

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
October - December 2025

the pledge

Edition 43



Just live

the **pledge**

Edition 43

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Front cover: (left to right) Luca Zambelli, MD (Istituto Nazionale Tumori), Verena Loidl, PhD (SPAGN), Claudia Giani, MD (Istituto Nazionale Tumori), Denise Robinson (EHE Foundation), Catarina Padilla, MSc (Netherlands Cancer Institute), Sania Choudhary (EHE Foundation)

Welcome

Celebrating 10 years!

We are delighted to issue our 43rd edition 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.

We love sharing stories about the activities of all those involved, especially as we continue to celebrate our tenth year of activities. We hope you will find the many stories included in the following pages inspiring.

They are all wonderful examples of the group's mantra:

“Alone we are RARE, but TOGETHER we are STRONG!!”.

Just Live!



Highlights

Giving Tuesday Fundraising hugely successful again

Both the EHE Foundation and EHE Canada ran matched-funding campaigns coincidentally with Giving Tuesday. Both were thrilled to report that they had more than met their fundraising targets.

EHE Group members collaborate on funding

Joint funding of research amongst the EHE not-for-profits continues to foster collaboration between the different groups. There are now EHE research projects being jointly funded in the US, Australia, Europe and the UK, helping to bring the global EHE communities and initiatives closer together.

EHE well presented at CTOS

The CTOS Annual Meeting held at Boca Raton in Florida included both verbal and poster presentations about EHE, as well as clinical trials and observational studies involving the disease. Denise Robinson, Executive Director of the EHE Foundation, was there. See her report on this exciting exposure for EHE in the research section of this edition.

Substantial EHE study published in Canada

This quarter saw the publication of the Canadian Sarcoma Research and Clinical Collaboration (CanSaRCC) and Multi-pronged Canadian Research in Epithelioid Haemangioendothelioma (PRO_CARE EHE) study involving 198 patients.

10th Year fundraising continues to deliver

Celebration of the 10th anniversary of the original three EHE not-for-profits continued with great grass roots fundraising.

Australia runs wonderful 10th Birthday celebration

Continuing the theme of 10th Anniversary celebrations, The EHE Rare Cancer Foundation Australia ran a wonderful campaign designed to celebrate their achievements over the last ten years while bringing the Australian and New Zealand communities closer together.

Details on all these stories, and much more, can be found in this, our edition 43rd of The Pledge. We hope you enjoy them.

the
pledge Edition 43



01 Patient Support and Advocacy

One of the key objectives of the EHE community is to create greater awareness of EHE, improve support for our patient community wherever they are on the globe, and promote and support EHE research which is so important to our ability to successfully treat EHE. Much of the support is provided by patients themselves, through the EHE social media platforms. At the same time, advocacy activities are also undertaken by the EHE Group entities in their respective regions. The following pages contain stories of just some of the activities that took place during the last quarter of 2025.

Fiona Ross advocates for EHE patients everywhere

Canadian EHE patient and passionate EHE advocate, Fiona Ross, has once again been busy with speaking engagements during 2025 at various academic institutions. Fiona believes that sharing the experience of being an ultra-rare cancer patient and highlighting the power and importance of the patient/physician relationship is a key part of continuing to move EHE research and advocacy forward.



In April and May of 2025, she spoke at conferences organized by the pharmaceutical company Boehringer Ingelheim, regarding the experience of clinical trials for rare cancer patients. In May she also spoke as a patient advocate at CISS (Canadian International Sarcoma Symposium) about how to be an engaged and proactive patient partner.



In October she did a zoom presentation for Grand Rounds at Kingston General Hospital about the partnership between medical professionals and patient advocates.

We want to thank Fiona for her ongoing

support for EHE patients and our EHE cause, wherever these may be in the world. It is without doubt thanks to people like Fiona that the EHE Group has been able to make the progress it has. Keep up the great work Fiona. You are helping to make a difference.

EHE Foundation - gaining momentum

The EHE Foundation in the US continues to go from strength to strength and was delighted to report two new developments in the fourth quarter:

Joining forces to defeat EHE

The Center for Research and Analysis of Vascular Tumors (CRAVAT) Foundation donated its resources to The EHE Foundation in a powerful alignment of vision and commitment to the people affected by epithelioid hemangioendothelioma (EHE) and the EHE scientific community.



Founded in 2015 by Guy and Mary Weinberg, CRAVAT has provided support to those affected by EHE, raised awareness, funded basic research, supported scientific conferences related to EHE, and contributed to the development of potential treatments over the past decade. The EHE Foundation was therefore honoured to have the trust of the CRAVAT Foundation as they carry forward their shared goals of patient support, global advocacy, and critical research into treatments for EHE.



01 Patient Support and Advocacy

As part of this alignment, Dr. Guy Weinberg will continue to serve the EHE community as a member of the EHE Foundation's Board of Directors, where his invaluable leadership will help guide the future of EHE research. Denise Robinson, Executive Director of the EHE Foundation said:

“

The EHE Foundation is indebted to Guy and Mary Weinberg for their vision and for placing their trust in The EHE Foundation. We are eternally grateful to long-standing CRAVAT Foundation supporters and collaborators, and we stand committed to the vision and legacy of this invaluable organization. Together, we are stronger and will remain acutely focused on tackling this ultra-rare disease.

Dr Guy Weinberg, MD, and Founder of the CRAVAT Foundation, said:

“

I am thrilled to join the EHE Foundation and help advance our shared goals of supporting the EHE community and finding a cure for this disease.

New Research Director appointed

The EHE Foundation was proud to announce the appointment of Kristianne (“Kristi”) Oristian, PhD, as their new Director of Research & Engagement. In this role, Kristi will work closely with Executive Director Denise Robinson, who previously led both organizational and research strategy, to advance the Foundation’s mission and strengthen its growing impact across the global EHE community.

Kristi joins the Foundation with a deep commitment to sarcoma research and patient advocacy. Originally from Maryland and now based in North Carolina’s Research Triangle

area, she brings more than a decade of experience at the intersection of scientific discovery and community engagement. Kristi earned her BS in Biochemistry from Elon University and her PhD in Pharmacology and Cancer Biology from Duke University, where her work centered on fusion-driven sarcomas, the Hippo signaling pathway, and preclinical model systems, all of which are, of course, directly relevant to EHE.



Her scientific expertise is matched by her passion for the people affected by rare cancers. Kristi has been an active voice in the sarcoma community, advocating for approaches that recognize both the shared challenges of rare diseases and the unique needs of each patient. She is a firm believer in collaborative science and in ensuring that research is rigorous, accessible, and meaningful to the patients it aims to serve.

In her new role, Kristi will help execute the Foundation’s strategic research and engagement priorities—cultivating partnerships, supporting emerging science, elevating patient needs, and driving progress toward better outcomes for all who face EHE.

Outside the lab and office, Kristi is known for her love of the outdoors and all things furry. When she’s not working, you can often find her camping, fishing, cooking, or cuddling a critter alongside her husband and stepson.

Here at The Pledge, we are also thrilled to welcome Kristi to the EHE Foundation.

Genomic profiling explained

One of the common requests we see from the EHE community is for explanations about genomic profiling. This is driven largely by the community's understanding that genomic profiling is important, together with a lack of knowledge about what it is and how it can help patients. A significant degree of variation in the use of genomic profiling from country to country, and even hospital to hospital within the same country, adds to the desire for more information.



