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
Rare Cancer – EHE Deutschland e.V.

Quarterly Newsletter for the EHE Group
January – March 2026

Edition 44

the pledge

the pledge

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Contents

Front cover: (left to right) Dr Sandro Pasquali (Istituto Nazionale Tumori, Milan), Dr Paul Huang (Institute of Cancer Research, London), Hugh Leonard (EHE Rare Cancer Charity UK), Professor Robin Jones (Institute of Cancer Research, London) Denise Robinson (EHE Foundation USA) at The Royal Marsden Hospital after a one-day EHE research review held at the Institute of Cancer Research.

Welcome

We are delighted to issue this 44th edition of **The Pledge,** the quarterly newsletter of the global EHE community and the EHE not-for-profit organisations that represent them.

We hope you enjoy the stories and photographs of the activities of all those involved, as we move into our eleventh year of activities. We also 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

Germany launch their EHE Association

With pride and excitement, the German EHE community launched their own EHE association. Congratulations!

A Day Dedicated to Sarcomas: Questions, Answers, Hope

EHE Italia co-organised a one-day conference with the Italian Sarcoma Group, dedicated to Epithelioid Hemangioendothelioma (EHE) and rare sarcomas. The day comprised a scientific symposium for leading Italian centres and specialists and a public session for doctors, researchers and patients.

EHE advocates attend ESMO Congress

The European Society of Medical Oncologists (ESMO) held their Sarcomas and Rare Cancers Congress 2026 in Lugano, Switzerland in March. Andrei Ivanescu (EHE Italia), Denise Robinson (EHE Foundation) and Hugh Leonard (EHE Rare Cancer Charity) all attended this highly-focused meeting to represent the EHE patient community and to engage with doctors, researchers and other patient advocates.

EHE Foundation research grants announced for 2026

The funding of two major new research projects were announced by the EHE Foundation. One will widen the search for new biomarkers, while the second will be investigating targeted T-cell immunotherapy for EHE.

TEAD inhibitors move forward into phase 2 clinical trials

Following encouraging results from its phase 1 trial , Orion Pharma announced that they have initiated a phase 2 trial of its ODM-212 TEADES inhibitor.

EHE Research review held in London

Following the Lugano Congress, Hugh Leonard and Denise Robinson participated in a full-day review in London of the ongoing EHE research collaboration between INT (Milan) and ICR (London) that has transformed into the international POEM Study.

Details on all these stories, and much more, can be found in this, our 44th edition of The Pledge.

We hope you enjoy them.

Edition 44

the pledge

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 first quarter of 2026.

Germany launches its own EHE Association!

The EHE Group were thrilled to receive wonderful news at the start of the year with the announcement that the EHE patient community in Germany had established and launched a Germany EHE Association. Here at The Pledge, we were excited to hear the news and of course agreed to include within this edition, their introductory message:

RARE CANCER EHE DEUTSCHLAND

Dear international EHE community, dear EHE family. We did it – it is official!!!!

If you live with a rare cancer, you learn quickly that rarity has consequences. Doctors may hesitate. Information is scattered. And sometimes the most difficult part is simply finding someone who understands the name of the disease you carry with you every day.

Many of us have walked this exact path. And perhaps that is why a shared idea slowly began to grow: maybe we could make the road a little less lonely for those who come after us — for us as well, because the path from now on should not have to be walked alone.

So we decided to build something that did not exist before: the patient organization Rare Cancer – EHE Deutschland e.V.—a place meant to become a center of connection and reliable information for the German-speaking EHE community, and a strong voice within the wider international EHE network.

Our aim is clear: to connect EHE patients, families and anyone interested in the disease across the German-speaking world; to increase awareness of EHE; and, in the long run, to support research through fundraising so that effective therapies can be developed.

We also want to improve awareness among physicians. As many of us know from personal experience, EHE is still unfamiliar territory for many doctors simply because it is so rare. Better information and greater visibility can make a real difference for future patients who are just beginning their journey.

Another reason why a German-speaking organization matters is language. Much of the information about EHE—research updates, clinical discussions, patient resources—exists primarily in English. For many patients and families, this creates an additional barrier at a time when clarity is already hard to find.

As an organization, we want to help bridge that gap. That means translating information into German, but also doing something just as important: translating medical language into words people can understand. Turning complex terminology into clear German explanations, so that patients and families can better grasp what is happening, what options exist, and what questions to ask.

Because understanding changes things. It allows space for informed decisions, for conversations with doctors, and—perhaps most importantly—for a little more hope and a little less fear.

One of our first steps in this direction has already been taken: as a team, we translated the patient version of the EHE Consensus Paper into German. For the layout and final presentation, we were kindly supported by the EHE ITALIA Associazione—an example of the generous collaboration that exists within the international community, and for which we are very grateful.

But before any of this became official, there was simply a group of people trying to build something together. We are a very mixed group. Different backgrounds, different professions, different talents. Over the past months we spent evenings, weekends and what sometimes felt like endless Zoom calls discussing what this organization should be and how it should work. We wanted decisions to be shared and supported by everyone—so we talked things through carefully, sometimes in great detail.

Everyone contributed in their own way. Those who like writing drafted texts. Those who enjoy digging into information prepared fact sheets. Those with a talent for editing combed through documents until even the smallest typo disappeared.

Parents agreed to let us use their home address as the official headquarters. Somewhere in the background of our meetings, husbands baked pizzas so their wives could keep working. Birthday presents were quietly collected as our very first funds to pay for the notary and the website hosting.

And then, in August, we finally met in person in Essen, Germany. Some of us had travelled for hours by train or car. We joined the Sarcoma Tour, a charity bike race around a lake in the city of Essen—and there, gathered around a table, we signed the founding documents.

Image by Vladimir Wegener - Image rights: Stiftung Universitätsmedizin Essen.

A small moment, perhaps. But for us, it meant that all those evenings, calls and shared efforts had turned into something real.

Finally, the organization came together. And now we have reached that moment.

- We have a name.
- We have statutes
- We have a website.
- We are still a small group but here we are!

We are ready to support German-speaking EHE patients as part of the global EHE community—collaborating, sharing knowledge and amplifying the voices of patients who are too often scattered across countries and healthcare systems. And ready to give our best in supporting the worldwide EHE organizations that have walked this path long before us, whose remarkable and groundbreaking work continues to guide and inspire us.

We may be few.
But we are loud.
And most of all: **We just live.**

Yours truly, the team of Rare Cancer – EHE Deutschland e.V.

All of the other EHE foundations and the EHE global community, who together make up the EHE Group, want to welcome Rare Cancer – EHE Deutschland e.V. to the EHE global network. Of course, the Pledge wants to add its voice to this message of welcome and wants the German EHE community to know how inspiring it is to see another EHE entity established. Congratulations to everybody who was involved, including the guys who made those pizzas. Every contribution mattered. Awesome.

