Rare Cancer Charity UK

Annual Report and
Financial Statements 2025



Epithelioid Haemangioendothelioma (EHE)

EHE Facts

A **destructive vascular sarcoma** that is found in the walls of blood vessels

Commonly appears in **liver and lungs** but can appear anywhere

Can present as **indolent** (passive) or **aggressive**

Typically more aggressive in **young people**

Can re-present after long period with no disease

Often presents with **multiple tumours** called 'multifocal'

May turn **aggressive at any time** without warning

Clinical signal that onset may be tied to **pregnancy** and **puberty** in young women

Living with EHE causes **enormous psychological stress**

Affects both males and females but is **more prevalent in women**

One of the **world's rarest cancers,** with approximately 20 patients per year in the UK

Limited treatment options with unpredictable outcomes

No known cure. Aggressive disease is **normally fatal**

Background slide: Harvey lab SMT image. Single frame of a movie showing DNA-binding proteins (shown in red) binding to DNA (shown in grey), captured on film for the first time. Read more on page 19.

Find out more at: www.ehercc.org.uk

EHE Rare Cancer Charity UK

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Message from the Trustees

2025 has been an exciting year for the Charity and the global EHE community. We have seen excellent progress with TEAD inhibitors, a new class of drug that targets cancers driven by fusion proteins resulting from chromosomal translocations. Early Phase 1 trials of these drugs have provided encouraging results, with a number of similar drugs in the pipeline.

Sirolimus, better known as the immunosuppressant Rapamycin, continues to demonstrate the ability to stabilise progressive disease in our patient community. Frustratingly, this drug is still only available 'off-label'. But, the Charity, together with other EHE foundations and clinical specialists, is heavily engaged in a dialogue with regulators to identify the quickest route to a label extension for EHE.

EHE projects that we are funding are also producing critical data and information. The pan-European EHE prospective registry, the European EHE prospective non-interventional observational study, the global EHE patient registry, and the UK EHE Biobank are just four examples where we are collating information that will be fundamental in our ability to manage the disease in the future, to the benefit of our global EHE community.

Our patient support and advocacy activities have continued. Much of this support is provided by the EHE patient community through different platforms, some local, some national and some global, like the EHE Patient Support Facebook page. As always, every opportunity has been taken to engage with all stakeholders to ensure that awareness of EHE continues to grow. Hugh Leonard was, for example, delighted to speak at the European Remedi4ALL drug repurposing conference, on behalf of EHE and all ultra-rare disease patients.

We are also excited to continue to be a participant and Executive Committee member of the PUSH project (Pushing Ultra-rare Sarcomas beyond Hope), a new global platform designed to promote, support and run ultra-rare sarcoma studies, trials and other forms of disease investigation.

2025 has also been another excellent year for fundraising, with amazing grass-roots support from our patients and their supporters. In recognition of 2025 being the Charity's tenth birthday, the Charity launched its Ten-for-Ten campaign where supporters did ten of something to raise fund. Ten mountains climbed, swimming 10km, or running 10km were all great examples. We also set out to get 100 runners in the year to participate in 10km runs, so that they would in aggregate run 1 million metres, in recognition of EHE being a 1-in-a-million sarcoma. The 114 runners that completed the challenge did not let us down!

We will always be so grateful for the brilliant contributions of the sarcoma clinical and research communities that we work so closely with, and our patient community and their supporters. As a group, they strive every day to raise the funds and discover and deliver better treatment options for EHE patients. We want to recognise every single person who contributed, in whatever form, to this amazing collective effort by saying a simple but profound "Thank you"!

Thank you!

Left to right:
Hugh Leonard (Chair of Trustees),
Jeff Collins (Trustee),
Kate Hooper (Trustee),
Sally Baker (Trustee),
Dr Oliver Pearce (Trustee).



01 Patient Support and Advocacy

In 2025 the Charity's core objectives were to support the UK EHE patient community while also collaborating with all other stakeholders, in the UK and internationally, to increase understanding and awareness of EHE, and engagement with our goal of finding new and effective treatments.

Engagement with the UK EHE patient community is of critical importance. The UK EHE patient WhatsApp group continues to be an active and hugely positive component of our activities. This may not work for everybody, however, so we continue to regularly communicate through multiple social media and other communication routes.

Our broader engagement with all stakeholders is driven by close collaboration, including with our sister EHE Foundations around the globe. In early January, the Charity, together with EHE ITALIA and the EHE Foundation (USA), hosted a meeting in Amsterdam with researchers and clinicians from Italy, the United Kingdom and the United States, to review our research programs and discuss key research priorities.

Also in January, the Charity participated in a full-day workshop at the European Medicines Agency (EMA) to discuss the challenges faced by ultra-rare sarcomas in securing approvals for new or repurposed drugs, and to explore ways in which appropriate procedures might be adopted. These discussions are ongoing.