The EHE Foundation was delighted therefore, when Dr. James L. Chen, a medical oncologist specializing in the diagnosis and treatment of sarcomas at The Ohio State University James Cancer Center and Senior Vice President for Medical Informatics at Tempus AI, agreed to participate in a webinar in December addressing genomic profiling as part of the EHE Foundation's 'EHE 360 Connect' educational programme.

The webinar allowed the EHE community to participate in a conversation about genomic profiling – an important tool that can help guide treatment decisions, support and inform clinical trials, and pave a path to progress in EHE research. Dr. Chen explained genomic profiling – also called next-generation sequencing – why it matters for people with EHE, and how it informs clinical care and drug development.

This was another excellent session with many attendees posting their thanks to Dr Chen for providing such valuable information. The EHE Foundation was also deeply grateful to Dr Chen for his time and expertise.

We want to send our thanks too to Dr. Chen, and to the EHE Foundation for another excellent webinar. And for anybody who missed the webinar, a recording can be found on the EHE Foundation website [here](#).

Can you share your story?

One of the core objectives of the EHE Group is to expand knowledge and awareness of EHE. One of the most powerful ways to do this is when EHE patients and caregivers actually tell their story, providing the public with direct insight into what living with EHE is like using video recordings.

It was for this reason that Maggie Cameron, EHE Patient and Director, Development & Communications, at the EHE Foundation reached out to the community:



Hey everyone! I'm looking for people in the group who would be willing to share their EHE story, either as a patient or a caregiver. Specifically, I'm looking for people to share a little video of themselves - nothing fancy, very quick and easy. Let me know if you're interested, and I can provide more info!

Maggie was very grateful to those who responded. We know that Maggie would like to get further contributions, so if you feel this is something you would like to do, please contact Maggie at maggiecameron@fighthehe.org.



01 Patient Support and Advocacy

EHE RCFA celebrates 10 years!

As many of our readers know, 2025 was the tenth anniversary of the setting up of the three original EHE not-for-profits. The EHE Foundation was first in Q2, with the EHE Rare Cancer Charity (UK) following up close behind in Q3. Last, but definitely not least, came the EHE Rare Cancer Foundation Australia (EHE RCFA) in Q4. We were delighted therefore to see EHE RCFA celebrations on the Facebook EHE Patient Support page during the last three months of 2025.



EHE RCFA started with reminders of their fundraising through the last decade:

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Did you participate in the 10K Steps Challenge between 2017 - 2023? Let's celebrate those memories! Share your favorite photo from the challenge in the comments below. We can't wait to see your throwback moments!

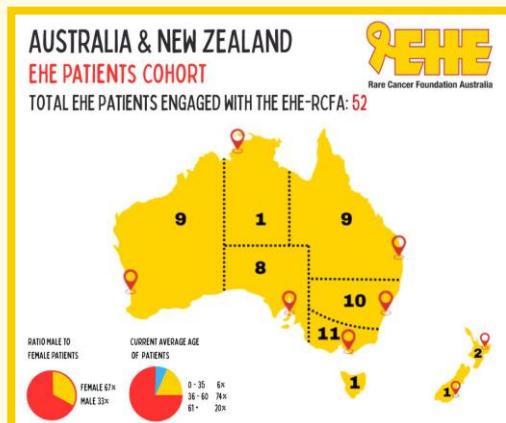
Since 2017, the EHE Rare Cancer Foundation Australia also hosted the 10K Steps Challenge every 2 years, with the support of patients across Australia. This event is more than just a fundraiser; it's a powerful reminder of our strength as a community. Every step you took helped raise vital funds for EHE research, pushing us closer to a future without this rare cancer.

The EHE RCFA also wanted to celebrate the wide distribution of EHE patients across Australia and New Zealand. Jane Biddlecome of the EHE RCFA said:

“

Our EHE community in Australia is growing, and we want to take a moment to celebrate how many of us there are and where we are located!

VIC: 11 patients;
NSW: 10 patients;
QLD: 9 patients;
WA: 9 patients;
SA: 8 patients;
NT: 1 patient;
TAS: 1 patient; and
NZ: 3 patients.



“

It's incredible to see our community growing and connecting all over the country.

Jonathan Granek, President of the EHE-RCFA also wanted to look back at the research they had funded:

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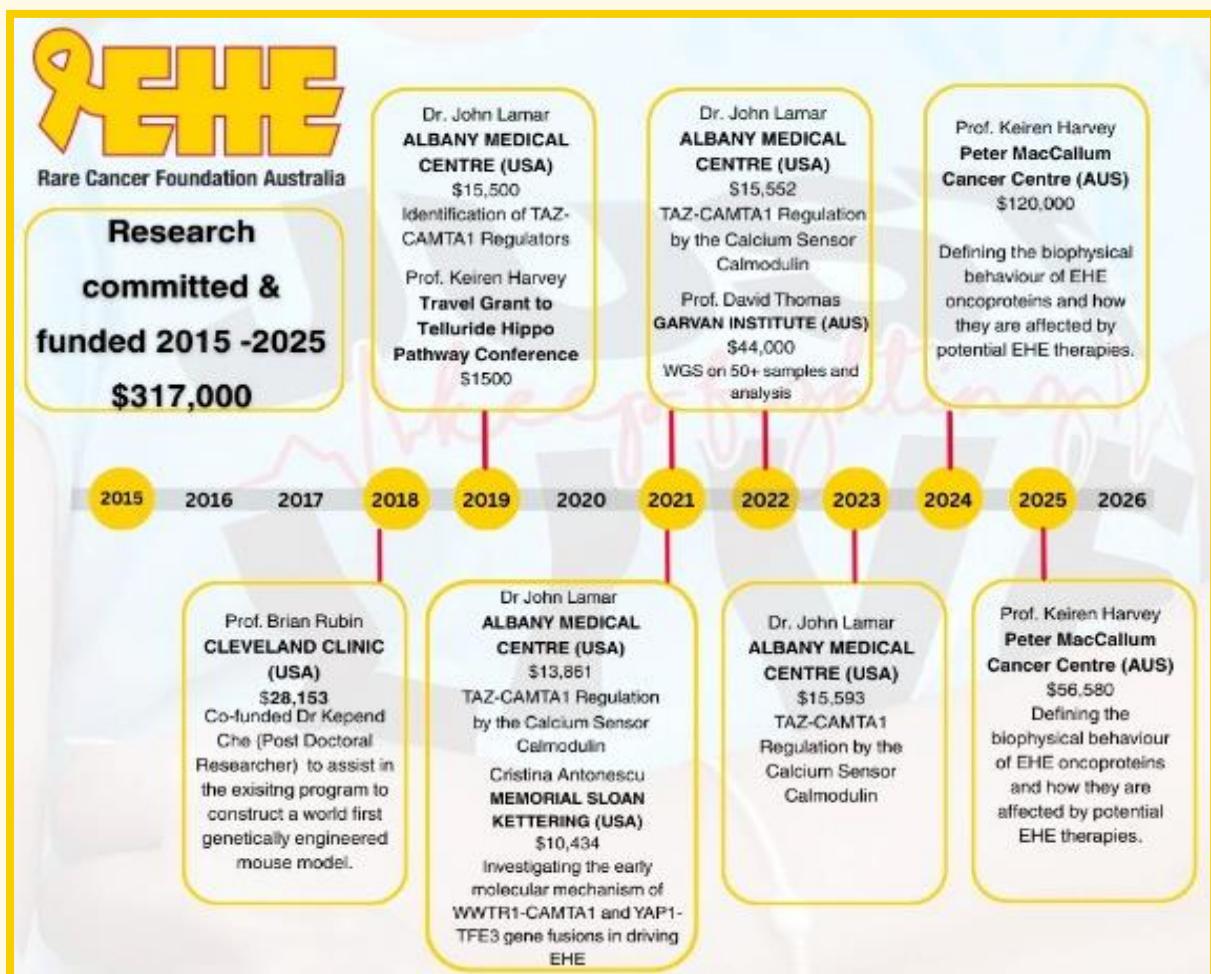
Thanks to the incredible generosity of the Australian EHE community of patients, carers, families and friends, we have, over the last 10 years, committed 317,000 dollars, raised through fundraising, to fund frontline & groundbreaking research.