EHE Deutschland can be found on social media as follows:

Website: here
Instagram: here
Facebook (association page): here
Facebook (private support group): here

EHE Advocates support ESMO Sarcoma and Rare Cancers Congress 2026

As part of the international network of sarcoma and rare cancer conferences, The European Society of Medical Oncologists (ESMO) held its annual European Sarcoma and Rare Cancer Congress in Lugano, Switzerland. The Congress not only attracts many of Europe's leading sarcoma specialists, but is also attended by specialists from around the globe, including Australia, Asia, the US, and Canada. Latest research thinking, patient advocacy, clinical trials and the results of multiple studies were presented and debated. It was once again exciting to see EHE included in several of the sessions, a testament to the work of our EHE Group worldwide.

The EHE Group was represented by Andrei Ivanescu from EHE Italia Non Solo Laura, Denise Robinson from The EHE Foundation and Hugh Leonard from The EHE Rare Cancer Charity. Over the three day event, they had the opportunity to discuss and expand their relationships with key researchers, with other sarcoma patient advocacy groups, and also doctors and other clinical experts involved with EHE. Hugh and Denise participated in the latest PUSH Executive Committee meeting where a key area of focus was the current POEM prospective observational study of EHE, initially a European, but now international collaboration of key sarcoma institutes, gathering patient data to help expand knowledge of the disease.

A Day Dedicated to Sarcomas: Questions, Answers, Hope

EHE Italia were thrilled to have previously announced their event dedicated to Epithelioid Hemangioendothelioma (EHE) and rare sarcomas, which took place on Thursday, 29 January 2026 at the Fondazione Ferrero in Alba.

Organized in collaboration with the Italian Sarcoma Group (ISG) and under the patronage of major institutions and organizations, the initiative involved some of the leading Italian centres and specialists, and represented a significant moment for EHE Italia, both from a scientific perspective and for its direct value to EHE Patients and their families. The programme comprised two key elements:

Morning – Scientific Session

The morning was dedicated exclusively to physicians, with an in-depth session focused on rare sarcomas and EHE. This reflects EHE Italia's commitment to promoting research, training, and collaboration among specialists.

Evening – Public Event

The evening session was open to the public, with particular attention to Patients, families, and associations. Doctors, researchers, and Patients engaged in dialogue to make complex topics related to sarcomas more accessible, address questions, and highlight the importance of research and support networks. The event was moderated by Nicoletta Carbone, Radio24 journalist and a well known voice in medical and scientific communication.

Andrei Ivanescu was hugely excited and was delighted to report back about the success of the event:

> **A day we will carry in our hearts** – Our event at the Fondazione Ferrero dedicated to EHE and sarcomas was an intense moment, rich in content, dialogue, and humanity.
>
> Thank you to the doctors and researchers who shared their expertise, passion, and generosity with us—both during the scientific session and the public session. Your commitment is what brings hope and confidence to those who face difficult diagnoses every day.
>
> A special thank you to Nicoletta Carbone and to all the panelists of the evening session, who were able to make complex topics accessible and create a genuine dialogue with Patients and families. The feedback we received confirms how important it is to continue building spaces for listening and learning.

Caterina Colaci also wanted to recognise all the different groups who helped make the day both possible and such a success:

> And thank you to everyone who worked "behind the scenes," to those who attended in person, and to those who joined us remotely: without each of you, none of this would have been possible.

EHE Italia closed their report with their motto:

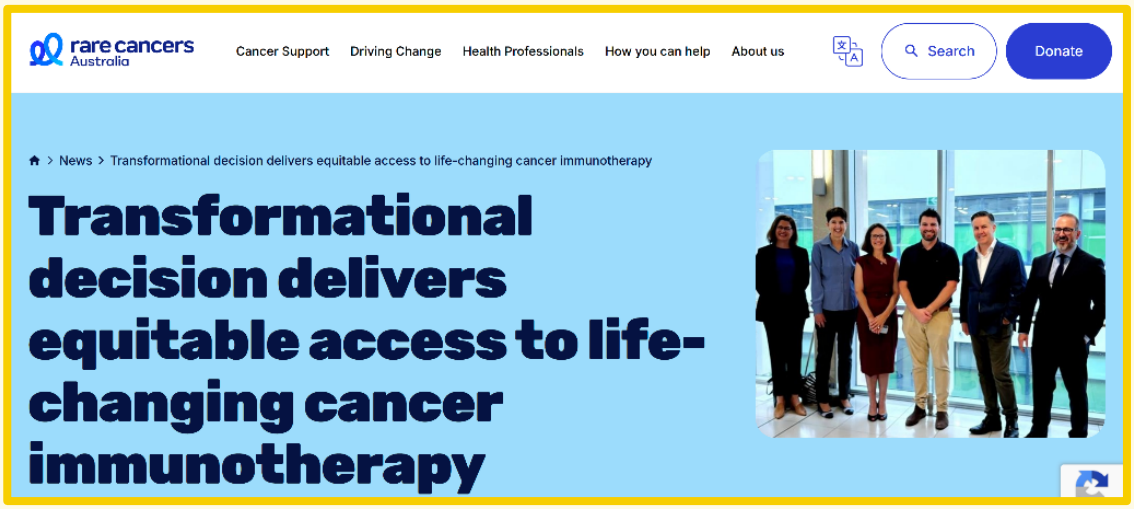
> Alone we are RARE, together we are STRONG. And this day was the most beautiful proof of that. T H A N K Y O U

Here at The Pledge, we want to send our congratulations and also say thank you to everybody who took part. And a video of the event can be found here.

FIRST ROUND TABLE: (from left: Host: **Nicoletta Carbone**, Radio24; **Dott.ssa Silvia Stacchiotti**, Fondazione IRCCS Istituto Nazionale Tumori, Milano; **Dott.ssa Elena Fumagalli**, Fondazione IRCCS Istituto Nazionale Tumori, Milano; **Dott. Lorenzo D'Ambrosio**, Università di Torino; **Andrei Ivanescu**, Presidente Associazione EHE ITALIA – Non Solo Italia ODV; **Dott. Felice Borghi**, IRCCS Candiolo, Torino; **Dott.ssa Sandra Aliberti**, IRCCS Candiolo, Torino)

SECOND ROUND TABLE: (from left: Host: **Nicoletta Carbone**, Radio24; **Matilde Dalmasso**, oncology Patient; **Dott.ssa Silvia Novello**, Università di Torino; **Andrei Ivanescu**, Presidente Associazione EHE ITALIA – Non Solo Italia ODV; **Dott. Alessandro Gronchi**, Fondazione IRCCS Istituto Nazionale Tumori, Milano; **Dott. Giovanni Grignani**, IRCCS Candiolo, Torino)

Australian Minister opens access to cancer drugs



Jonathan Granek was excited to post important news for Australians concerning increased access to drugs for treating cancer:

> Transformational progress..... It will be interesting to see how combination therapies, eg with TEAD inhibitors will work one day...

