39% have not had any treatment, only active surveillance. Of those treated, only 22% reported any systemic therapies. Even this data is invaluable and can be analysed, but greater numbers will provide more confidence in the results and also expose more important differences across our patient community.

Everyone diagnosed with EHE, in any stage of their disease, is essential to understanding treatments, including those in active surveillance. Your experience may reveal new patterns and information that could help to identify new therapeutic ideas and research. If you or someone you are the caregiver for is diagnosed with EHE, we urge you to join the EHEGPR to share your experience. You have the power to directly impact research from the comfort of your home. If you have questions or would like assistance, you can find more information at https://fightehe.org/registry/ . If you wish to join the EHEGPR, or have further questions, please contact the EHE Foundation at registry@fightehe.org .

New EHE Clinical Trial Announced

As reported in the Patient Support and Advocacy section of this edition of The Pledge, Denise Robinson of the EHE Foundation shared that a new EHE study was announced by Dr. Michael Wagner, Dana-Farber Cancer Institute, at the SARC Semi-annual Meeting. SARC (Sarcoma Alliance for Research through Collaboration) will sponsor and manage conduct of the study, entitled 'A Phase II Trial of Nab-Sirolimus in Patients with Progressing or Symptomatic EHE,' which should begin in late summer 2025. Dr. Michael Wagner has dedicated significant time and effort in consulting with the EHE Foundation, clinical experts, and industry representatives to design this trial for the best chance of success.

Denise shared that once details of the study are finalized, The EHE Foundation will invite Dr. Wagner to discuss this study opportunity with the community. Watch out for more information in the coming months. We are grateful to Dr. Wagner, Stephen Young, SARC CEO, and many experts who have supported this trial design.

(Pictured left to right: Steven Young, SARC CEO, Denise Robinson, Dr Michael Wagner)

Advancing EHE Research at the Annual YAP/TAZ and TEADs Workshop

The 9th Annual 'YAP/TAZ and TEADs: At the Crossroads of Cancer' workshop took place June 9-13, 2025, in Telluride, Colorado. Hosted by the Telluride Science and Innovation Center and organized by Drs. Guy Weinberg and John Lamar, this unique gathering brought together top-tier researchers and clinicians from academia and industry to explore cutting-edge strategies for targeting the Hippo-YAP/TAZ-TEAD pathway in human disease.

A major topic of the workshop is epithelioid hemangioendothelioma (EHE), with multiple EHE researchers presenting their latest findings and forging new connections. The workshop is designed to spark collaboration through a blend of rigorous morning science sessions and informal, idea-rich afternoon "walks in the woods," where conversations continue against the backdrop of Colorado's breathtaking natural beauty.

Dr. John Lamar explained:

> **The interactions and discussions this year were truly exceptional—especially around EHE. We saw long-standing collaborations deepen and exciting new ones form. Perhaps most importantly, EHE researchers gained invaluable insight from other leaders in the Hippo-YAP/TAZ field. This is exactly what we envisioned when Guy launched this workshop in 2017.**

Dr. Guy Weinberg, who founded the workshop, has long championed the inclusion of early-career scientists alongside established experts. Guy explained:

> **This advances and assures continued interest in important research relevant to EHE.**

That vision was on full display in Telluride, with fresh perspectives and new voices adding vibrancy to the scientific dialogue. As part of The EHE Foundation's engagement with the Telluride workshop, they were proud to have supported Sarah McMullan, a PhD candidate studying EHE in the Lamar Lab, with a 2025 Fellowship Travel Grant to attend the conference. More information about Sarah and her participation can be found on the EHE Foundations website at www.fightehe.org

Sarah was delighted to have had the opportunity to participate:

> **I am so grateful to the EHE Foundation for sponsoring my participation in this workshop. It brought together scientists from around the world researching YAP, TAZ, TEADs, and EHE to share ideas, form collaborations, and push the science forward. To be part of this, and to listen to these established and world-renowned experts in the field was an unbelievable experience for somebody at my stage of their career.**

Workshops like these are crucial in accelerating EHE research. By creating space for shared insight and spontaneous collaboration, they help fuel the progress that EHE patients around the world are counting on. The Pledge wants to extend its thanks once again to all those who took part and contributed so much, making the 9th workshop particularly impactful.