In May, Hugh Leonard was invited to speak at the European drug repurposing conference, *iDR25*, in Amsterdam. Hugh addressed the challenges faced by patients with ultra-rare diseases, and the importance of drug repurposing for these diseases where novel drug development is very unlikely due to the tiny patient numbers.

Throughout 2025, the Charity continued to promote the PUSH project, a new global platform to also maximise the knowledge of ultra-rare sarcomas and support the development of new treatments. A substantial number of institutes and academic centres across the globe have already joined the project, giving the PUSH Platform real momentum. Hugh Leonard remains a member of the PUSH Executive Committee.

02 Research

The multi-faceted European research collaboration involving Istituto Nazionale dei Tumori (INT) in Milan, the Institute of Cancer Research (UK), and the Royal Marsden Hospital, London, remains at the core of the EHE research we are funding. This programme has already identified Growth and Differentiation Factor-15 (GDF-15) as a biomarker for the disease, with latest results published both in journals and as a poster presentation at the CTOS Annual Conference in 2025. INT have also identified four potential miRNAs which could also be correlated to disease status and progression, and may therefore also act as biomarkers for EHE.

As part of this international collaboration, the previously established non-interventional observational study of EHE patients is being continued for a further three years, with the objective of increasing the total number of patients included from 50 to 150. The study protocol will be updated and modified to ensure rigorous prospective data collection that we expect will be acceptable to regulators for drug repurposing and associated label extensions. This study expansion is being jointly funded by the Charity, EHE Italia and the EHE Foundation.

The Charity continued to fund the first ever EHE-dedicated, prospective observational registry, a pan-European initiative, which is part of the European STARTER project, and is managed and coordinated by a dedicated team also based at INT in Milan.

The National EHE Biobank, funded by the Charity and based at The Royal Marsden Hospital in London, continues to gather critical bio-samples. The Charity and the Royal Marsden are continuing to promote awareness of the biobank with hospitals across the UK, supported by enthusiastic support from the UK patient community.

2025 also saw the Charity join the EHE Rare Cancer Foundation Australia in funding Professor Kieran Harvey at the University of Melbourne and Peter MacCallum Cancer Centre. Professor Harvey's research is using state-of-the-art microscopy to help unlock details of EHE biology by imaging and mapping individual proteins in EHE cells.

03 Fundraising

As we have often said, fundraising is the life blood of the Charity, without which we would not be able to operate, or invest in and support critical EHE research. Fundraising through 2025 was again a combination of grass-roots activity, and charity-driven events, all amplified due to it being the Charity's tenth anniversary.

Our **Ten-4-Ten** initiative challenged our supporters to do something involving the number **10** to raise funds for EHE research while celebrating the Charity's tenth birthday. The Charity itself set out to secure 100 runners throughout the UK to each run 10km, and so run 1 million metres in aggregate, reflecting the fact that EHE is a 1-in-a-million sarcoma. We were thrilled that a total of 114 runners took up the challenge.

One of our EHE patients decided to swim 10km over the month of April, being EHE Awareness Month. Another patient set out to climb ten different peaks with her dog, together with support from family and friends.

But a lot of fundraising not focused on '10' also took place: quiz nights; an EHE live stream event held by students in Bournemouth; the Three Peaks Challenge; the Tour de 4 cycling event; the Sodbury Slog; and a 430km trek in the Vosges Mountains in France were all organised.

One of the most poignant fundraising campaigns was instigated by the sister of an EHE patient. 'Team Emma' engaged in a dynamic and sustained fundraising campaign, involving multiple events, including a riotous race night, the Bath 50 Ultra, a Feeling Great Fundraiser, and several events in the Albion Ale House. More details about all these events can be found in the later Fundraising section of this report.

The Charity received great support from so many different groups and individuals. We are so grateful for their fantastic engagement.

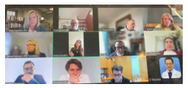
More information about these and other events can be found in this report.

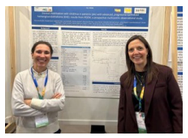
Achievements for 2025 and objectives for 2026

We believe that an honest assessment of our year's activities and achievements against the goals we set ourselves is important for all our supporters and stakeholders. Below is the 2025 assessment; on the opposite page you will see our objectives for 2026