Jonathan's excitement was caused by confirmation from the Australian Minister for Health and Ageing, the Hon Mark Butler MP, that Australia were unlocking affordable access to a life-changing cancer treatment and were opening the door for a new approach to medicines access with nivolumab (Opdivo) and ipilimumab (Yervoy) approved for a pan-tumour listing on the Pharmaceutical Benefits Scheme (PBS). The statement continued:

> For the first time, patients with advanced or metastatic cancers will have subsidised access to these immunotherapies based on clinical judgement rather than a specific tumour type – ending a long-standing inequity that left many Australians with rare and less common cancers facing exorbitant out-of-pocket costs.

> Until now, patients with certain cancers could access these treatments on the PBS for around $25, while those with rarer cancers were often forced to self-fund treatment at a cost of thousands of dollars, draining savings, accessing superannuation early or turning to community fundraising."

Attending a press conference held by Minister Butler in Adelaide this morning, Rare Cancers Australia (RCA) CEO Christine Cockburn said the decision marked a historic turning point after years of sustained advocacy.

> "We commend Minister Butler for making a landmark decision that prioritises patient outcomes over outdated system constraints and delivers a more equitable chance at life beyond cancer; this is a defining moment for the Australians diagnosed with rare and less common cancers – a step towards a system where access to treatment is no longer determined by a person's tumour type, geographic location or bank balance.

The decision follows years of advocacy, multiple pan-tumour submissions from pharmaceutical sponsors and two positive recommendations from the Pharmaceutical Benefits Advisory Committee (PBAC). It is the first time a Minister has approved a pan-tumour PBS listing for a cancer immunotherapy. Ms Cockburn continued:

> **I also would like to recognise the many patient advocates in our community, including our Co-Founders Kate and Richard Vines, who started advocating for pan-tumour eight years ago. They have used their voice to bring about meaningful change, and this decision is the culmination of years of collaboration and determination. We are encouraged to see long-standing barriers finally begin to shift. This decision proves that meaningful reform is possible when government takes a pragmatic and patient-centred approach and patients, clinicians, industry and policy-makers work together to tackle access barriers.**
>
> **Our focus remains on ensuring fast and fair access to treatments for every person with a rare cancer, by maintaining this momentum. What we hope for now is a clear path for other medicines to be listed in this way. If we are serious about equity and improved cancer outcomes, we need a system that embraces innovation, clinical judgement and timely decision-making. Australians with cancer cannot afford delays when life-changing treatments are within reach.**

The EHE Group wants to congratulate Australia on this significant step forward with regards to giving rare and less-common cancer patients affordable access to potentially life-changing treatments. The objectives and benefits of this decision would of course be equally applicable to rare and less common cancer patients globally. Sadly, the decision announced by the Hon Mark Butler MP only relates to Australia, but here at The Pledge, we are sure that patient advocacy groups around the globe will be looking very carefully at this announcement and the associated campaigns to deliver it and thinking about how similar decisions might be achieved in their own countries..

Canadians, can you help?

Fiona Ross has been driving the EHE Canada programme for many years, delivering major fundraising as well as established the hugely valuable collaborative relationship with the Sarcoma Canada Foundation Canada (SCFC). This relationship created a structure that has allowed Canadians to provide funding for EHE research with full tax benefits, while SCFC matching EHE funds raised, has also been instrumental in establishing the major multi-pronged PRO Care EHE research initiative being led by Dr Albi Razak in Toronto.

Fiona has achieved all of the above, and much more, while having to battle with her own progressive EHE. Her drive and determination has been inspirational, but she needs help and put out a call for assistance at the start of the year:

Dear Canadians,

I have been the lead patient advocate in Canada for 8 years now. Michelle Lynn is amazing and a huge help, but she runs her own events and not-for-profit. I need help!

I can't continue to do this alone. Canadian EHE needs a website, perhaps our own not-for-profit status, someone who helps organize fundraising etc, etc, etc.
My worst fear is that I will die from EHE and everything in Canada will stop.

So, I am asking 3-5 Canadians to step up. DM me if you can help. It does not have to be a patient. It could also be a caregiver, spouse, other family or friends.

Fiona, we hope that you will be deluged with offers of help, and that we can report on your progress in future editions of The Pledge. But right now, most of all, we want to say a massive thank you for all that you have done for EHE in Canada, and for delivering the support and structure that has delivered the ongoing PRO Care research programme. You are a true star.

The slender lefty is coming into his own!!

We love stories which, at their heart, are about EHE patients getting on with life, and abiding by the group motto "Just Live". One such story was posted by Sasha DeKramer Straub about her son Colin, who started taking sirolimus at the end of 2021 to treat his EHE, and is currently still taking 1 mg of the drug twice a day together with weekend antibiotics. Sasha reported:

There were no changes in Colin's scans last year, no reduction but no growth! Liver continues to be diffuse with a few small lesions in the lungs. No side effects from sirolimus and no symptoms of disease.

That is of course wonderful news, but Sasha was not posting just about his treatment regimen. She wanted to update us on Colin's other achievements.

Colin is finishing out his senior year of high school. He'll be turning 18 in June! This year, he has put on 25 lbs of muscle and has worked really hard in the gym to build strength and stamina for his spring pitching season. He's worked on his appetite and is eating a lot of protein and as anti-inflammatory as possible. Recent bullpen has him up to 87 mph (last year 83) with his fastball.
The slender lefty is coming into his own!!

Even if you don't know much about baseball, the crack of Colin's fastball pitch hitting the Catcher's glove screams 'velocity'! Congratulations, and keep going with the practice Colin, and keep those updates coming Sasha. 90mph is within reach!!

Colin will be attending SUNY Cortland in the Fall '26 to study Business Economics and he will be pitching for Cortland's nationally ranked Division III Red Dragons baseball team. Awesome.

Photography credit for Tracie McCarthy

Meeting old friends and discussing EHE

Sally Baker, and her husband Hugh, had the huge pleasure of meeting up with an old friend, catching up on their respective stories, and discussing different possible initiatives for the EHE community. Hugh and Sally both agreed it was a special occasion:

> Last week we spent a lovely two hours in London with the fantastic Mariana Coutinho, her partner Ricardo and her dear mother. Some of you will have seen that Mariana was in London for treatment, so it was lovely to see her looking and doing so well.
>
> There were a lot of laughs, a huge amount of catching up, and of course a lot of talking about EHE, and what more we can do to defeat this disease. We discussed at length how to progress with building an EHE patient network across Europe, involving the 'EHE Rare Cancer Charity', 'EHE Italia Non Solo Laura' and now the newest EHE association, 'Rare Cancer – EHE Deutschland e.V.'

Both Sally and Hugh wanted to thank Mariana for giving them the time to meet, and also confirmed that they would indeed be coming to see Mariana and Ricardo in their new home in Portugal.

New ISG courses about clinical studies take place!

EHE Italia were pleased to post news of a new programme to training courses relating to clinical trials. Andrei Ivansecue, President of EHE Italia explained:

> Understanding what clinical studies are, why they are essential, and how they truly work can make a real difference in a person's care journey.
>
> For this reason, the Italian Sarcoma Group has created a series of meetings designed for patients and their families — a safe space to learn, ask questions, and become informed, active participants in their own choices.