03 Fundraising

Fundraising is so critical for ultra-rare diseases. Without it, none of the EHE Group's activities would progress. That is why we will always be so grateful for the amazing effort, organisation and generosity of so many people, which has enabled us to raise the funds we need to drive EHE research. And it is only the research that will ultimately lead us to new and improved treatments

The following pages included 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 and are doing.

The 2025 Fun Run and Walk

This Spring, the EHE community showed up stronger than ever for the EHE Foundation's 2025 EHE Fun Run & Walk, raising an astounding $90,000+ to fund research aimed at improving outcomes for people diagnosed with EHE. This marks a record-breaking year for the Foundation's signature awareness and fundraising event!

Each year, the Fun Run & Walk brings together patients, families, friends, and supporters from around the world—united by one goal: to advance research and improve outcomes for those affected by this ultra-rare sarcoma. Whether walking in their neighborhood, running a 5K, or simply wearing a shirt in support, every step moves us closer to answers and, one day, a cure for EHE.

Maggie Cameron expressed special thanks:

> The EHE Foundation extends our deepest gratitude to this year's incredible team captains, who rallied their communities, raised awareness, and helped make this milestone possible. Your leadership and creativity sparked generosity and inspired hope across the globe. Take a look at the 10 Top Teams for 2025:

2025 Top Teams

Team Jennifer Ness – $27,140.00

Aimee's 3rd Annual EHE 5K – $10,515

Courtney's Team! – $7,500

Do It For Drew – $5,815

Leah's Fight Club – $5,569

Bridget's Buddies – $3,846

Jay's Legacy Walk — #26 Forever – $3,745

Team Amy Houston – $3,145

Team John – $1,850

Team Jenni – $1,850

Maggie continued:

> We also like to thank this year's generous sponsors. Their support helped make this event possible and amplified its impact in meaningful ways. We are incredibly grateful for their partnership in the fight against EHE. To every participant, donor, and advocate—thank you. Your energy, compassion, and commitment bring strength to the EHE movement. Together, we're making bold strides toward a future where EHE no longer means uncertainty.

We could not agree more, Maggie. For those of us who remember the very first EHE Fun Run and Walk, it is truly inspiring to see how this event has grown through the years.
It is even more inspiring to see the generosity of so many people who have taken part.
And here are just some of the photographs of those amazing teams and individuals who helped make the 2025 EHE Fun Run and Walk such a huge success!

Raising money for The EHE Cancer Foundation by doing the EHE walk in memory of PFC Tim Webb

Park in Hollywood in honor of Jonathan Garcia, the father and

coach was just 23 when he was diagnosed with EHE sarcoma, a

‘10 for 10’, our 10k challenge

As many of our readers know, 2025 is the 10th anniversary of the first three EHE foundations in the US, UK, and Australia. To celebrate this fact, and of course raise funds for EHE research, the UK charity decided to launch its 10 for 10 challenge, namely doing something with the number 10 in to raise funds for EHE research. This included supporters taking on a 10k run during the year for EHE patients everywhere.

Hugh Leonard, Chair of Trustees explained:

> **In the UK, we set ourselves and our brilliant supporters a challenge. Could we celebrate our 10th birthday by getting 100 runners to each run a 10k for us in the year? That would be a total of 1,000,000 metres run in the year for EHE, a 1 in a million sarcoma.**

Sally Baker, Patient Trustee of the Charity said:

> **We had previously had places in the London landmarks Half Marathon, but as part of our 10 for 10 campaign we wanted to focus on more regional events to make it easier for more people to participate. We therefore aligned with the AJ Bell Great Run Company and enrolled in six of their different events around the country in Birmingham, Bristol, Manchester, London, Newcastle and Glasgow. And in London we signed up for the Saucony 10k run.**

The charity’s target was to try and get 100 runners to take part. Sally was delighted to be able to report that this had been achieved:

> **Once again, our supporters stepped up for the challenge - when have they ever not? - and we have 108 runners registered so far across all the runs, which is so awesome. Most are doing 10k runs but several are also running half marathons where they are available, so we will exceed our 1,000,000 metres by some margin.**

A heartfelt thank you!