“

This is a testament to the power of our community, and shows that every contribution to the EHE-RCFA, big or small, has made a difference.

Your contributions, right here in Australia, have enabled us to support vital studies, including groundbreaking work into the Hippo Pathway and the unique proteins that drive EHE.

Thank you for your continued trust and belief in our mission.



01 Patient Support and Advocacy

Contacting Europe!

Marianna Coutinho is an EHE patient and lives in Portugal. She has been a wonderful ambassador and advocate for EHE since the day of her diagnosis, even speaking at the EU Assembly on behalf of young cancer patients. Marianna has always been passionate about bringing the EHE community together and at the end of last year posted a question for her fellow EHE patients in Europe:

“

Hi everyone! I'm going to create a WhatsApp group specifically for European EHE patients. I know there's already a fantastic group for UK patients, so this new group would aim to bring together those of us living in other European countries - to connect, share experiences, and stay updated on research and clinical opportunities.

The idea is to make it easier for us to stay closer in touch and support each other, regardless of where in Europe we live because living with a rare cancer like EHE can feel less lonely when we're connected. If you'd like to join, then please leave a comment below or send me a private message.



This is a wonderful initiative, Marianna. We hope that you will be able to get many of our

European EHE community connected and break down the feelings of isolation that rare disease can cause. To assist in this initiative, Marianna, Andrei Ivanescu of EHE Italia, and Hugh Leonard of the EHE Rare Cancer will be coming together to talk about their combined European plans and reaching out all European EHE patients.

Supporting Adults with EHE

The EHE Foundation, in collaboration with Dr. Maeve Baechler, an EHE patient herself, established the 'Adults Affected by EHE' forum as part of its 'EHE Support Groups' initiative.

These sessions are intended for adults aged 18+ who understand and experience the challenges of the disease and are open to both EHE patients and those whose loved ones are diagnosed with the disease.



Facilitated by Dr. Maeve Baechler, an EHE patient and psychiatry resident, these meetings offer a chance to share, listen, and support one another in a private, supportive space. Occurring monthly, the sessions are free, and participants are required to register [here](#).

Exploring Histotripsy as a Treatment Option for EHE

With significant interest in the EHE patient community concerning the new histotripsy treatment that was becoming more widely available in 2025, the EHE Foundation was delighted when three clinical specialists agreed to participate in a one-hour webinar and Q&A session about the technique as part of the EHE Foundation's 'EHE 360 Connect' educational seminar programme.

Dr Wang and Dr Wagner from the Dana-Faber Cancer Institute and Dr Shyn from Brigham and Women's Hospital provided an overview of how the system works and the criteria for assessing whether the technique is suitable for treatment of a specific patient. They then answered a range of questions posed by the EHE community through Denise Robinson, Executive Director of The EHE Foundation, who was the facilitator for the session.



We want to thank Drs. Wang, Shyn, and Wagner for giving their time to explain Histotripsy to our community. For anybody who may have missed the webinar, a recording is available on the EHE Foundation website [here](#).

Histotripsy was also the subject of an article posted by Mark Roby involving a BBC interview with Professor Zhen Xu, a member of the University of Michigan team that developed the process. Professor Zhen Xu explained:

“

For treatment of liver cancer, histotripsy devices channel ultrasound waves into a focal zone of about two by four millimetres – 'basically, the tip of your colouring pen. Then, a robotic arm guides the transducer over the tumour to target the correct area.



The full interview can be found [here](#).

These developments are exciting, but we note that these treatments are not specifically approved or proven for EHE and encourage patients to discuss all treatment options with their sarcoma medical oncologist.



02 Research

In this Research section of our newsletter, you will find news and articles relating to EHE research and our understanding of the disease. A significant amount of this work is supported and funded by the EHE Group entities thanks to the wonderful contributions from the global EHE patient community. It is this research that will ultimately help doctors find new ways to treat and manage EHE. We hope you will be inspired by the work taking place. Together with our patient community, the researchers and clinicians are at the heart of everything we do.

EHE Research on the Global Stage: Highlights from CTOS 2025

The EHE Group were represented at CTOS by Denise Robinson, Executive Director of the EHE Foundation, who had the privilege of attending the CTOS 2025 Annual Meeting, held November 12-15, in Boca Raton, Florida. The Connective Tissue Oncology Society (CTOS) is a global medical professional organization of clinician-scientists, translational researchers, and patient advocates united by a single goal: advancing the treatment of sarcomas. Denise Robinson explained:

“

For the EHE community, this annual gathering is one of the most important opportunities to elevate our voices on the global research stage. As professional advocates, the Foundation makes a point to be actively engaged, connecting with drug developers, researchers, clinician-scientists, and the world's leading experts in EHE. This is advocacy in action: creating opportunities for collaboration, generating new ideas, and driving the momentum needed to accelerate progress for people living with this ultra-rare sarcoma.

Here are some of the EHE highlights from the CTOS Conference:

Ultra-rare Sarcoma Working Group (URSWG)

The Ultra-Rare Sarcoma Working Group (URSWG) meeting featured progress on the PUSH Platform, a consortium of the global sarcoma community focused on collecting and using all available evidence to accelerate the development of new treatments for people with ultra-rare sarcomas. The consortium has several sarcoma-subtype working groups, including the EHE Working Group. This is an active group of clinicians from several countries, plus EHE patient advocates, working to improve understanding of the disease,

integrate data from all known sources, and advance translational and clinical research to accelerate treatment development. Denise Robinson and Hugh Leonard from the EHE Rare Cancer Charity are members of this working group, as well as being members of the PUSH Executive Committee.



SARC Semi-annual Meeting & SARCO46

The Sarcoma Alliance for Research through Collaboration (SARC) convened its semi-annual meeting, featuring the new EHE study, SARCO46: A Phase II Trial of Nab-Sirolimus in Patients With Progressing or Symptomatic Epithelioid Hemangioendothelioma, planned to open in early 2026.

This new clinical trial, led by Dr. Michael Wagner at Dana-Farber Cancer Institute, will be open at several locations across the United States. The EHE Foundation hopes to have further information in early 2026.