The meetings started on 26 February and will end on 4 June. held online on Thursdays, once a month, from 7:30 PM to 8:30 PM, and will cover key topics such as:

- the difference between interventional and observational studies
- endpoints
- the phases of drug development
- what "significant" means in a study
- the ethics of clinical research.

Each session will be led by expert clinicians who will guide participants with clarity and openness. EHE Italia invited their members to register and take part in a program designed to offer practical tools, simple language, and an open dialogue with professionals. More information can be found here. Or by emailing the Italian Sarcoma Group here.

Adults Affected by EHE

This group is facilitated by Dr. Maeve Baechler, an EHE patient and psychiatry resident, and provides participants with the chance to share, listen, and support one another in a private, supportive space. These monthly meetings are intended for adults aged 18+ who understand and experience the challenges of the disease. The meetings are free to attend, and participants do need to register. So whether you're living with EHE or a loved one is, you will be most welcome here.

You can find more information about Dr. Maeve Baechler, the meetings, their schedule, and how to register, here.

The importance of second opinions

Many EHE patients within our EHE Group have posted stories of complex and confused diagnoses, with uncertainty in their histopathological diagnosis. This is not a criticism of the pathologists involved, but more a fact of life when faced with an ultra-rare sarcoma that many oncologists have never faced.

Jonathan Granek, President and Co-Founder of the EHE Rare Cancer Foundation Australia, was therefore keen to share news of a publication about this very challenge faced by patients, oncologists and pathologists, published in 'Pathology, the journal of the Royal College of Pathologists of Australia'.

Jonathan Granek, partially quoting the paper explained:

> Accurate subtype diagnosis of sarcoma is crucial for optimal patient management, requiring integration of clinical, radiological, morphological, immunohistochemical, and molecular findings.
>
> The evidence-based recommendation of the ANZSA working group is that the diagnosis of suspected sarcoma should be confirmed by a pathologist with expertise in bone and soft tissue tumour pathology.
>
> Primary bone and soft tissue sarcoma diagnosed outside the context of a specialised sarcoma centre should be reviewed by a specialised sarcoma multidisciplinary team with the relevant clinical history and radiology.
>
> The authors are currently in discussion with the Royal College of Pathologists of Australasia on an overarching statement in a bone and soft tissue tumour reporting protocol to encourage referral to a specialised sarcoma centre for management.

As patient advocates focused on an ultra-rare sarcoma, we whole-heartedly support this initiative and congratulate the authors of this excellent paper for focusing a spotlight on this important issue.

The paper is entitled 'The value of a second expert opinion in histopathological diagnosis of bone and soft tissue sarcoma: a systematic review'. It can be found here.

Italy launches its 2026 Membership Campaign 2026

Associazione EHE ITALIA – Non Solo Laura ODV started the new year by updating their supporters on achievements and launching their 2026 membership Campaign. Andrei Ivanescu, President of EHE Italia said:

> 2025 was a year filled with meaningful achievements, made possible thanks to your continued support. Among the milestones reached:
>
> - A donation of €30,000 to the National Cancer Institute of Milan to support an international research project dedicated to Epithelioid Hemangioendothelioma (EHE);
> - The organization of medical meetings, informational events, and fundraising initiatives that strengthened our network and increased awareness of the disease;
> - Ongoing support for Patients and Caregivers through dedicated activities;
> - Over €9,000 raised through the 5x1000 program, allocated to new research projects.

Caterina Colaci, Head of Communications at EHE Italia, continued:

> These results demonstrate the invaluable strength of our community. To continue supporting research and providing concrete help to families, we also need your contribution in 2026. The annual membership fee is just **€20.**
>
> **And here is how you can join:**
> - Fill out the online form available on our website: www.ehe-italia.it/diventa-socio ; or
> - Download and complete the paper form available on our website www.ehe-italia.it/diventa-socio and send it to info@ehe-italia.it ; or
> - If you are already a 2025 member, simply proceed with the payment of the fee and inform us by email at info@ehe-italia.it
>
> If you have any questions or need clarification, please do not hesitate to contact us. Together, we can make a difference.

Both Andrei and Caterina finally commented:

> Thank you sincerely for your support and for the trust you continue to place in our work. Together, we can carry forward essential projects for research and for all those living with EHE.
>
> **THANK YOU FOR YOUR PRECIOUS CONTRIBUTION!**

Supporting other cancer days

The EHE Group recognise that there are other important 'cancer days' in the annual calendar and work hard to support these. EHE Italia produced wonderful graphics and powerful messages for two such occasions.

> On 4 February, World Cancer Day the world comes together to remember that the fight against cancer is a shared responsibility. It is a journey made of research, care, listening, and presence — a journey no one should have to walk alone.

> 28 February is Rare Disease Day, and EHE wanted to recognise this as an occasion dedicated to bringing visibility to realities that too often remain unseen.

New UK legislation recognises sarcomas and rare cancers

The UK sarcoma patient community were excited to see the Rare Cancers Act 2026 receive Royal assent on 5 March 2026 and so become part of UK legislation. The Rare Cancers Act, sponsored by Dr Scott Arthur MP and Julie Elliott, is seen as a vital step towards improving clinical trial access, driving research and ensuring rare cancers are treated with the urgency they deserve.

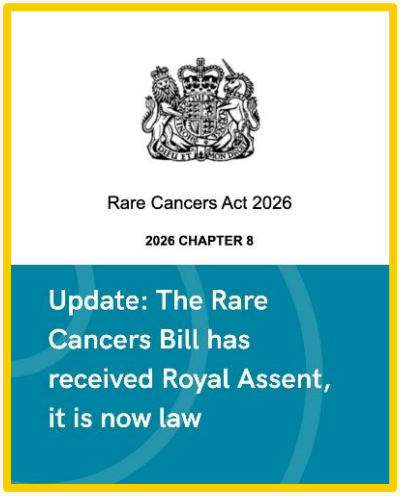
Key Aspects of the Rare Cancers Act 2026 include:

1. Enhanced Research Focus: The Act encourages and facilitates increased investment and research into rare cancer types.
2. Clinical Trial Access: It improves the identification of patients for clinical trials, making it easier for them to access potential treatments.
3. National Leadership: It establishes a National Specialty Lead for rare cancers within the National Institute for Health and Care Research (NIHR) to coordinate efforts and provide expert advice.
4. Orphan Medicine Review: The legislation mandates a review of the regulatory framework for "orphan drugs"—treatments for rare diseases—to accelerate their approval and availability.

On the Rare Cancers Bill completing its third and final reading in the House of Lords at the of February, Sarcoma UK's Chief Executive Richard Davidson said:

> Today is a landmark moment for everyone affected by sarcoma and all rare cancers. Sarcoma accounts for about one per cent of all cancer diagnoses, yet carries a disproportionate burden of mortality. The passing of the Rare Cancers Bill sends a clear signal that patients with rare cancers matter and that the system must work harder for them.