EHE-Italia wanted to express their deep gratitude to a member of their community for supporting the association at a very important moment:

> **We want to express all our gratitude to Noemi, who chose to dedicate the party favors for little Nicolò's baptism to our Association EHE ITALIA. Your gesture, Neomi, was one of great sensitivity and generosity that fills our hearts with joy and hope. Thank you for turning such a special moment into an act of support. Your support is invaluable and will help us carry forward our mission even stronger.**
>
> **Best wishes to Nicolò for this special day and a warm hug to the whole family!**

EHE ITALIA
ASSOCIAZIONE NON SOLO LAURA ODV

Supporta EHE ITALIA

DESTINATARIO:
Associazione EHE ITALIA – Non Solo Laura ODV

IBAN: IT05E0501803400000017044942
SWIFT CODE: ETICIT22XXX
Oppure tramite:
PayPal satispay

DONA IL 5x1000:
Associazione EHE ITALIA – Non Solo Laura ODV
CODICE FISCALE: 95294240635

Ogni contributo conta, ogni gesto di amore rende il futuro più luminoso. Dona oggi per un domani migliore!

08 giugno 2025
Nicolò

Per lasciarti un ricordo di questo giorno speciale, in occasione del mio Battesimo, con mamma e papà abbiamo scelto di sostenere l'Associazione EHE ITALIA - Non solo Laura ODV perché, grazie alla ricerca, tutti potremo sperare in un futuro migliore.

Grazie per aver condiviso con noi questa giornata!

Thank you Noemi for this wonderful gesture. But far more importantly, we want to congratulate you on the baptism of Nicolò who we sincerely hope will have a long and wonderful life full of joy and happiness.

Pediatric Cancer Club supports EHE again!

Jennifer Mulligan and family were honored to share news of further support for their son, Joe, and EHE:

> **We are so grateful for the generosity of Joe's school's Pediatric Cancer Club. For the last several years they have donated money to the EHE Foundation at the end of the year and today we accepted a $1,000 check! Julie Rivers Wahl and Delany were on hand virtually to inspire the club members with stories about the Foundation's start and its activities. Thank you to all involved for coordinating this annual gift! And a huge thank you to the Pediatric Cancer Club at Briarcliff High School for their superb ongoing support for EHE research.**

We have reported in previous editions of The Pledge about the support that Joe and EHE have received from the Briarcliff High School Pediatric Cancer Club. We are delighted to be able to add this report to the set, and want to also thank them for their wonderful ongoing support. You are all stars.

Live Stream delivers!

In the Patient Support & Advocacy section of this edition of The Pledge, we reported on the EHE Live Stream broadcast that was produced and transmitted on social media. This fantastic broadcast presented facts and information about EHE and the Charity and has made it available to a national audience.

But the group of students who produced the Live Stream understood how critical fundraising is to our charity and our ability to understand and ultimately defeat this horrible disease. They quickly became strong supporters of the cause and so included a fundraising element in to the broadcast. Reannah De Souza, who was the Producer of the whole programme was delighted to report the results of the fundraising:

> **My team and I are very happy with the whole production. We are so proud of everything we accomplished and how many people can say they did a charity livestream and raised £1,700**

Indeed Reannah, how many people can make that claim. We thought the production was very good and so professional. It captured the Just Live spirit of the EHE community, perfectly mixing the different elements of fun and getting on with life, the impact the disease has, and the optimism created by the research. Huge thanks to you and the whole team for such a great show.

Nicola swims her 10k for EHE

Nicola Henderson is an EHE patient who lives in Yate, in the west of England. Diagnosed with EHE 11 years ago, Nicola subsequently had a liver transplant, a process that is incredibly gruelling, taking a huge toll both physically and mentally. But Nicola, like so many other EHE patients, is a fighter and is determined not to let her EHE define her or limit what she does and can achieve. So when the 10 for 10 challenge was launched, Nicola was there for the fight, together with her huge group of wonderful supporters!
Nicola explained:

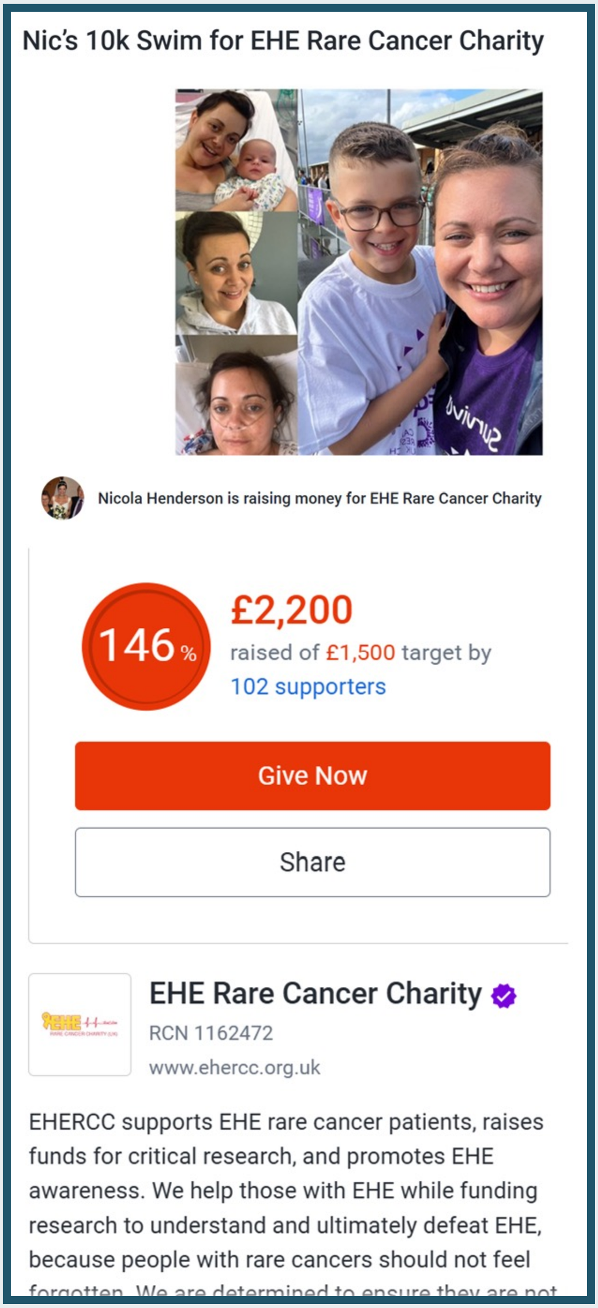
> **I'm taking on a huge personal challenge to swim 10 kilometres—400 lengths of a 25-meter pool (not in one go!) but hope to complete it within 1 month over various sessions in the pool!!! I want to raise awareness and funds for EHE (Epithelioid Hemangioendothelioma), a rare cancer that myself and others live with every day.**
>
> **EHE is a rare form of cancer, and those diagnosed often face an uncertain future with no support from government funding for research. Fundraising is down to Patients and their families making it harder for families and patients to get the support they need. My goal is to change that, to raise awareness, and to push for more research and resources so that others don't feel as alone as many of us do.**
>
> **Why am I swimming? Swimming 10 kilometres is a massive physical challenge for me. Since my transplant I suffer with low energy, fatigue and medication side effects everyday. The mental toll of living with a rare and incurable cancer is huge. This challenge will be a test of endurance, strength, and mental resilience. It's a way for me to channel the energy and focus I need while I wait for my next scan on April 22nd.**

> EHE is always on my mind, and this swim is my way of taking control and turning my emotions into something meaningful. It's also a way for me to push myself and see what my post-transplant body can do. I also hope to raise much-needed funds for a cause that I believe deserves far more attention.
>
> So please support me on this journey! Your donations will help fund research into EHE, support patients, and contribute to the fight against this rare cancer. Every contribution counts, no matter how big or small, and will make a real difference in the lives of those affected by EHE.

Nicola posted regular updates as she progressed with her swimming through April. Then on 11 April Nicola announced:

> Just completed my 10k swim challenge! 400 lengths done! Feel so proud of myself!!! Raised £1765 so far! Hoping when I add that I've completed I can get to a bit more!!!! And I thought of all my fellow EHE patients today in the pool.

As readers will see on Nicola's Just Giving page, she did indeed raise 'a bit more', with donations totalling £2,200 plus the associated gift aid of over £500. We want to congratulate Nicola on this amazing achievement and for the huge amount raised for EHE research. Just Live and Just Swim!