02 Research

Poster Reception at CTOS

EHE was well represented at the CTOS Poster Reception. Teams from multiple countries presented new data that broaden our understanding of EHE and point toward better ways to treat this complex disease. Some of this work has resulted from research sponsored by the EHE Group, which in turn has been possible only because of the amazing energy, dedication, and generosity of all those who have raised funds for EHE research. Posters included:

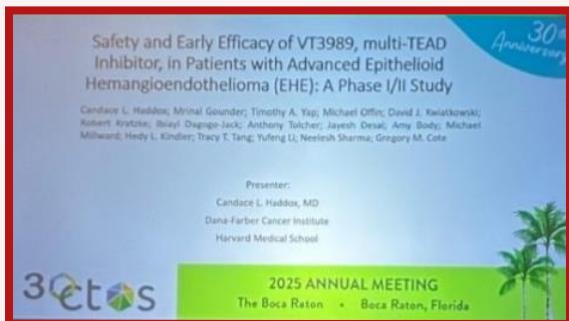
- Overcoming Challenges in Ultra-Rare Sarcomas: a Centralized Biobank for Epithelioid Hemangioendothelioma as a Resource to Accelerate Discovery
- Understanding Gaps in Knowledge and Patient-Reported Pain in Epithelioid Hemangioendothelioma: Results from a Global Patient Registry
- GDF-15 As A Prognostic Factor in Patients with Epithelioid Hemangioendothelioma

- Health-Related Quality of Life (HRQOL) Challenges in Patients with Epithelioid Hemangioendothelioma (EHE): Analysis of an Ultra-rare Sarcoma Group
- Pain Assessment Criteria (PAC) Anticipate RECIST Progression and Correlate with Blood Levels of Growth Differentiation Factor 15 (GDF15) in Epithelioid Hemangioendothelioma (EHE)
- Determinants of Diagnostic Interval in Epithelioid Hemangioendothelioma: a Linear and Quantile Regression Analysis of Patient-Reported Data From the SPAGN Global Sarcoma Diagnosis Pathway Survey
- First-Line Pazopanib in Patients with Epithelioid Hemangioendothelioma: A Retrospective Single-Center Analysis

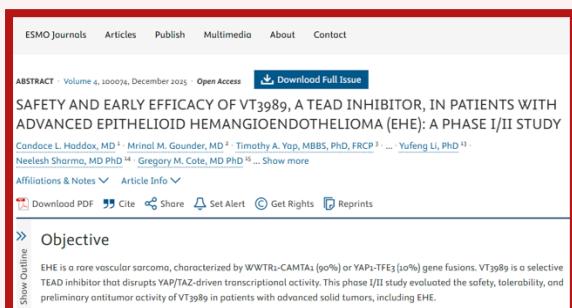
We extend our sincere thanks to all the authors and collaborators whose work strengthens hope for patients and families, and of course to all those fundraisers and supporters who have raised such amazing sums of research funding.



VT3989 Study Data Presented



Dr. Candace Haddox, Dana-Farber Cancer Institute, presented safety and early efficacy data of VT3989, a multi-TEAD Inhibitor, in patients with advanced EHE. VT3989 is currently being investigated in a Phase I/II multi-center trial. Dr. Haddox reported on 14 patients enrolled, concluding that VT3989 has a favorable safety profile, meaning generally, the drug has been shown to be safe and well tolerated, with limited side effects. The data demonstrate compelling efficacy in EHE and support further investigation.



Dr Haddox and her team have also published preliminary results of the trial in ESMO Journals, entitled "SAFETY AND EARLY EFFICACY OF VT3989, A TEAD INHIBITOR, IN PATIENTS WITH ADVANCED EPITHELIOID HEMANGIOENDOTHELIOMA (EHE): A PHASE I/II STUDY". The paper can be found [here](#).

Denise Robinson from the EHE Foundation said:

“

The EHE Foundation will continue working closely with Vivace to advocate for the continuation of studies. We remain grateful to the patients who participate and the physicians and study teams whose expertise drives this research.

TEADES Phase I/II Study of ODM-212 Preliminary Results in EHE



Orion Corporation presented preliminary data from its TEADES Study, an early-phase investigation of its novel oral pan-TEAD Inhibitor, ODM-212. Early data demonstrate durable tumor regression with TEAD inhibition by ODM-212. This study is ongoing, with new study centers anticipated. Please stay alert for more information regarding this clinical trial.

Radiologic Response in EHE: Beyond RECIST?



Dr. Andrea Vanzulli, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, presented an overview and results of the utilization of RESCORe (Response Evaluation by Serosal Changes and Outcomes Reporting Criteria) to assess tumor response to treatment in patients with aggressive EHE who have EHE-related serosal involvement. Study data showed that this newly defined assessment tool could serve as an extension of RECIST (the current standard criteria for tumor response assessment) for patients with aggressive EHE. Ongoing research will yield additional data, with further studies anticipated.



02 Research

Canadian EHE study published

Fiona Ross, one of our powerhouse EHE advocates in Canada, was delighted to share a publication of a study of EHE patients in Canada, published in the European Journal of Cancer in December. The study represents the largest collection of data from people with EHE in Canada yet published.



Original Research

Incidence, prevalence and treatment of patients with Epithelioid Haemangioendothelioma (EHE) in Canada: A Canadian Sarcoma Research and Clinical Collaboration (CanSaRCC) and Multi-pronged Canadian Research in Epithelioid Haemangioendothelioma (PRO_CARE EHE) study

Catherine S. Weadick ^{a b 1}, Aisha Alshibany ^{a b 1}, Michelle Jude Michael ^{a c}, Caroline Holloway ^d, Xiaolan Feng ^{e 2}, Christopher Lemieux ^f, Nikol Kuleshov ^f, Luigi Russo ^d, Yusra Kassim ^g, Hugo Styves ^h, Evonne Henning ^h, Joel Werier ^g, Ramy Saleh ^h, Jonathan Noujaim ⁱ, Abha A. Gupta ^{a c}, Hagit Peretz Soroka ^{a c 3}, Albiruni Abdul Razak ^{a b 3}  

The study team, led by Drs Catherine Weadick and Albiruni Razak, again demonstrated that EHE can behave significantly differently from one patient to the next. About one-third of patients were diagnosed by chance and did not need immediate treatment, while others had more aggressive disease. About half of the patients had disease that had already spread at diagnosis, most commonly to the liver or lungs. The study also showed that many patients did not receive molecular testing to identify their fusion gene, and only about one-third were treated with systemic therapies such as sirolimus or other targeted drugs.

Overall survival was just over eight years, reinforcing that EHE is often a long-term, chronic condition. Outcomes were generally worse for patients with lung involvement, fluid buildup around the lungs or abdomen, older age, or metastatic disease. The authors emphasize that treatment decisions must be highly individualized—some patients can be

safely monitored, while others benefit from therapy based on symptoms and disease behavior.

This excellent paper is yet another example of the importance of collating patient data from as many patients as possible, allowing detailed analysis of that data in the search for patterns and correlations that can help in the identification of new treatment ideas, or suggest likely biological mechanisms that may give us greater understanding of the disease. This was another important study, and adds to the globally growing momentum in EHE research.

We want to thank the Canadian team for this excellent study.