> For too long, patients with sarcoma and other rare cancers have been left behind, receiving fewer treatment options, less research investment and little hope of accessing a clinical trial. The Rare Cancers Bill changes that. The fact that 82 per cent of rare cancer patients have never been offered a clinical trial place is a scandal that this legislation will begin to address.
>
> Sarcoma UK has long called for rare cancers to be treated with the same urgency and ambition as common cancers, and today Parliament has listened. The commitment to improving clinical trial access, driving research and reviewing orphan drug regulations are exactly the kind of bold, joined-up actions we have been calling for. We look forward to the government implementing this legislation swiftly and with genuine intent. People are dying from sarcoma while waiting for better options. That has to change, and it can change, starting today.
>
> We are deeply grateful to Dr Scott Arthur MP and all those who championed this Bill. Sarcoma UK will continue to work tirelessly alongside government to ensure its promises are turned into real and lasting change for our community.



Upcoming events

EHE Education Day in Boston, MA

The EHE Foundation was delighted to post news of an upcoming event to be held at the Dana-Farber Cancer Institute in Boston, MA.

> The EHE Foundation and Dana-Farber Cancer Institute (DFCI) are pleased to host an in-person EHE Education Day in Boston on Saturday, April 11th. Dana-Farber is home to one of the nation's leading high-volume, multidisciplinary sarcoma programs, bringing together medical oncologists, surgeons, pathologists, radiologists, and research teams dedicated to advancing care and clinical research for sarcoma patients.
>
> Dr. Michael Wagner, Medical Oncologist and Director of Sarcoma Clinical Research, is opening a new clinical trial for epithelioid hemangioendothelioma (EHE) at DFCI and will share details about this important development. Members of the sarcoma team will also discuss current treatment approaches and care-related topics, with time set aside for community connection and conversation. Family members and caregivers are welcome.

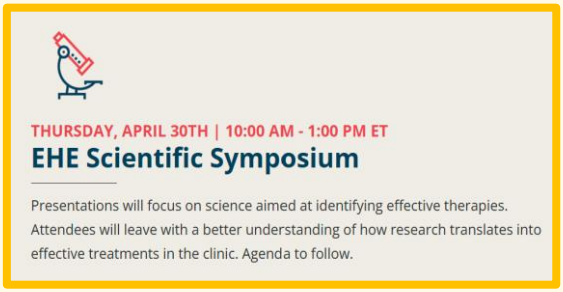
The 2026 EHE 360 Global Conference

The EHE Foundation are delighted to confirm that the EHE 360 Global Conference will take place on Thursday 30th April and Friday 1st May 2026. Denise Robinson, Executive Director of the Foundation explained:

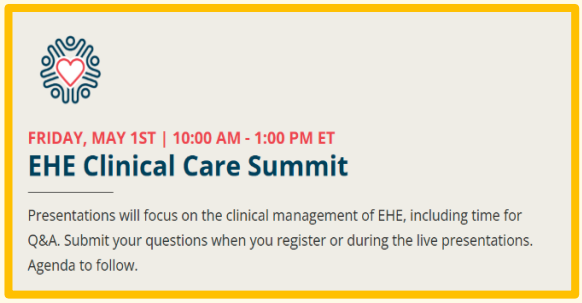
> The key objectives of our annual Conference, the largest annual gathering dedicated entirely to epithelioid hemangioendothelioma (EHE), are to advance EHE research, build knowledge of this ultra-rare sarcoma, and strengthen the overall EHE global community. By bringing together patients, caregivers, clinicians, and researchers from around the world, we believe we can learn, connect, and move research forward.

The conference will be structured so that each of the two days has a specific focus. Denise continued:

> Day 1, 30th April, will be focused on science and identifying effective therapies, and will be designed to help participants gain a greater understanding of how EHE research translates into new and effective treatments for the disease.



> Day 2, the 1st May, will be focused on the clinical management of the disease. This will include a Q&A session where clinical experts respond to community members' questions. This is always a highlight of the conference for the patient community.



Maggie Cameron, Director of Development and Communications at the Foundation added:

> The conference is held in a virtual format so that the global community can participate. It's free to attend and designed to give people diagnosed with EHE and their families direct access to the experts shaping the future of care. Through live presentations and interactive discussions, participants:
>
> - Learn about the biology of EHE and how it impacts diagnosis and treatment;
> - Hear updates on emerging research and potential therapies;
> - Gain insight into clinical care and quality of life considerations; and
> - Can have their questions put directly to leading researchers and clinicians

Jenni Kovach, President of the Foundation, concluded:

> We have no doubt that the knowledge shared at the EHE 360 Conferences helps advance research, inform clinical care, and ensure the patient voice remains central to progress in EHE, an objective that sits at the heart of everything we do. When patients, caregivers, and experts share and learn together, progress moves faster, and the entire EHE community benefits.

The EHE Foundation also wants to thank its generous sponsors, AADI Bioscience and SpringWorks Therapeutics, for their wonderful support and assistance in delivering the conference.

Here at The Pledge, we want to congratulate the EHE Foundation and all those involved in the conference for organising what we are sure will be another great event. Although free, those who want to attend do need to register in advance. Further details, registration, and the developing agenda of the EHE 360 Conference can be found here.

02 Research

One of the key objectives of the EHE Group is to find new, better and more effective treatments for EHE. It is through research that EHE patients can ultimately help doctors find new ways to treat and manage EHE. Together with our patient community, the researchers and clinicians are at the heart of everything we do.

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. We hope you will be inspired by the work taking place.

EHE Foundation research grants announced

The EHE Foundation was proud to announce $335,000 in funding through the 2026 EHE Foundation Research Grants Program to support two innovative research projects in EHE.

Selected for their scientific merit, potential impact, and clinical relevance, these projects address two important priorities in EHE research: biomarker development and new therapeutic approaches. Together, they represent high-risk, high-reward investments in work that could help improve how EHE is monitored and treated.

Because EHE is an ultra-rare cancer, research progress depends on targeted investments in promising ideas. The Foundation's research grants program is designed to support bold, carefully selected projects that address urgent unmet needs in the field. This year's awards reflect that strategy.

Biomarker Discovery in Epithelioid Hemangioendothelioma

a) John Lamar, PhD | Albany Medical College, USA
b) Sandro Pasquali, MD | Fondazione IRCCS Istituto Nazionale dei Tumori, Italy
c) Award Amount: $155,000 over two years

This project aims to identify EHE-specific biomarkers in the blood that could help monitor disease progression and response to treatment using a non-invasive approach. The research team will use advanced technology to label and capture proteins released by EHE cells into the bloodstream. These proteins will then be compared across preclinical models of EHE and blood samples from EHE patients to determine whether they can reliably track disease activity and treatment response.

If successful, this work could identify additional biomarkers for monitoring EHE without invasive procedures and could help clinicians and patients better understand what is happening over time.

Immunopeptidome-Guided Target Discovery for T-Cell Based Immunotherapy in Epithelioid Hemangioendothelioma

a) Jens Bauer, PhD | University and University Hospital Tubingen, Germany
b) Award Amount: $170,000 over two years

This project will explore a novel immunotherapy approach for EHE by identifying abnormal peptide targets created by EHE fusion proteins and presented by human leukocyte antigens for recognition by the immune system. Those peptide targets would then be used to support the development of a T-cell based immunotherapy strategy specifically for EHE.