Nic's 10k Swim for EHE Rare Cancer Charity

Nicola Henderson is raising money for EHE Rare Cancer Charity

146 %

£2,200

raised of £1,500 target by

102 supporters

EHE Rare Cancer Charity

RCN 1162472

www.ehercc.org.uk

EHERCC supports EHE rare cancer patients, raises funds for critical research, and promotes EHE awareness. We help those with EHE while funding research to understand and ultimately defeat EHE, because people with rare cancers should not feel forgotten. We are determined to ensure they are not

"Throwing it together" for EHE Research

Sarah Bright posted news of a special day supporting EHE research:

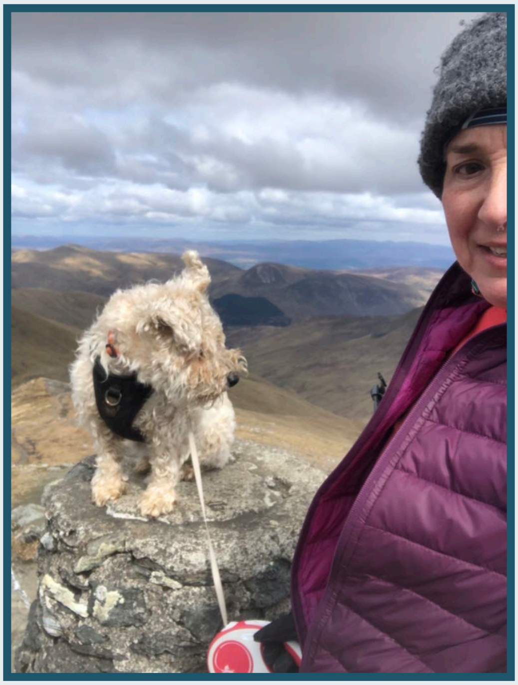
> It was a beautiful day for an EHE neighborhood walk and gathering! Life has been so busy that planning was hard. We kind of threw this together during one of the busiest months of the school year, but we were happy to raise some funds for EHE research! While I feel joy to be with friends, it is always bittersweet to commemorate the sadness and despair of my diagnosis, the gratefulness I feel in still being here, alongside grief for those we've lost. Keep loving, and keep living, fellow warriors. Just Live!

We love the 'Just Live' aspect of these photos, and of Sarah and her family's very obviously happy gathering; all while raising funds for EHE research. Thank you, Team Bright, once again.

Climbing 10 mountains to fundraise for EHE cancer research

Judith Gordon is an EHE patient based in Scotland. Like many others, Judith wanted to take on the 10 for 10 challenge and raise funds for EHE research.

> “
>
> I’m back, with more of a challenge this time. A lot of my fellow patients from WhatsApp are doing 10k runs, in ten different cities, to fundraise and raise awareness of EHE and a number run triathlons and even more difficult events to promote funding and awareness of the cancer they have, wow. I’m not great at running and not interested in training for it so have gone along a lazier route, but honestly I think it’s probably more difficult, certainly for me. I’ve set myself the challenge of climbing 10 mountains to fundraise, each one as near 3,000 ft as possible.
>
> I have already started and wasn’t sure of my ability so hadn’t posted this till I was sure I could do this ,since it’s been years since I walked up a mountain. The first was the Merrick ,which my husband turned into an adventure , and I thought the mountain would be that.



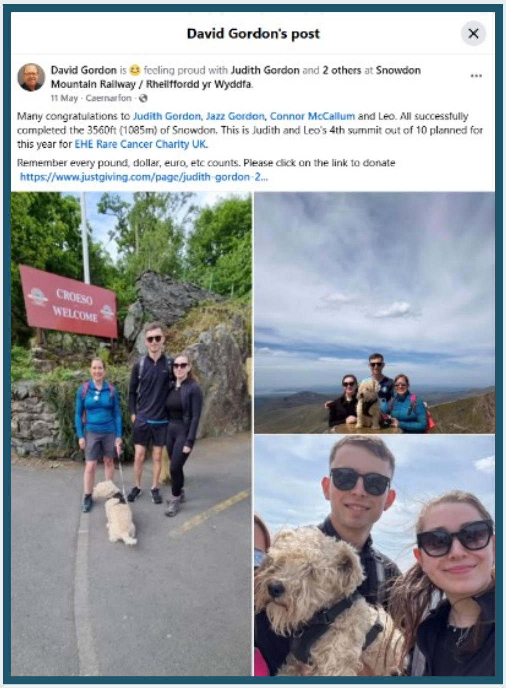
> The next two, Beinn Ghlas and Ben Lawer came as a package ,lovely hills ,lovely day and the ever gorgeous Leo as my constant loyal companion, who has walked every step beside me facing whatever the weather and mountains throw at us, what more could you ask for as encouragement. I have Slieve Donard organised for August and Snowdon next weekend , with daughter Jazz and partner Connor keeping me company and others will join me on the rest of the mountains to come this year.