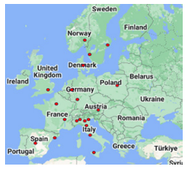
	What we said we would do...	...and what we achieved
01 Patient Support and Advocacy	Continue to promote sirolimus repurposing	Maintained engagement throughout 2025
	Engage with other repurposing groups and platforms	Represented EHE at the iDR25 repurposing conference
	Remain engaged with PUSH	Continued as PUSH participant and Executive Committee member
	Support UK patient community, and international patients where possible	Engaged with and supported UK and international patients throughout the year
	Attempt to define European strategy	Discussions initiated with EHE Italia and European patients
02 EHE Research	Support existing research	Engaged with all researchers
	Execute research extensions where possible	INT/ICR/RMH collaboration extended and expanded, including EHE POEM prospective observational study
	Continue to search for new research opportunities	Early discussion regarding immunotherapy initiated
	Identify joint funding opportunities within the EHE Group	Joined EHE RFA Australia in funding Prof Kieran Harvey
03 Fundraising	Support and encourage grassroots fundraising	Excellent engagement throughout tenth anniversary year
	Promote **10 for 10** fundraising campaign across 2025	Excellent take up by supporters across many events
	Re-evaluate timing of fundraising strategy with NOVA fundraising	We have suspended this work to concentrate on structure first
	Evaluate ways to systemise fundraising engagement ideas through website modifications	The Charity's running focus is now on the website with systemised enrolment
Charity Organisation	Consider appropriate support for research strategy	Dialogue started and ongoing with patient volunteers
	Implement fundraising strategy	Suspended as stated above
	Establish structures for European engagement	Currently under review with EHE Italia and European patient community
	Evaluate need for additional structures and personnel for the above	Ongoing dialogue with patient community and supporters











Our Forward Focus for 2026

Because rare cancers are not rare to those who have them!

01 Patient Support and Advocacy

- Support UK patient community, and international patients where possible.
- Continue to support the POEM study and sirolimus repurposing.
- Continue to support PUSH.
- Move European strategy from 'embryonic' to 'preliminary'.

02 EHE Research

- Support existing research.
- Progress immunotherapy opportunities.
- Evaluate joint funding opportunities, both within the EHE Group and external.
- Review biobanking protocols and engagement with patients.

2026 AND BEYOND

03 Fundraising

- Support and encourage grassroots fundraising.
- Continue to systemise fundraising where possible.
- Reduce fundraising drive for 2026 after 2025 focus, but prepare for 2027 re-engagement.
- Engage community in fundraising ideas.

Charity Organisation

- Develop structures for European engagement and initiate as appropriate.
- Continue to evaluate need for additional structures and personnel for key areas of activity.

Foreword from Hugh Leonard



As 2025 was the Charity's 10th anniversary, we thought it would be appropriate to use the Foreword to look back at our achievements and progress, and also comment on our future ambitions.

Our inception and fundraising
The initial catalyst for mobilising the global EHE community was the launch of the EHE Patient Support Facebook page which today has more than 3,300 people connected to the page in more than 85 countries. For an ultra-rare cancer, that global connectivity has been hugely important in bringing together and organising the patient community.

Although the Facebook page has globally connected the EHE community, it alone would not improve the clinical ability to treat this ultra-rare sarcoma. To do that we needed to drive an active research programme, which would need to be funded. Sadly, as ultra-rare diseases get little or no funding from governments or big pharma, our community understood that we would need to raise those funds, and to do that we would need appropriate legal and fiscal structures. Therefore, in 2015, the first three EHE not-for-profits – the UK, the USA and Australia – were launched, each independent but closely linked through the community. And Canada, Italy and Germany have since organised their own associations. We hope others will follow.

As we set up the not-for-profits, there was no guarantee that we would be able to raise meaningful funds. Nor was there any certainty that we would find researchers willing to focus on such a rare sarcoma and, if we did, that the research would be positive. But we had to try, and the results have amazed us.

Fundraising has been exceptional, largely driven by grass-roots activity. Our community may be small but they are dedicated, determined and enjoy amazing support from family, friends, colleagues, employers and the general public. In several cases, their connections have also led to significant donations from the charity arm of corporate groups or other philanthropic entities. Since establishment in 2015, the Charity had raised, at the end of 2025, more than £1.42 million, which is far beyond our 2015 expectations.

Research
We were also delighted to discover that many within the clinical and research community were indeed interested in helping to find new treatments for EHE. Research, partially funded by the Charity, is now progressing in a number of key areas:

–Patient data and disease information: A major multi-year research collaboration between the Istituto Nazionale Dei Tumori (INT) in Milan and the Institute of Cancer Research (ICR) and The Royal Marsden Hospital (RMH) in London is running a prospective non-interventional observational study of EHE, now called **POEM**. Alongside **POEM**, INT is also running the pan-European EHE Prospective Registry involving more than 20 European hospitals. In both the study and the registry, data is being rigorously collected under detailed protocols. With the objective of enrolling more than 200 patients in aggregate across both projects, we are delivering valuable information about the disease and its natural biology, as well as information that will support the application and approval of new treatments, such as the repurposing of sirolimus as a drug for the treatment of EHE.

–Disease models and cell lines: A key priority was the development of cell lines and models of EHE, as no such models existed in 2015. Today we have Dr Brian Rubin's excellent and robust genetically engineered mouse model and associated cell lines. The research team at INT in Milan have successfully established two PDX models of EHE. In a further breakthrough, Dr Munir Tanas's team at the University of Iowa have developed four separate human EHE cell lines, the first of their type in the world. These models are critical to helping to accelerate EHE research, for example, in the development and testing of TEAD inhibitors.