This has not yet been meaningfully explored in EHE, but the research team is well-positioned to pursue it, given prior success with another fusion-driven tumor. If successful, this work could open the door to a new, targeted treatment approach for patients.

As far as the EHE Group is aware, this is the first significant investment in immunotherapy research for EHE. It is a highly novel project with the potential to create an entirely new path forward in treatment development.

A thoughtful, impact-driven approach to funding

Both projects include clear milestones and interim review points after year one. For the biomarker project, continued funding into year two will depend on whether the research identifies proteins that meaningfully change in abundance in response to treatment. For the immunotherapy project, continued support will depend on whether fusion-derived HLA ligands are successfully identified. This allows the EHE Foundation to maintain strong stewardship of donor-supported research funding by including checkpoints to help ensure that funded work is making meaningful progress.

Advancing Hope Through Research

Research is how progress in the treatment of EHE is achieved. By funding innovative research that is focused on urgent unmet needs, the EHE Foundation is helping to move the field forward and build momentum toward better tools, treatments, and improved outcomes for everyone affected by EHE. We are deeply grateful to the researchers, expert reviewers, donors, and community members who make this work possible.

Understanding Quality of Life for People Living With EHE

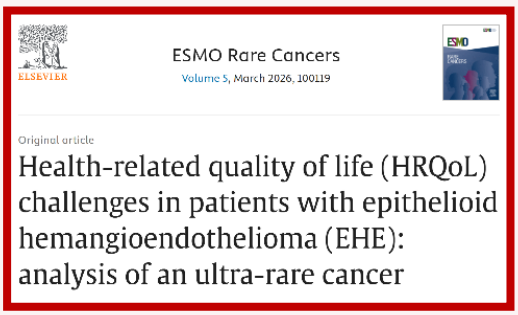
The European Organisation of Research and Treatment of Cancer (EORTC) is conducting research to better understand health-related quality of life (HRQoL) concerns among people living with rare cancers. Recently, researchers analysed results from a group of 31 people with EHE from 11 different countries who participated in the study. The findings showed that pain–and the extent to which pain interferes with daily life–was the most significant quality of life concern reported by people with EHE.

As part of the study, researchers evaluated how well an existing standardized HRQoL questionnaire captured the lived experience of people with EHE. They found that while many parts of the questionnaire were relevant, the survey alone did not fully reflect the range of challenges faced by people with EHE. Participants shared a broad range of physical, social, and mental health concerns, and the researchers found that people with EHE have a unique burden that is complicated by the rarity of the disease and lack of information about treatment and disease progression.

The findings from this study will help researchers improve the assessment of health-related quality of life for people with EHE in future research. Studies like this highlight the vast and varied experiences of individuals living with EHE, and that those differences matter. By learning to better measure the impacts of EHE on a person's quality of life, researchers can better understand how effective new therapies and drugs are at improving HRQoL.

As a partner in this important work, the EHE Foundation would like to thank the researchers, patients, and their families for their essential role in advancing patient-centered EHE research.

The publication can be found in the EHE Library or directly linked here.



EHE research reviewed in London

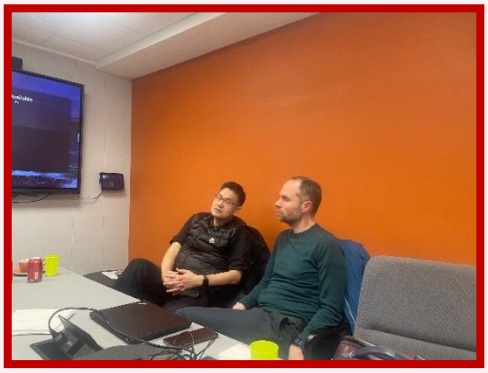
In late March, Hugh Leonard posted an update for the EHE community on a day spent in London discussing EHE research. Hugh, of the EHE Rare Cancer Charity, and Denise Robinson from the EHE Foundation, wanted to review progress of the EHE collaborative research programme involving INT in Milan and The Royal Marsden Hospital and the Institute of Cancer Research (ICR) in London, which is jointly funded by the EHE Rare Cancer Charity, the EHE Foundation and EHE Italia Non Solo Laura.

The meeting took place in London on Friday 20 March, with Hugh and Denise from the EHE Group, Dr Sando Pasquali from INT and Dr Paul Huang from the ICR, together with two of their team members, allowing a full review of the ongoing research.

This research has multiple targeted objectives, including (i) the generation of EHE PDX models; (ii) the generation of EHE cells lines from these PDX models; (iii) the use of these models to investigate the efficacy of different drugs, both individually and in combination; and (iv) the identification and evaluation of new biomarkers of EHE, including GDF15 and micro RNAs. An underlying and fundamental component of this research is the ongoing observational study of EHE, now being conducted through the international POEM prospective observational study which is being delivered under the PUSH (Pushing Ultra-rare Sarcomas Beyond Hope) initiative.

Both Hugh and Denise agreed that the review was very useful, allowing a full and open discussion, not only of results, but some new areas of research that may be significant for EHE progress. We want to thank INT, the Royal Marsden and ICR; and Drs Pasquali and Huang for their huge contributions and their diligent and dedicated work on EHE. We also want to thank Dr Silvia Stacchiotti and Professor Robin Jones for their guidance and support as the PIs for the programme in their respective institutions.

As always, here are just a few photos from the day. We hope you enjoy these too.



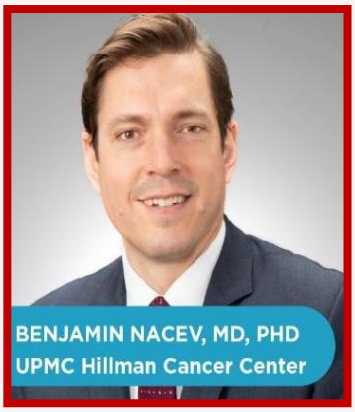
THE EHE Foundation Advisory Board expands

EHE Foundation were delighted to announce the appointment of two distinguished physician-scientists to its Scientific & Medical Advisory Board: Nam Quoc Bui, MD; and Benjamin A. Nacev, MD, PhD. Their expertise in sarcoma medical oncology and translational research will greatly strengthen the Foundation's advisory capacity as we work to accelerate progress in understanding and treating EHE.

Nam Quoc Bui, MD

Dr. Bui is a Clinical Associate Professor of Medicine – Oncology at Stanford University School of Medicine and a member of the Stanford Cancer Institute, where he specializes in sarcoma care and research. He combines clinical expertise with a strong background in bioinformatics, applying large-scale data analysis to tumor sequencing and the development of novel therapeutics for rare malignancies. Dr. Bui also plays an important role in investigator-initiated cancer trial oversight as Chair of the Data Safety Monitoring Committee at Stanford and contributes to medical education as a mentor to students, residents, and oncology fellows. Additionally, he is the founding Editor-in-Chief of the international journal Current Problems in Cancer: Case Reports. Dr. Bui earned his medical degree from the University of Texas Southwestern Medical Center and completed his residency and fellowship training at Stanford and UC San Diego, respectively.