> I'm unsure of the end date but should be finished by mid-November since the weather won't be so favourable after that, so please show appreciation of the hopefully not blood sweat and tears that are usually a part of these climbs and of course the swearing on my part that keeps me going when I'm struggling. Thanks again guys for your support and if speaking to me or hubbie David ask about the first climb, that's a story to give you a laugh. As you can see I'm doing well and hope to continue to be well, it's certainly not stopping me doing what I want.

Later, Judith reported on her early progress:

> I'm going to get my own just giving page set up since I've completed 3 mountains so far, Snowden's in 2 weeks and 6 more to organise. This is all instead of running a 10k , Dunno if it might have been easier to train and run!

Judith has received wonderful support from friends and family. David, her husband, has been supporting throughout. Clearly, from Judith's report above, David helped turn her first climb up Merick into 'an adventure'. We hope to have the full story in our next edition.



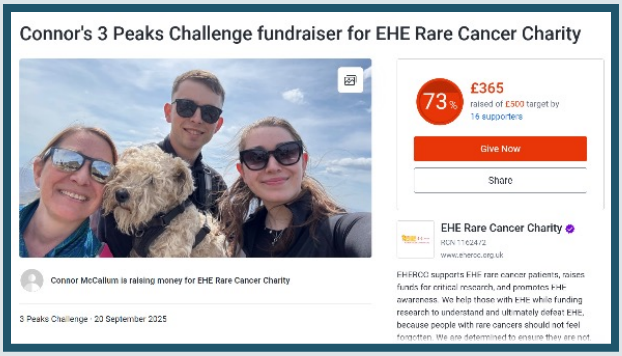
David Gordon's post

David Gordon is 😊 feeling proud with Judith Gordon and 2 others at Snowdon Mountain Railway / Rheilffordd yr Wyddfa.
11 May · Caernarfon

Many congratulations to Judith Gordon, Jazz Gordon, Connor McCallum and Leo. All successfully completed the 3560ft (1085m) of Snowdon. This is Judith and Leo's 4th summit out of 10 planned for this year for EHE Rare Cancer Charity UK.

Remember every pound, dollar, euro, etc counts. Please click on the link to donate https://www.justgiving.com/page/judith-gordon-2...

Judith has also inspired others to engage with fundraising for EHE research by supporting the EHE Rare Cancer Charity. Connor McCallum has also decided to take up the climbing theme and will be taking on the Three Peaks Challenge in late September which involves climbing the three highest peaks of Scotland, England and Wales, often within 24 hours.



Connor's 3 Peaks Challenge fundraiser for EHE Rare Cancer Charity

£365

73%

raised of £500 target by 16 supporters

EHE Rare Cancer Charity

RCN 1162472

www.eheroc.org.uk

EHERCC supports EHE rare cancer patients, raises funds for critical research, and promotes EHE awareness. We help those with EHE while funding research to understand and ultimately defeat EHE, because people with rare cancers should not feel forgotten. We are determined to ensure they are not.