Dr Albiruni Razak



Dr Catherine Weadick

Supporting the EHE Patient Registry

This Canada paper again shows the huge value of patient data when it is collected and analysed. We therefore also want to encourage all the members of our EHE patient community, wherever you are, to please consider joining the EHE Patient Registry. It does not take much time to fill in yet could lead to break-throughs in our understanding of this horrible disease. Information about the Registry can be found [here](#).

Exciting Progress in EHE Research – Powered by Patients

The EHE Foundation were thrilled to share a new publication, 'EHE cell cultures are a platform for mechanistic and therapeutic investigation', made possible by its partnership with the University of Iowa. Under the leadership of Dr. Munir Tanas, Nicholas Scalora, PhD, and colleagues in the Tanas Lab sought to develop long-term EHE cell cultures from biospecimens obtained through the EHE Biobank. These new cultures will allow researchers to better understand how EHE grows and make it possible to test new treatments in these human-derived models.

The EHE Foundation sponsors and manages the EHE Biobank with this purpose in mind – to accelerate research that will lead to better therapies for people living with EHE. Patient-donated tumor tissue, blood, and fluid are the only pathways to develop human EHE cell models for research.

The EHE Foundation extended their sincerest gratitude to all the patients who have donated tumor tissue or other specimens to the EHE Biobank. Denise Robinson, Executive Director

of The EHE Foundation, wanted to address those patients who supported the EHE Biobank:

“

This exciting EHE science and research milestone was made possible by many of you who contributed tissue to the EHE Biobank in the U.S! Your donations of tissue, coupled with our partnership between the Tanas Lab at the University of Iowa, and the amazing work of Drs. Tanas, Scalora, and their colleagues have led to great results which have just been published!

The Foundation is also deeply grateful to the Tanas Lab for their partnership and perseverance in this effort, and to Dr. Brian Rubin and the Cleveland Clinic Biorepository for providing oversight and professional resources to the EHE Biobank.

You can learn more about how you can be an EHE tissue donor [here](#).



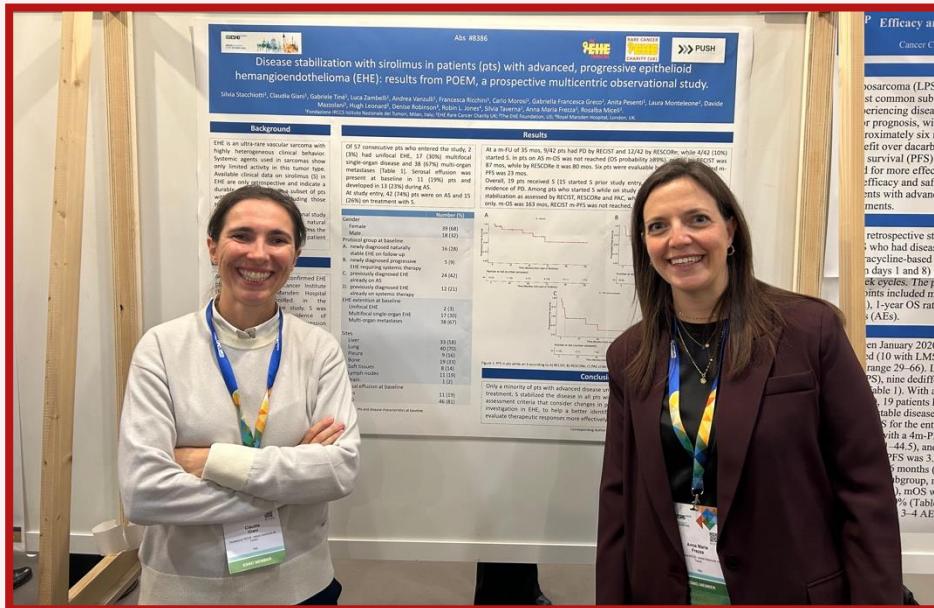
O2 Research

EHE Stabilization with Sirolimus: Results From POEM, a Prospective Multicentric Observational Study

Drs. Claudia Giani, Anna Maria Frezza, Silvia Stacchiotti, and colleagues from the Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy, and the Royal Marsden Hospital, London, UK, presented results from POEM: a prospective observational study on Epithelioid Haemangioendothelioma at ESMO Congress 2025.

The data presented included 57 consecutive molecularly confirmed EHE patients who entered the study, with sirolimus offered to patients with evidence of symptomatic and/or radiologic progression (PD).

Median Overall Survival (m-OS) was compared between patients undergoing active surveillance (AS) and those receiving sirolimus. Progression-Free Survival (PFS) was assessed by RECIST v1.1. As additional exploratory endpoints, pain changes were evaluated retrospectively by newly defined Pain Assessment Criteria (PAC); and radiologic and effusion changes by Response Evaluation by Serosal Changes and Outcomes Reporting (RESCORE).



Dr. Claudia Giani (left) and Dr. Anna-Maria Frezza (right)

Overall, 19 patients received sirolimus. Among patients who started sirolimus while on study due to PD, 3/4 achieved disease stabilization as assessed by RECIST, RESCORE, and PAC, while 1/4 by RECIST and PAC criteria only. m-OS was 163 mos, RECIST m-PFS was not reached, RESCORE m-PFS 52 mos.

The researchers conclude that, in addition to RECIST, other assessment criteria that consider changes in pain and serosal effusion warrant further investigation in EHE to better identify patients requiring treatment and to evaluate therapeutic responses more effectively.

This study is being expanded and has been extended by a further three years and is jointly sponsored by EHE Italia-Associazione Non Solo Laura, the EHE Foundation, and the EHE Rare Cancer Charity. All three of the EHE sponsors are grateful to the researchers and patients who contribute to these findings which once again amplify the importance of collating data from patients with ultra-rare sarcomas.

Translating molecular mechanisms of EHE to improve patient outcomes

Translating molecular mechanisms of epithelioid hemangioendothelioma to improve patient outcome

Alessia Beretta ¹, Silvia Stacchiotti ², Yuen Bun Tam ³, Robin L Jones ⁴, Claudia Giani ²,
Nadia Zaffaroni ¹, Paul Huang ³, Sandro Pasquali ⁵

Scientists know that EHE tumors are caused by specific genetic changes called gene fusions. In about 90% of people with EHE, two genes, WWTR1 and CAMTA1, are abnormally fused. In a smaller number of cases, a different fusion involving YAP1 and TFE3 is present. In a recent review published in Critical Reviews in Oncology/Hematology, the authors, many of whom are directly engaged in research sponsored by the EHE Group, bring together what scientists have learned about how these gene fusions change normal cell behavior and drive EHE tumor growth.

They describe how these fusion genes disrupt key cell signaling pathways that regulate cell growth, survival, and movement. When these pathways are overactive, tumors may become more aggressive or harder to treat. By studying EHE cells in the lab and in animal models, researchers are beginning to identify biological markers that may help predict how the disease behaves, as well as specific pathways that could be targeted with new treatments. New research must also focus on identifying how the biology of aggressive and indolent forms of EHE differs to develop more effective therapies for patients.

Here at The Pledge, we want to add our thanks to the authors for focusing on these important EHE issues.

YAP1-TFE3 effects exposed

The EHE community met Dr Jason Hanna, PhD, at the 2025 EHE 360 Global Patient Conference, where he highlighted work his lab is undertaking in EHE. The EHE Foundation was therefore thrilled to share a recent publication in Molecular Oncology from the Hanna Lab at Purdue University, highlighting their findings from a study focused on the YAP1-TFE3 subtype of EHE.