Benjamin A. Nacev, MD, PhD



Dr. Nacev is an Assistant Professor of Medicine in the Division of Malignant Hematology and Medical Oncology at the University of Pittsburgh and Section Chief of Sarcoma Medical Oncology at UPMC Hillman Cancer Center. A laboratory-based physician-scientist, his research focuses on cancer epigenetics and chromatin dysregulation, with the goal of identifying novel therapeutic strategies for rare and aggressive tumors such as sarcomas. Dr. Nacev's work bridges cutting-edge basic science with clinical oncology, informed by his experience treating adult patients with sarcoma and his collaborative involvement in clinical trials. He received his MD and PhD from Johns Hopkins University and trained in medical oncology at Memorial Sloan Kettering Cancer Center before establishing his research program at Pittsburgh.

Their appointments reflect the EHE Foundation's ongoing commitment to building a Scientific & Medical Advisory Board comprised of leaders who bring both clinical insight and research excellence to the field. The EHE Foundation looks forward to the impact their guidance will have on the Foundation's work, from advancing research priorities to enriching patient-centered strategies.

The Pledge joins the EHE Foundation, and indeed the global EHE Group in welcoming Drs. Bui and Nacev to their new roles.

Dr. Michael Wagner in conversation with Dr. Scott Okuno

In our previous edition of The Pledge (Edition 41, Q2 2025), Denise Robinson of the EHE Foundation reported from the SARC (Sarcoma Alliance for Research through Collaboration) Semi-annual Meeting held at ASCO 2025 that a new EHE study (SARC046) had been announced by Dr. Michael Wagner of the Dana-Farber Cancer Institute in Boston, MA. The study, entitled 'A Phase II Trial of Nab-Sirolimus in Patients with Progressing or Symptomatic EHE,' would be led by Dr. Wagner, Medical Oncologist and Director of Sarcoma Clinical Research. We are delighted therefore to be able to announce that the trial has now opened at the Dana-Farber Cancer Institute in Boston, with additional study locations to open soon.

The EHE Foundation was also therefore pleased to highlight a new podcast from the SARC Talk series where Doctor Wagner was talking to Dr Scott Okuno of the Mayo Clinic, about the trial, including:

- How stakeholders collaborated to bring this study to life;
- The critical role of patient advocacy — including the EHE Foundation;
- Why people with EHE should seek care at sarcoma reference centers within large academic medical centers, where physicians have experience with EHE and access to clinical trials.

During the conversation, Dr. Wagner reinforced a fact that our community is all too aware of where you receive care matters. Specialized sarcoma centers have the expertise and research infrastructure that can open doors to trials and emerging therapies.

We are grateful to Dr. Wagner and the SARC team for their collaboration and commitment to advancing research for the EHE community. You can watch the full episode here.

Orion initiates Phase 2 trial of TEAD Inhibitor

The EHE Group were delighted to see news that Orion Pharma, a globally operating Finnish pharmaceutical company, had initiated a phase 2 trial of its ODM-212 TEADES inhibitor.

Orion Pharma, in its press release, stated:

> The TEADES trial is a Phase 2 multi-center, open-label study that will enrol approximately 300 patients with malignant pleural mesothelioma, EHE or other solid tumors with dysfunction in Hippo pathway. The trial will include patients who have progressed after receiving standard treatments and have no further treatment options. The primary endpoints of the study are safety and tolerability with secondary endpoints including Overall Response Rate, Progression Free Survival and Overall Survival. This is a global trial conducted at leading oncology centers in the US and Europe.

Praveen Aanur, MD, MPH, MBA, Chief Medical Officer, Oncology Therapy Area, Orion Pharma, was quoted:

> **Treating the first patient in this Phase 2 study represents an important milestone for ODM-212 clinical development program and more importantly for patients. The encouraging Phase 1 results demonstrated clinical activity as monotherapy with manageable safety profile across different doses and schedules that were tested. We are also excited for the potential of combination treatments with ODM-212 given its mechanism to overcome resistance in standard therapies and emerging therapies in multiple tumor types. Building on the promising Phase 1 data, we are advancing ODM-212 with urgency and scientific rigor as monotherapy and combination therapy for patients across multiple cancers.**

The EHE Group will be following further developments closely, especially as the trial expands to new centres in the US and Europe.

Exploring Eribulin as a Potential Treatment Option for EHE

Prior research has shown that a class of medications called microtubule inhibitors may be effective at controlling the growth of EHE tumors. Recently, researchers conducted a phase 2 study to test whether the microtubule inhibitor eribulin is a safe and effective way to treat patients whose tumors continued to grow after prior treatment.


CLINICAL CANCER RESEARCH

ABOUT ARTICLES COLLECTIONS FOR AUTHORS ALERTS CANCER HALLMARKS

Article Contents

Abstract

CLINICAL TRIALS: NOVEL MECHANISMS | JANUARY 22 2026

A Phase 2 Study of Eribulin in Patients with Metastatic Angiosarcoma and Epithelioid Hemangioendothelioma

Gregory M. Cote; Mason Aberoumand; Edwin Choy; Lucille Sebastian; Emanuele Mazzola; Peter Grimison; Priscilla Merriam; Mandy Ballinger; Subotheni Thavaneswaran; Frank Lin; John P. Grady; Michael Millward; Michael P. Brown; Rosemary Harrup; David Espinoza; George Demetri; Bruce A. Littlefield; R. John Simes; Suzanne George; David Thomas

Six (6) people with EHE enrolled in the study, and two (2) of them experienced meaningful tumor shrinkage while enrolled. Although most patients had a brief period of stable disease before their tumors began to grow again, averaging 2.6 months, some patients had stable disease for as long as 13.5 months. The researchers also reported that side effects, like anemia and lung infections, were generally manageable by reducing the dose of the drug or increasing the time between doses.

Although this small study enrolled only people with progressive EHE, it is possible that some patients could benefit from treatment with eribulin as first-line therapy, or in combination with other kinds of treatment, such as immunotherapy. The authors suggest further study of eribulin for people with EHE is warranted.

While this is a very small study, a promising treatment response is always encouraging. While researchers don't yet understand which patients might benefit, future studies could test whether the drug works for patients who haven't been treated with other therapies, or whether it works better when combined with other therapies.

Clinical studies in EHE like this one move research forward step by step. Progress in rare diseases requires collaboration among researchers across institutions and countries, as well as the willingness of patients and families to participate in research.

The EHE Group wants to thank the study authors for continuing to explore new treatment options and extends sincere gratitude to the people living with EHE who took part in this trial, whose participation helps build the knowledge needed to develop safer, more effective treatments for everyone affected by EHE.