–Biomarkers: In 2015 we had no recognised biomarker for EHE. Biomarkers are important as they can not only alert doctors to the onset of a disease but also provide information relating to the nature of the cancer (how aggressive it is), and act as an indicator of efficacy of new or repurposed drugs. The INT collaboration has identified GDF-15 as a biomarker of EHE, and is now focused on two different identified miRNAs, which seem to correlate with disease aggressiveness. This work continues.

–Biosamples are critical: One of the most acute limitations when dealing with and researching an ultra-rare disease is that of tissue, blood and other fluid samples. We were delighted therefore to fund the setting up and ongoing administration of the UK National EHE Biobank, allowing us to gather critical biosamples to support EHE research.

–Natural history of EHE: Research we have funded has also focused on aspects of the natural history and biology of EHE. A four-year PhD at Manchester University under Dr Valerie Kouskoff developed our first EHE model using pluripotent stem cells with the EHE translocation construct inserted to create EHE cells. This work suggested that high levels of DNA damage and corruption of the DNA repair pathways might be a significant component of EHE progression. Our INT-ICR collaboration has focused on biomarkers of the disease as described above, while Professor Kieran Harvey's cutting edge research in Melbourne is leading to a better understanding of how TEAD and TEAD binding actually behave within our cells.

Funding
At the end of 2025, the Charity had funded more than £998,000 of EHE research in single-institute projects and major international collaborations. These major international collaborations are particularly exciting as we bring together research and clinical specialists from different institutes and different countries.

Collaboration is not restricted to the researchers and clinicians. The EHE not-for-profits have also collaborated in the funding of research, ensuring we have a coordinated overall programme through active involvement of the foundations across multiple projects. Joint funding involving the Charity has been provided to Dr Rubin and Dr Lamar in the USA, to the INT-ICR-RMH collaboration, and to Professor Harvey in Australia. We should also note that this report only deals with the Charity's activities. Significant additional EHE research has been funded and is progressing, predominantly in the USA, Australia and Canada, under programmes driven and funded by the EHE Foundation, The EHE Rare Cancer Foundation Australia and EHE Canada, respectively.

Looking Forward
The Charity has ongoing commitments to the long-term components of our European research, namely: the INT-ICR-RMH collaboration; the EHE observational study and pan-European registry being run from INT; and the UK National EHE biobank at The Royal Marsden Hospital. We will continue to fund this important work.

Together with our sister EHE foundations, we will also continue to seek and support new EHE research, particularly focused on projects that have a clear and direct ability to pull forward and help deliver new EHE treatments. We were particularly excited to see the EHE Foundation commit to our first immunotherapy research project in 2025 in Dr Bauer's lab at the University Hospital Tubingen, Germany.

In summary
In 2015 we had no EHE models, no biobanks, no prospective studies or registries, no biomarkers and no efficacious systemic treatments to deal with progressive disease. At that time, as far as we were aware, Dr Brian Rubin's lab at the Cleveland Clinic in the USA had the only dedicated EHE research team in place.

Today we have multiple disease models, and established biobanks. We have both a prospective EHE study and EHE registry ongoing, and our own global patient registry, all gathering disease data and information to inform clinical practice and research hypotheses. The fusion proteins that drive EHE were isolated and the importance of TEAD binding understood. The ongoing clinical trials of different TEAD inhibitors, involving EHE patients, are producing very encouraging results. Drug screening has identified established drugs that could have a positive effect on the treatment of EHE and are being further evaluated.

We think this progress is exceptional for such a rare sarcoma, and want to thank all the supporters, donors, researchers, clinicians and other stakeholders who have combined to deliver these advances in our understanding and treatment of EHE. There is, however, a huge amount more to do, so we must be as relentless as EHE, continuing to raise the funds and drive the research that will deliver ever better and more reliable treatments of the disease.

The first 10 years have produced great progress. We are now focused on ensuring the next 10 years are even better.

01
Patient Support and Advocacy

Our patient support and advocacy activities lie at the core of the Charity's activities and comprise two simple objectives. The first, inward focused, supports the patient community, while the second, outward looking, is about spreading awareness of EHE and the impact that an EHE diagnosis has on patients.

Support for EHE patients is largely provided through EHE social media platforms, both local and global, by the patient community itself. These are the people with real EHE understanding, allowing them to share experiences and provide valuable information on a range of topics.

Our outward-looking advocacy objectives are to ensure we bring these facts to the attention of as many people as possible. We therefore take every opportunity to engage in dialogue and expand collaboration as we continue to believe that there is no better way to spread awareness than by speaking to actual audiences.

We also share news about the Charity and its activities, in the EHE Group quarterly global newsletter, *The Pledge*, edited and produced here in the UK. We will also share this Charity Annual Report with as many people as we can as part of our awareness and patient support programme. We hope that people find the content of these different publications inspiring and share them as widely as possible.