The YAP1-TFE3 subtype accounts for only about 10% of EHE cases, so while EHE is understudied, this very small subset receives less research focus. In this work, researchers found that the YAP1-TFE3 fusion protein forces endothelial cells to change their identity in a process called endothelial-to-mesenchymal transition (EndMT). This causes the cells to lose their endothelial characteristics and take on more mesenchymal-like properties. The cells become more mobile and resist anoikis, a type of cell death that usually occurs when cells become detached. These changes can potentially help the cancer recur, spread, and progress.

In short, this work shows that YAP1-TFE3 hijacks endothelial cells, making them more aggressive through EndMT. This process depends heavily on TFE3 activity, suggesting that targeting TFE3 could be a viable approach to treating this EHE subtype.

The EHE Foundation is grateful to Dr. Hanna and his research team for being active contributors to their collaborative research network. The Pledge wants to add its thanks too for further exposing important attributes of YAP1-TFE3 driven EHE.



03 Fundraising

One of the most critical objectives of the EHE Group, and for ultra-rare diseases in general, is fundraising. Without funds, our other activities such as advocacy and research would be impossible. So we want to say a massive thank you to every single person who has helped the EHE Group raise these critical funds and for their extraordinary effort, organisation and generosity. The following pages contain highlights of some of the fundraising undertaken by our EHE patient community and their supporters. We hope you enjoy them, and if you should want to organise a fundraiser then please contact your local EHE foundation or charity who will be thrilled to assist you.

Luke and family take on huge challenge

Luke Harrison is a lawyer based in London who was diagnosed with EHE in 2024. Luke immediately engaged with advocacy and has become an active contributor within the UK patient community. Luke has also been a great supporter of the EHE Rare Cancer Charity's fundraising objective, so we were not surprised to see his family take on a huge challenge at the end of 2025 coinciding with Luke having started a clinical trial of a TEAD inhibitor being run at the Royal Marsden.

Melissa, Luke's wife, explained:

“

We have decided as a family to raise as much money as possible for the EHE Rare Cancer Charity. In 2024, Luke was diagnosed with EHE, a very rare cancer which affects 4 in every 10 million people in the UK. Luke is currently taking part in a clinical trial as there are limited interventions available for treatment at this stage. Our children Rohan and Zahra have come up with a beautiful idea of trying to raise money for much needed research and to support the charity in helping those affected by EHE and their families. Please watch the video [here](#) which explains more.

Our "happy place" as a family is in the Vosges mountains in France and we have enjoyed so much time there over the years. We have chosen a specific trail to hike together (along with our dog Marley) over the next year and would appreciate any donation as an incentive for us to achieve this. The trail is 430km in length and supposedly France's most historic hiking route. We always enjoy our hikes as a family. This trek will be a challenge but one we are ready to take to raise as much money as we can for this very much needed charity. To support us in the journey (and read more about Luke's own journey as an EHE sufferer) please visit our [Just Giving page](#).

On da 1 of their hike, Luke added:

“

Melissa, the kids (Rohan 16 and Zahra 11), Marley (our cockapoo) and I have just started our 430km hike through the Vosges and Alsace today in aid of the EHE RARE CANCER CHARITY (UK). The sun was shining but the terrain, all above 1100m in the Haute Vosges, was tricky. There was snow and ice for parts and a powerful wind as we reached the summit of Hohneck at over 1300m. We are tackling this epic hike of 19 days over the next two years. Thank you to all those who have already donated. Your generosity has taken the total raised so far to over £17,000. We hope the images of our journey inspire a journey of your own. And you can find more about the hike [here](#).



Thank you Luke, Melissa, Rohan, Zahra and Marley for your tremendous support. You are all awesome!



03 Fundraising

Rising to the Giving Tuesday Challenge

Each November, on Giving Tuesday, The EHE Foundation coordinates its annual matched-donations fundraiser, and 2025 was no different. Maggie Cameron, Director of Development and Communications, explained:

“

Here's an easy way to donate to EHE-specific research to help all people affected by EHE! Donations made to our Giving Tuesday Facebook fundraiser are matched by the EHEF Board of Directors through Tuesday, December 2nd.



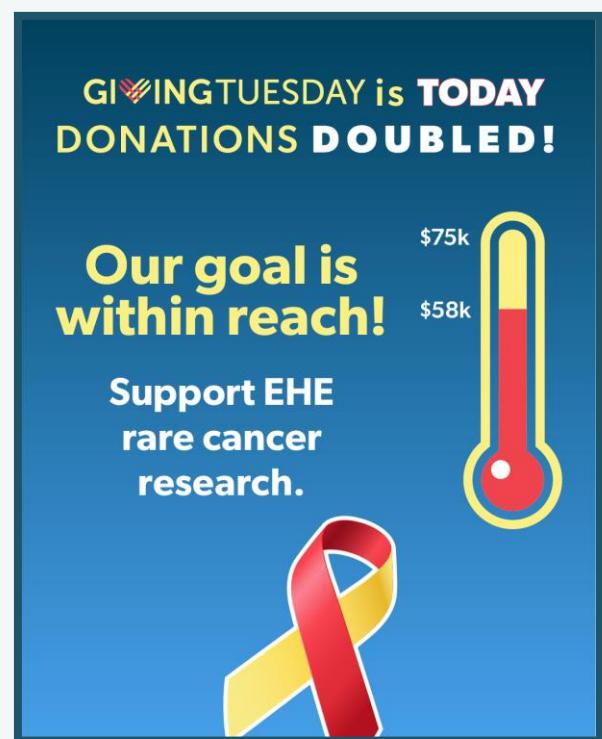
As in previous years, the Board's matching was beyond generous, and was once again equalled by the generosity of the EHE community as donations began to flood in. The EHE Foundation never takes these donations for granted, with members of the Foundation Board and management team taking to the airwaves to promote the event.



Julie Rivers Wahl, one of the original founders of the EHE Foundation and now Board Member Emeritus, provided an exciting update together with a last plea for those priceless donations:

“

Once a year, we have the opportunity to double the impact of every dollar we donate. The EHE Foundation is matching donations for Giving Tuesday, and they are so close to reaching their goal. Every dollar matters. Donate \$5 and it becomes \$10! \$10 becomes \$20. Today's donations become tomorrow's research!



After all this work, the Foundation were thrilled to be able to announce that the EHE community had once again met the challenge, something for which they were truly grateful:

“

With the generosity, heart, and determination of the EHE community and the EHE Foundation Board of Directors, we raised more than \$155,000 – and counting – for EHE Research this Giving Tuesday! In a world with so many urgent needs, we are profoundly grateful for how this community continues to show up for one another to advance our mission of finding treatments and a cure for EHE. Thank you!



The Pledge wants to add its congratulations for another great event, and its thanks to all those who donated, allowing the target of \$150,000 to be exceeded. You really are the most amazing supporters a foundation could hope for. Thank you.