Copy of the paper can be found here or in the EHE Foundation Library here

Biobanking is critical

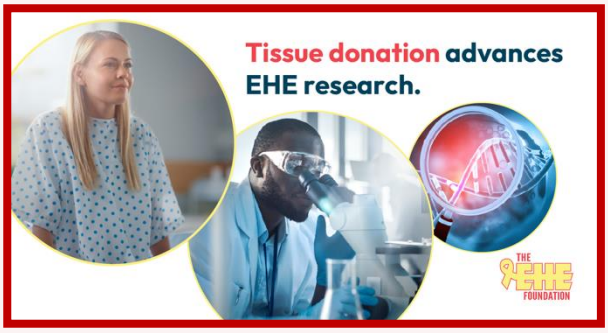
In the Patient Support and Advocacy section of this edition of The Pledge, we reported on the importance of EHE patients sharing their data by joining the Global EHE Patient Registry. Equally important resources that patients can support are the EHE Biobanks that have been established by the EHE Group foundations in the US and UK.

The EHE Foundation posted messages explaining the importance of tissue and fluid donations to research progress in EHE.

Seth Haddix, PhD, EHE Biobank Coordinator for the EHE Foundation, explained why working together to bank biospecimens is so important:

> **When patients are thinking about surgery, a new biopsy, or other procedure, their minds are filled with decisions and worry. Tissue donation isn't usually top of mind, and for more common cancers, it is not something we think about as a priority. For an ultra-rare cancer like EHE, every single EHE surgery or procedure is an opportunity to advance science and ultimately improve lives. When only 1 in a million people have the disease, and only a fraction of those people have a procedure that could provide EHE cells to study, it takes everyone working together to make progress.**

At The Pledge, we want to thank the EHE Foundation for reminding us all of the importance of biobanking. If surgery is being considered or planned as part of your treatment, please contact your nearest EHE biobank to coordinate collection.



For biobank information:

In the U.S. contact biobank@fightehe.org

In the UK contact either the EHE Rare Cancer Charity (hleonard@ehercc.co.uk) or the EHE Tissue Manager at the Royal Marsden Hospital (rmh-tr.ehebiobank@nhs.net).

In Australia contact the EHE Rare Cancer Foundation Australia (info@ehefoundation.com.au)

03 Fundraising

Fundraising is one of the most critical objectives of the EHE Group, and for ultra-rare diseases in general. 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.

EHE Foundation Fun Run & Walk is underway

Every year the EHE Foundation holds its EHE Fun Run & Walk, a community-driven awareness and fundraising event, in support of EHE patients and to raise awareness and critical funding for EHE research. 2026 is no different, and Maggie Cameron of the EHE Foundation was delighted to fire the starting gun for this year's event.

> Happy Friday! I am thrilled to have just launched registration for the EHE Foundation's 2026 EHE Fun Run & Walk! For those of you who are new to the community, this is our 10th year holding this virtual awareness and fundraising event. Through this virtual event, you can participate from anywhere — on your own, with friends, or by organizing a local walk, run, or gathering in your area.
>
> Whether you walk, run, cheer from the couch, or rally your community, you are helping raise critical funds, amplify awareness, and move EHE research forward. Every registration strengthens the global effort to improve outcomes and find better treatments. This year, international participation means our impact can travel farther than ever before!"

Julie Rivers Wahl, who organised the first EHE Fun Run & Walk, and many of the subsequent events, wanted to amplify the role of teams:

> Teams are at the heart of the EHE Fun Run & Walk! Last year, most participants joined through teams, bringing together friends, families, and communities to support an EHE patient and EHE research. So we would be delighted if you started your own team or joined one near you! And we have different team options:
>
> Option 1: Peer-to-Peer (small or virtual) is perfect for individuals or smaller groups looking to fundraise and participate from anywhere.
>
> Option 2: In-Person Events are ideal for larger gatherings with tracked registrations! Bring your community together and make it an event.

The EHE Foundation would love to hear about all these events, big or small, and love it even more if you can send in photos. Please contact:

Maggie Cameron (maggiecameron@fightehe.org) with your event date and details. And remember, no matter how you participate, you're helping drive awareness and progress in EHE research. For more details about the event, and registration, please go here.

100kms run to fight cancer

Kim Delannoy, from Belgium, was excited to post news of her team's participation in a major running event, raising money to fight cancer. Kim said;

> Today we ran the 100km for Fight Against Cancer in Belgium. Aiming at our goal on EHE cancer. We raised a very nice amount, with our team alone, of 3,700 euros and the whole event taised 3.2 million euros. I'm so proud that so many people support us. This is my goal to bring EHE into the spotlight and hopefully it will help in hopes of more research.

And here are some photos of the event. Thank you for sharing Kim, and congratulations to all who took part.

A new year, and races to be run!

After the great support it received in 2025, its tenth anniversary year, the EHE Rare Cancer Charity was unsure if its supporters would understandably want a break from running in 2026?

Some did, but others were once again out training and looking to run. Paul Dean, an EHE patient himself, fitness fanatic and charity supporter, decided he would help by taking on the role of race coordinator. Paul systemised the running registration process for the charity so that supporters can now simply select their preferred races from those listed on the charity website here.

May will see the first of the 2026 runs starting in Birmingham, where Paul and his supporters will once again be pounding the streets for EHE research.

If you fancy running for the charity, you can see and register for a race here, or email the EHERCC Race Coordinator here (that's Paul Dean) who will then sort things out.

We want to that Paul, and everybody who runs this year, for their fabulous support.

Quiz Nights and Sky Dives

Kelly Denton posted news of two fundraising events held for the EHE Rare Cancer Charity.

The first was her annual EHE Quiz Night held at the Bridge House Pub in Penge in South London. This year was a dual quiz night, shared with the Beckenham and Penge Dementia Cafe., another great local cause.

The second was Kelly's brother doing a sky dive for the charity while in Australia.

Kelly was rightfully thrilled to post news of both events:

> **Hey all. Wanted to share a bit of positive news, last week the quiz night raised £830 and my brother raised over £1000 including gift aid with his sky dive. More pennies for research x**

That is great news Kelly. Thanks once again to you and your family for such brilliant support, and for these great photos!

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.

2026 welcomed!

Jane Gutkovich started 2026 with a message of hope wishing everybody . a healthy and happy New Year to everyone!! Let it bring only good news!!

A message shared

Geanina Dani Marita posted this photo, capturing the one-in-a-million

Teddys are special!

Stephanie Kennedy meanwhile wanted to show that you are never too old to receive a cuddly teddy bear. Stephanie was deeply touched by this cuddly one given to her by her granddaughter!

An EHE tattoo in memory of Kylar

We often post photographs of tattoos in The Pledge within our community that involve EHE. Many are the Just Live heartbeat logo, but every so often, somebody will decide to go a little further. Taz Beacher-Kelly was one such person, as she explained:

> Begun on January 31st, today I finished my tattoo honoring our daughter Kylar.
>
> Kylar resembled Rapunzel and we loved "Tangled". Kylar also loved "Silence of the Lambs", hence the Death's Head Moth, which my husband and daughter also have tattoos of. I changed the head of the moth to be Jack Skellington because we are fans of "A Nightmare Before Christmas" as well.

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

Rare Cancer – EHE Deutschland e.V.
www.rarecancer-ehe-deutschland.de