Review by Sally Baker

"2025 saw the dialogue progress with the European Medicines Agency as we continued to seek approval of sirolimus for the treatment of EHE. We remained a member of the PUSH Consortium, with Hugh Leonard continuing on the PUSH Executive Committee. Hugh spoke at the iDR25 Medicines Reimagined conference, a major annual platform for drug repurposing. We were also pleased to host a Research Roundtable in Amsterdam in January involving EHE clinical and research specialists. We continue a positive and dynamic engagement with the UK patient community through our WhatsApp group. More information is provided below concerning our Patient Support and Advocacy activities through the year."

Research Roundtable: advocacy in action

In January, EHE advocacy leaders from EHE ITALIA Associazione Non Solo LAURA ODV and The EHE Foundation (USA) joined The EHE Rare Cancer Charity (UK) who were hosting a meeting in Amsterdam, The Netherlands, with researchers and clinicians from Italy, the UK, and the USA to review progress on ongoing collaborative research programs and explore key research priorities aimed at improving patients' lives.



This research roundtable was one of several important meetings with multidisciplinary experts who continue to generously give their time and expertise to advance knowledge and care in EHE. The full-day meeting provided time for all attendees to contribute to three core areas of discussion, namely: (i) a review of the latest developments in ongoing research; (ii) key areas of EHE treatment where our treatment options and understanding of the disease are insufficient to deal with the challenges presented; (iii) new research that might be considered to address these challenges.



The natural biology of EHE, with its heterogenous nature, was again recognised as an area where greater understanding would be highly beneficial. For this reason, a number of ongoing developments were strongly supported, including: (i) the pan-European EHE Prospective Registry and the Prospective International Observational EHE study (POEM), both coordinated at INT in Milan; (ii) The EHE Global Patient Registry managed by the EHE Foundation in the USA; (iii) the expansion of EHE biobanks to capture tissue and fluid samples for research purposes.

It was also recognised that with such small patient numbers, a global focus was required across all areas of activity associated with developing new and better treatment options for EHE patients. It was extremely positive therefore to see several examples of research and clinical international collaborations involving the UK, Europe, the USA, Canada and Australia. Although much work remains, the Charity is deeply grateful to everyone who supports the EHE Group's mission through these invaluable collaborations.

01 Patient Support and Advocacy - continued

Ultra-rare pushes forward at the EMA

On 31 January, the day after the EHE research roundtable reported above, expert clinicians, researchers, and patient advocacy leaders met in Amsterdam with the European Medicines Agency (EMA) under the auspices of European Organisation for Research and Treatment of Cancer (EORTC) to explore strategies to develop and obtain approval for new treatments for ultra-rare sarcomas as a model for ultra-rare tumours. The discussions focused on lessons learned from efforts in the EU to secure regulatory approval for sirolimus for the treatment of EHE, highlighting progress and ongoing challenges in ultra-rare disease drug development.



Hugh Leonard, Chair of Trustees of the EHE Rare Cancer Charity (UK), spoke at the meeting on behalf of all ultra-rare sarcoma patients, again highlighting the need for urgent progress while at the same time recognising key areas of challenge.



The Charity, together with EHE Italia and the EHE Foundation are playing an active role in ensuring regulatory bodies understand the urgent unmet needs of people living with EHE. Together, we support critical research that not only generates data for regulatory review but also helps inform treatment practices for EHE patients worldwide.

EHE at iDR25 Medicines Reimagined

In early May, Hugh Leonard, our Chair of Trustees, was delighted to attend the fast growing and powerful drug repurposing conference, iDR25, in the stunning Felix Meritis, Amsterdam!



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

The conference featured four pathways delivered over two days:

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

Hugh Leonard was also delighted to have been invited to speak during the "Repurposing for the under-served..." session on day one.

Hugh addressed a topic that he feels passionately about, namely the challenges faced by ultra-rare diseases (URDs). His talk was entitled "Repurposing for Ultra Rare Diseases – Critical but flawed". Why critical? Because of the utterly desperate unmet patient need of ultra rare diseases. And why flawed? Because repurposing of drugs is unable to progress in the required time frame; it is facing many of the same barriers as 20 years ago; and it is definitely not meeting the critical need!

Hugh explained:

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



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

Hugh concluded:

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

The role of AI in drug repurposing

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

Innovative trial designs and patient centricity in drug repurposing

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

Drug repurposing for under-served populations

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

A sustainable business model for drug repurposing

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

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

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

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

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

01 Patient Support and Advocacy - continued

EHE live stream raises awareness

The EHE Rare Cancer Charity were thrilled when a group of final year students studying Television Production at Bournemouth University approached the Charity and asked if they could do a Live Stream production about EHE. Their goal was to raise awareness of EHE through a live stream event involving EHE patients and the Charity.

The live stream was broadcast on Friday 25th April. In preparation, the team filmed Kelly Denton's EHE Quiz Night, and conducted interviews/filming at the Institute of Cancer Research in Sutton, south-west London.