Darran takes on the Sodbury Slog... again

Every year in Yate in South Gloucestershire in the UK, an event involving mud takes place. Nicola Henderson, EHE patient who lives in Yate, explained:

“

We have a local event here in Yate called the 'Sodbury Slog'. It's 10 miles of mud, fields, cattle prongs and pure hell! The brave runners who take it on do so to raise funds for great causes, and this year my dear friend Darran ran it for the EHE Rare Cancer Charity. I am so grateful. Xx



Hugh Leonard from the EHE Rare Cancer Charity added:

“

We are also so grateful to Darran for his ongoing support for all we do. Whenever we organise runs, or any events, Darran is always there, one of the first to put up his hand and say, "count me in". Thank you so much Darran for taking on 10k of mud and hard work to raise EHE research funding. You are a true star.



03 Fundraising

EHE Italia at Artigiano in Fiera

Over the past three years, EHE Italia has taken a stand at Artigiano in Fiera to help raise funds for EHE research. These events have been hugely successful, not only raising funds, but spreading awareness of EHE amongst those who visit the EHE Italia stand. 2025 was no different and Andrei Ivanescu and Caterina Colacci were delighted to once again share photos of their time there.

Andrei and Catarina particularly wanted to thank all those who came to the EHE Italia stand, bought items, or were just interested in the Associazione.

We want to congratulate everybody involved on yet another great event, and for the fabulous support provided. We also hope you enjoy these photos.



Canadian Matched-Funding a Great Success



Canada also wanted to use the donation momentum of Giving Tuesday as a fundraising platform, as Fiona Ross explained:

“

Dear Canadian Patients, my husband and I, and another generous donor are doing a matching donation drive for #GivingTuesday up to \$2500 from now to December 5th. All money will go to the PRO CARE EHE project at Mt. Sinai/ Princess Margaret Hospitals. We will be able to issue tax receipts, so if you can support us, please contact me for more information or if you have any questions.

Fiona was therefore delighted when she was able to post a banner headline confirming that the matched-funding campaign had exceeded the matched-funding target.

**The Canadian #GivingTuesday total is: \$7060
Thank you all!**

Easy Fundraising is Easy Money

Easy Fundraising is an online shopping platform where everything you buy from one of the 8,000 participating retailers including groups like eBay, Argos, John Lewis & Partners, Etsy, Tesco and Just Eat etc, results in a small donation to the EHE Rare Cancer Charity UK.

Kim Alexander-Bird is one EHE patient who has embraced Easy Fundraising and wants to encourage others to do the same, posting news that Easy Fundraising had donated over £1,000 to the charity.

It's Donation Day, let's celebrate!

Thousands of good causes have been paid!

The EHE Rare Cancer Charity has received

£1,046.09

easyfundraising has paid out over £1.8 million in donations this quarter.

Sally Baker also uses the platform:

“

Once you are registered with the site, you can select EHERCC as your charity and then every time you buy something from a participating retailer, the charity gets a small donation. And it does not increase the price that you pay. The retailer pays that small donation. So please join up if you can.



03 Fundraising

Irene's 10 doing 10 for 10 in aid of the EHE Rare Cancer Charity

In January 2024, Irene Bell was diagnosed with EHE. Sadly, Irene didn't get the chance to *Just Live* and passed away on 5th July 2024. To mark the 1st anniversary of her death, Irene's daughter, Lorraine, and her friend Lynne ran in the Great North Run 10k in Newcastle on 6th July. But that was not all, as Lorraine explained:

“

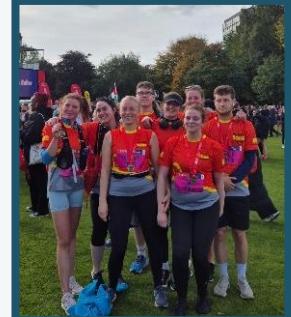
EHE has no cure and no treatment protocol. Unlike the more common cancers, it doesn't receive research funding from the pharmaceuticals simply because of its rarity. Due to this the charity and many of the patients adopted the phrase "Just Live" as their motto.

“

This year is the 10th anniversary of the EHE Rare Cancer Charity so they asked their supporters to do 10 for 10. Therefore Irene's 9 grandchildren, Laura, Louise, Lisa, Aaron, Finlay, Leah, Lana, Wallace & Hazel and I will all be doing the Great Scottish Run 10k in Glasgow on October 5th. The youngest two will actually do the 5k as they are not old enough to participate at 10k, but we are still calling it "Irene's 10 doing 10 for 10!"

It was not just the running that Lorraine and the other 9 in her group provided. They were also highlighted and interviewed on the starting line by Heart Radio because the PR company representative had never heard of the EHE Rare Cancer Charity and she wanted to try and highlight local or unknown charities.

We want to send Lorraine, and Irene's 9 grandchildren our thanks for all their efforts, not only raising funds, but introducing EHE to a new audience. You are all stars.



Raising funds in support of Drew

Krista Sheeley is a board member of the EHE Foundation. With Giving Tuesday in the calendar, Kristy and her family wanted to contribute in honour and support of their son/brother Drew. Krista came up with the idea of a month-long daily raffle through December, with all proceeds going to the Foundation's Giving Tuesday matched campaign. Krista explained:

“

As a family, we decided to organize a raffle to benefit the EHE Foundation, which is dedicated to advancing research for Epithelioid Hemangioendothelioma (EHE)—an ultra-rare sarcoma that affects fewer than one person in a million. EHE is cancer of the cells that line the blood vessels, and as a result, this cancer can develop anywhere in the body, but most commonly it appears in the lungs, liver, and bone.



The family's connection to this mission began in April 2024, when their 20-year-old son, Drew, was diagnosed with EHE and found to have innumerable nodules in both his lungs and his liver. The diagnosis was devastating—not only because of the severity of the disease, but because EHE currently has no well-established treatments or cure. Families like the Sheeleys are left navigating uncertainty, relying on hope and the tireless efforts of organizations like the EHE Foundation.

Krista continued:

“

Research in ultra-rare cancers like EHE faces unique challenges. Because these conditions affect so few individuals, they often receive limited attention and funding. Pharmaceutical companies and research institutions prioritize more common diseases, leaving rare cancer patients with few options and little data to guide treatment. Yet for those of us affected, the need is just as urgent—if not more so.

That's why funding is critical. Every dollar raised helps support scientific studies, clinical trials, and collaborative efforts that bring us closer to understanding EHE and developing effective therapies for our son Drew and all those impacted by EHE. The EHE Foundation is leading this charge, driven by patients, families, and researchers who refuse to let rarity be a barrier to progress.

All proceeds from the Sheeley raffle sales were submitted to the EHE Foundation's 2025 Giving Tuesday Campaign. And the Sheeley family wanted to express their gratitude to all those who had supported their event:

“

THANK YOU for choosing to make a difference in Drew's life and the lives of all the EHE warriors!! Your support sends a powerful message of solidarity to families like ours who are fighting for answers and for hope. We could not be more grateful. Thank you. Jeremy, Krista, Maizey & Drew, the Sheeley family.

We are tremendously grateful to the Sheeley family for their dedication to EHE research.



03 Fundraising

Looking forward to 2026

The EHE Rare Cancer Charity enjoyed wonderful support for its 10k running challenge in 2025, celebrating its 10th Birthday. Paul Dean, EHE patient and advocate again mobilised his wonderful supporters to great effect. After the event however, Paul wanted to try and establish a process that could enable an even wider group of runners in the future to engage in fundraising through running.