Connor McCallum is raising money for EHE Rare Cancer Charity

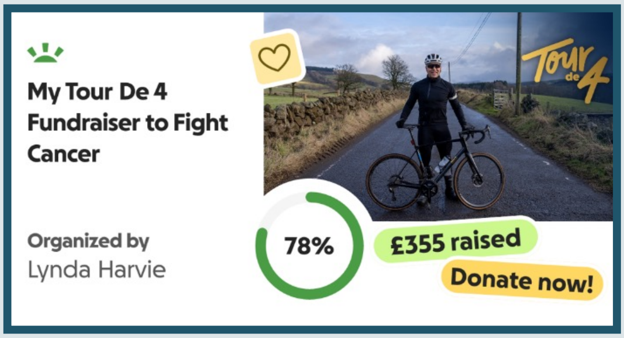
3 Peaks Challenge · 20 September 2025

As we go to press Judith has four more mountains to climb, while Connor has the 3 Peaks Challenge ahead of him. It's a fantastic effort from both of them. Here at The Pledge, we want to congratulate Judith and Connor and their support teams for such inspiring campaigns. Just Live and Just Climb

Lynda is a special friend

Judith Gordon is an EHE patient based in Scotland. She was very happy to be able to post news of her great friend, Lynda Harvie's fundraising for EHE research. "This is my friend fundraising for my cancer, helping us to develop treatment specifically for us, of which there is currently none, thanks for your help".

We want to thank Lynda too. Great job!



My Tour De 4 Fundraiser to Fight Cancer

Organized by
Lynda Harvie

78%

£355 raised

Albion fundraisers continue

The parents-in-law of one UK EHE patient, Emma, run a micro-brewery and bar called the Albion. Becs and Kevin have been wonderful supporters of EHE research, organising a string of events from the bar. Their customers too have taken up the challenge, all supported and promoted by Emma's family and friends. Becs and Kevin saw Easter as another chance to support the charity and ran a simple 'guess the number of eggs in the jar' challenge to raise research funding.

Hugh Leonard was very grateful:

> **Having a family member with EHE is very stressful indeed for all involved. So, for Becs and Kevin to think of fundraising at this time is exceptional. We could not be more grateful. It really is a gesture of such compassion at this difficult time.**

Here at the Pledge, we want to thank Becs and Kevin and all their customers too.

04 And in other news...

The motto of our global patient community is “*Just Live*” because patients are determined not to let their EHE define who they are or what they can do. Here are some photos of the community doing precisely that. We thank them for posting these photos and sharing their adventures.

Getting together is great to see

Every quarter we are thrilled to see photos of our global patient community meeting each other to make contact, share experiences, and provide that unique support that only EHE patients can give to each other. Here are this month's get-togethers.

Bettina Klöti posted news of her meeting with Maeve Baechler:

> **Yummy lunch with Maeve Baechler in the world's oldest Veggie Restaurant, "Hiltl" in Zurich. Happy about the shirt and happy to exchange with someone who really understands what it means to live with EHE... Thank you for the shirt-campaign and thank you Maeve for being you!**

Maeve was also delighted to meet with another EHE patient;

> **I met up with Alessandra Kobel in beautiful Küssnacht in Rigi, Switzerland!**

Jane Biddlecombe from Australia and Hugh Leonard were both thrilled to get together in Londo:

> **A sunny 27 degrees, avoiding the tourists and doing a sneaky pub crawl through the elegant streets of Mayfair! Extra special was starting my day with a very important person in my world, Hugh Leonard, if you know you know**

A special message for Mother's Day...

Each year, as Mother's Day approaches, Jane Gutkovich posts a fantastic photo, with powerful message, capturing the power and essence of motherhood. We always share this with the community as for us, it speaks to the power of parental advocacy. Never stop posting this photo Jane. We know you won't.

Powerful picture... Fear nothing in front of you because of who is behind you !!!!

... and a special message for cancer!...

Émilie Fagot-Barraly posted this photograph with it excellent message to cancer. Emilie simply said "I love this one". We do too Emilie. It made us smile.

... and fantastic cookies!

Sally and Hugh travel to the Royal Marsden in London for Sally's scans,, and celebrate stable results by buying some Ben's Cookies – the best in London. Hugh says it's almost worth the trip! Hugh was introduced to Ben's by Holly Barker, a visiting cancer researcher from the WEHI Institute in Australia. "Thank you, Jono Granek, for the introduction.,

The EHE Foundation (USA)
www.fightehe.org

The EHE Rare Cancer Charity (UK)
www.ehercc.org.uk

The EHE Rare Cancer Foundation (Australia)
www.ehefoundation.com.au

EHE Italia-Associazione Non Solo Laura ODV
www.ehe-italia.it

EHE Canada
website not yet available

Just live