On the day of the production, Hugh Leonard, Sally Baker, Kim Alexander-Bird and Sue Glyde all participated. Sally, Kim and Sue spoke of the challenges of living with EHE; their fears and their hopes for the future. Hugh, Sally's husband, also spoke about their story, as well as explaining why they set up the Charity and their commitment to finding better treatments and ultimately a cure for EHE.

Overall, they were all amazed at the professionalism of the whole process and the production itself, as Sally explains:

> *"Not sure what to expect, we were amazed to find ourselves in a real TV studio with a huge cast of young, budding TV specialists ready to go. We did several rehearsals and then went live at lunch time on the Friday. The programme was streamed on social media which was very exciting. We understand that it has been watched nearly 1,000 times which is fantastic in terms of spreading awareness about the disease. We could not be more grateful to the whole team."*





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



Hugh also wanted to thank the research team from Dr Paul Huang's lab at the Institute of Cancer Research in Sutton, in south-west London, who did such an impressive job explaining what they do as they seek answers to questions about EHE and sarcomas generally. Their contribution was also important to expand awareness of the work going on and challenges faced in finding new treatments.



As if that was not enough, the Bournemouth team wanted to also use their event to raise funds for EHE research. The Producer of the event, Reannah, was so proud of everything they accomplished and was thrilled to confirm that the charity livestream had raised £1,700 for EHE research. We were so grateful to all the students for picking the Charity as the subject of their production. It was very special.

Another Paul Dean *'Just Live'* moment

The motto of the global EHE Patient community is ***Just Live,*** so we love it when patients post news of events and/or achievements that show them living up to the group's ***Just Live*** mantra. Paul Dean, from the UK, posted just such a story from Africa.

> *Hey all, in true 'Just Live' fashion. Yesterday morning I summited Africa's highest mountain, Mt Kilimanjaro! Just for fun. We did it in 5 days on the Machame route and my god it was tough at that altitude. The gods sent us a blanket of snow 2 hours before we climbed so that made it even more interesting!*
>
> *I've been almost 4 years diagnosed with EHE in my liver and lungs, I'm posting this to show that having an EHE diagnosis isn't necessarily the end and you can still do things you've always wanted; don't let a little thing like EHE stop you if you can! I hope this inspires someone to chase their goals*
>
> *EHE related points: I was concerned about a low oxygen environment affecting my liver pain but it didn't seem to do anything. Hopefully hasn't done anything to my tumors but so far so good! Also I don't particularly recommend doing Kilimanjaro as a health journey as it was very, very tough on the body but I did enjoy it."*

Congratulations Paul, and here at The Charity, we were actually slightly surprised that you did not either run or cycle to the top. All joking apart, well done on a great achievement. ***Just Live*** indeed!



02
EHE Research

The Charity, and indeed the global EHE Group, is both excited and inspired by the levels of EHE research engagement we are seeing in the UK and globally. Thanks to our wonderful supporters we are also delighted that we have been able to expand and extend our existing research while also considering new research projects, together with our sister EHE Group entities.

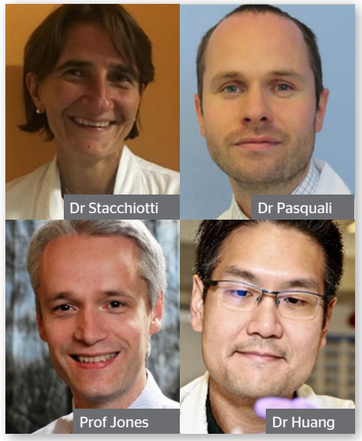
In 2025, the collaborative EHE research being led by Istituto Nazionale dei Tumori in Milan, and the Institute of Cancer Research and the Royal Marsden Hospital in London, has delivered important results together with a number of new and exciting research ideas. The observational study and the prospective registry of EHE patients has also continued to grow, both also managed by INT in Milan.

We are also delighted at the excellent support for, and progress of, the National UK EHE Biobank. This important infrastructure is maintained at the Royal Marsden Hospital, collecting critical EHE bio-samples for future research, funded by the Charity.

Summaries of these research programmes can be found on the following pages.

Review by Dr Oliver Pearce and Dr Kate Hooper

*"2025 was another good year with the extension and expansion of our European collaborative research. Key progress included further work on the verification of GDF-15 as a biomarker of EHE, the identification of two possible miRNAs as additional biomarkers, and the agreed three-year extension of the **POEM** prospective non-interventional observation EHE study. We were also delighted to join the EHE Rare Cancer Foundation Australia in funding Professor Kieran Harvey's state-of-the-art project in Melbourne, Australia, imaging actual TEADs and TEAD-binding in the nuclei of EHE cells. More on these and other ongoing research can be found below."*



European collaboration

We have previously reported on the progress of the major European collaboration involving the Istituto Nazionale dei Tumori (INT), Milan, the Institute of Cancer Research (ICR) in London, and the Royal Marsden Hospital (RMH) in London.