“

So, with this year drawing to a close, we look to 2026. We are now in a position to register runners for next year's UK EHE running events if you and anyone else are interested. The runs are now integrated into the charity website and it asks for a £30 donation towards the entry costs which is up to 70% off the retail cost. There is NO minimum fundraising amount. This change is to encourage our regular supporters (you guys) that have fundraised in previous years but may be concerned with the pressure to raise a certain amount having previously run and raised money for EHERCC. We just ask that you open a JustGiving fundraising page and try to raise what you can, that is all.

RUN FOR EHE!

£30.00

Sign up here to run for EHE! £30 for any race, once you've paid. YOU'RE IN! Thank you for raising money for EHE Rare Cancer Charity and Good Luck!

We hope you can join us this year and please spread this far and wide!! Here is the link to the race entry page on the Charity website:

[Run for Us](#)



Our Target Events for 2026

After an amazing year in 2025, we're already looking ahead! Here are the events we'll be targeting in 2026

- **Great Birmingham Run – 10K / Half Marathon (Birmingham):** Sunday 3 May 2026
- **Great Bristol Run – 10K / Half Marathon (Bristol):** Sunday 10 May 2026
- **Great Manchester Run – 10K / Half Marathon (Manchester):** Sunday 31 May 2026
- **Great North 10K (Newcastle):** Sunday 5 July 2026
- **Saucony London 10K (London):** Sunday 12 July 2026
- **Great North Run – Half Marathon (Newcastle):** Sunday 13 September 2026
- **Great Scottish Run – 10K (Glasgow):** Sunday 4 October 2026

Bridge House Quiz Night is back on!

Kelly Denton held her first EHE Quiz Night in 2022. It has become an annual event supported by the Lipstick and Laptops business association and the Penge SE20 Community Magazine.

We were delighted therefore when Kelly posted news of the 2026 event which will again be held at the Bridge House Pub in Penge on 6th March. This year the event is supporting not just the EHE Rare Cancer Charity, but also the Beckenham and Penge Dementia Café, so turn out will be even greater. Kelly hopes that as many as possible can make it.

Sally Baker, EHE patient and Trustee of The Rare Cancer Charity (UK) has attended the last three of Kelly's Quiz Nights, and hopes that as many as possible will turn out to support the event:

“

These quiz nights are great fun. The Bridge House Pub is a great venue, with two levels and a conservatory where we can fit many guests. They do great food too which always goes down well. In each of the last three years the support from the local community has been fantastic and Kelly has been thrilled to report significant sums raise for EHE research.

We have included a few photos here of previous quiz nights just to give you a feel for the evening. If you can join us, we and Kelly will be so grateful.



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 from the EHE patient community sharing stories not all about EHE, and indeed, *Just Living*.

We thank them for sharing these with us.

Paul Dean is Just Living!

Paul Dean is an EHE patient most certainly is not going to let his EHE slow him down. He personifies our 'Just Live' motto, and in December posted news of his latest achievement:

“

I have actually recently passed my HGV Class 1 driving licence (after 6 months waiting to hear back from my doctors for the medical!!) Driving has always been a passion of mine and I've been enjoying learning new things and taken on some agency jobs which I've been thoroughly enjoying. This is something I never would've imagined I'd be doing almost 5 years after I was told I had only months to live in 2021. Hopefully that gives you all some inspiration if you're struggling at the moment or recently diagnosed.



We love this story, Thanks for sharing it Paul, 'ten-four'.

Jane and Blanka together

“

I've been so flat out the last two weeks, it's taken a Cat 3 Cyclone to slow me down long enough to share this very special photo with a very special person. Blanka is a fellow EHE'er from Sydney and well known to most of us as the first EHE IRE patient anywhere in the world, over 15 years ago!

We enjoyed a beautiful afternoon, for a low tide beach walk, followed by a monsoon walk then a mangrove walk!

It is always special to meet another EHE patient, words can't express! Having a giggle remembering us having to scramble up a cliff face to get off the beach hahaha so funny! For now, time to hunker down and wait out Cyclone Fina!

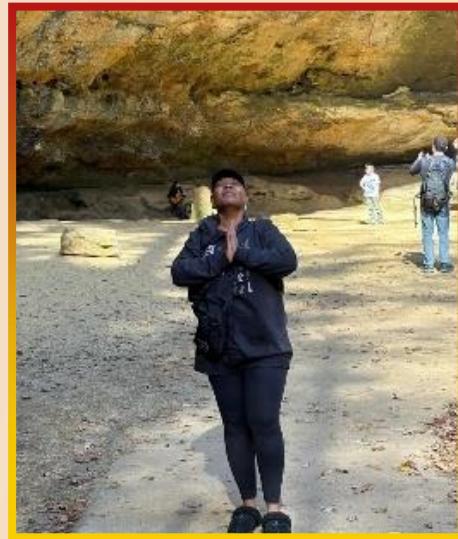


04 And in other news...

Stephanie Kennedy posted photos of two important events:

“

Me and my husband came to Ash Cave in Hocking Hills to celebrate my 56th birthday. It was amazing to be in nature; it gives you oxygen to stop and breathe! I am thankful to still be alive. I pray they find a cure for all of us. I pray and tell God when you're ready, I am ready, I have lost so many people and family from this ugly disease. Keep fighting - giving up isn't an option. *Just live.*



“

My beautiful Mom?

Moms indeed have a special place in all our hearts Stephanie, so thanks for sharing this photo with us.

The Ever After Garden

Kim Alexander Bird shared a lovely photo from the Royal Marsden Hospital Ever After Garden.

“

The Ever After Garden is a tranquil haven where everyone everywhere can remember treasured friends and family they have lost. Over the festive season, Duke of York Square, in the heart of Chelsea, is lit up with over 30,000 illuminated white roses. You are invited to donate and dedicate a rose in memory of a loved one, in support of The Royal Marsden Cancer Charity.



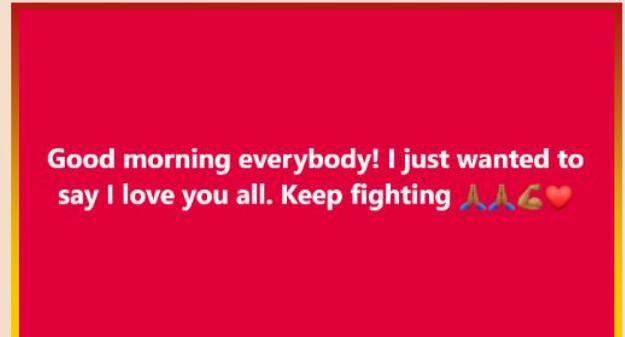
This is a truly lovely tribute to so many who have left us far too early. Thank you, Kim for sharing this photo.

Simple messages of love, and support

Keren Stern wanted to wish everybody a Happy Thanksgiving;



Sylvia Williams just wanted to post a message of love;



Caroline Flamand had a message for cancer;

“

Fckin' cancer, I fckin' hate you!



and Barbara Justiniani, who had scans looming on the horizon, wanted to:

“

forget about cancer so I am trying to learn from my doggie and living each moment without thinking further!



Here at the Pledge, we also love the pets in our community, knowing that they all provide therapy, calmness and love even in the most difficult times.





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