The overall research program entitled 'Evaluation of Cytokines and Hormones as Biomarkers for EHE' comprises a number of different objectives or projects as follows:

i) the identification and validation of novel circulating and tissue biomarkers to inform patient management (prognosticators and predictors of response to medical agents) as well as potential therapeutic targets **(Project 1)**

ii) the development of patient-derived xenograft (PDX) models **(Project 2)**

iii) the assessment of the activity of drugs relevant for the disease **(Project 3)**

iv) the generation of PDX-derived cell lines to investigate the cellular and molecular determinants of drug activity and to be submitted to a CRISPR whole-genome screen to identify new therapeutic targets **(Project 4)**

v) the identification and evaluation of miRNAs **(Project 5)**

vi) the description of the radiologic characteristics of EHE and their correlation with the clinical outcome **(Project 6)**

Underpinning this work was the concurrent establishment of a non-interventional observational study of EHE, with patients enrolled in Milan and London.

Dr Silvia Stacchiotti, one of Europe's leading sarcoma clinicians, and Dr Sandro Pasquali, a leading sarcoma researcher based at INT in Milan, are joint Principle Investigators (PIs) of the project at INT; Dr Paul Huang is the PI at the ICR, and Professor Robin Jones is the PI at the RMH.

Biomarker focus

A key focus of this research continues to be the assessment of circulating cytokines, hormones (and miRNAs), and the identification of novel biomarkers for EHE.

As previously reported the researchers identified and focused on Growth and Differentiation Factor-15 (GDF-15) as a biomarker of EHE. Having verified a statistically significant association of GDF-15 levels with EHE aggressiveness in two patient cohorts, and also demonstrated changes in GDF-15 levels corresponding to treatment with sirolimus, the team published the results in their research paper, entitled 'GDF-15 predicts epithelioid hemangioendothelioma aggressiveness and is down-regulated by sirolimus through ATF4/ATF5 suppression', published in *Clinical Cancer Research* at the end of 2024.

Results of this groundbreaking research show that:

a) In the two models used, a patient-derived xenograft (PDX) and paired EHE cell line, EHE cells produce and release GDF-15. GDF-15 is a cytokine that cancer cells produce and is used as a biomarker for the severity of many diseases.

b) These results indicate that GDF-15 could be a useful novel biomarker to predict EHE aggressiveness and disease progression.

c) In the EHE models used, sirolimus was shown to reduce GDF-15 expression.

d) Additionally, sirolimus (not yet approved for EHE treatment) had a higher anti-tumor activity than doxorubicin (approved for soft tissue sarcoma) when compared in the model systems.

For EHE patients, these findings give hope for further preclinical drug development using human-derived EHE models, better-informed treatment decisions, and the ability to monitor disease progression, all with the goal of improving patient outcomes.

02 EHE Research Continued

In addition to GDF-15, and as also previously reported, the research team identified possible miRNAs that may also be novel biomarkers of EHE. Work continued through the year to identify whether these miRNAs are in fact biomarkers of EHE, and whether they might also indicate the nature of the disease in terms of its aggressiveness. We await the results of this work, which we will report in 2026.

Observational EHE study
2025 also saw the extension and expansion of the non-interventional observational study of EHE in Milan and London, as mentioned above. Importantly, the study results presented to the European Medicines Agency when discussing the repurposing of sirolimus, were assessed to be retrospective in nature due to the lack of a common protocol under which data was collected. This was frustrating as retrospective data is typically not accepted by regulators as part of their drug approval procedures.

Critically, therefore, the study protocol has been revisited and amended so that data collected has a high chance of being accepted as prospective and therefore results from it acceptable as data supporting a repurposing application. Each patient under this revised 'Prospective International Observational study on EHE' (POEM) is being treated under this new standard protocol, creating a significant, high-quality study of the disease, not only for drug repurposing, but which will inform ongoing thinking regarding EHE research and treatment. The POEM study will also be undertaken under the PROSPER Framework Agreement, part of the PUSH Platform initiative, and has a current target of 100-150 patient participants.

In addition to the new protocol, study participation has been expanded, with international institutions from Spain, Germany, Holland, Poland, Canada, USA, Australia, Taiwan, Brazil, Korea, India and Singapore all joining the POEM study. This is an exciting development, with the EHE cohort expanding significantly. We look forward to providing further updates in the future.

The expansion in collaboration does not just include participating institutes. Funding of this important study also saw an expanded collaboration among the EHE foundations. As partners in EHE research, seeking to find better treatments for people with EHE, the Charity, the EHE Foundation, and EHE Italia were excited to share the expansion of this multi-national collaborative research project. With continued progress and clear potential to improve lives, the EHE entities agreed that the project continued to produce exciting results and is likely to unlock answers for EHE, leading to better disease understanding and improved treatments.



Andrei Ivanescu (Italy), Denise Robinson (USA) and Hugh Leonard (UK)

Hugh Leonard, Chair of Trustees of the Charity, commented on behalf of all the patients' advocates:

"We are incredibly fortunate to have this opportunity to fund some of the most passionate and brilliant doctors and researchers leading the fight against EHE. The collaboration among these institutions combined with our funding partnership across the EHE foundations is an excellent model for how we can make progress in dealing with a disease as rare as EHE."

Unlocking EHE biology with state-of-the-art microscopy

In July 2024, a two-year research project was initiated, funded by the EHE Rare Cancer Foundation Australia (EHE-RCFA), proposed by Professor Kieran Harvey at the University of Melbourne and Peter MacCallum Cancer Centre, using state-of-the-art microscopy to help unlock details of EHE biology.



Professor Kieran Harvey

A key regulator of EHE biology is the Hippo Pathway. This is a fundamental cell signalling network that controls cell proliferation and ultimately organ size. Originally discovered using genetic screens in *Drosophila* flies but common to many animals including humans, it is now known to be comprised of more than 40 proteins that communicate information from neighbouring cells, the microenvironment, as well as mechanical forces, to control organ growth. YAP and TAZ are two important Hippo pathway proteins that critically must bind (connect) to proteins called TEAD1, 2, 3 and 4, in our cells. Importantly for EHE, YAP and TAZ are also key components of the genetic mutations and resultant fusion proteins that drive EHE by encoding different transcription factors in our cells. This occurs not only in EHE, but also in other cancers, such as meningiomas.

Given that both the fusion proteins YAP-TFE3 and TAZ-CAMTA1 must form a physical interaction with TEADs to enable their tumour-promoting ability, a new class of drugs called TEAD inhibitors, which bind to the fusion proteins and prevent their binding to TEADs, have the potential to be effective therapies for EHE. This is why the recent ongoing development of TEAD inhibitors is so important for EHE patients.

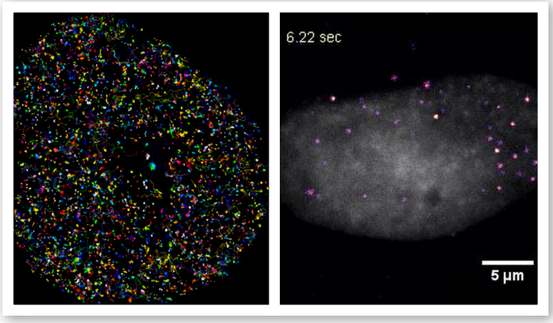
Although the development of TEAD inhibitors is ongoing, there is still a lot we don't know about EHE biology, which is why Professor Harvey's research proposal was so interesting. Despite the great promise of YAP/TEAD inhibitory compounds (TEADi's), and a growing understanding of their impact on cell biology, we still have a limited understanding of their mechanism of action at the molecular level. In particular, we lack a detailed understanding of how different TEADi's change the biophysical behaviour of TEADs and the mechanism by which they bind DNA and regulate transcription. Defining these key outstanding questions will help explain how EHE fusion proteins induce and sustain cancer, and how we can target them for therapeutic benefit.

At the core of Professor Harvey's project is a completely different approach to gain new insights into EHE biology and treatment that utilises a powerful combination of high-resolution microscopy and computational methodologies. The research team were able to start to capture YAP-TFE3 and TAZ-CAMTA1 behaviour in living cells using an array of cutting-edge microscopy techniques and compare this to YAP, TAZ, TEADs and other YAP cancer fusion proteins. They also hoped to assess the impact of different drugs on these proteins. The approaches they will use have never been used to study EHE proteins.

Professor Harvey's project was fascinating, so when a chance arose for the Charity to jointly fund the project, with the EHE RCFA, for its second year, we were delighted to participate. The Charity was thrilled to join the project, and support Professor Harvey's work, as Hugh Leonard, Chair of Trustees of the Charity explained:

"We are thrilled to be jointly funding Professor Harvey's exciting work. His project has already discovered aspects of how the fusion proteins behave in EHE cells that were previously not known, and we hope that these sorts of discoveries may lead to greater understanding of the disease and further research ideas, as we seek new and better treatments for EHE."

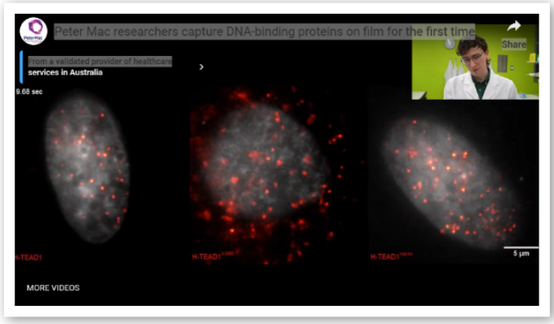
In the meantime, here are just two examples of the imagery that this project is generating.



Harvey lab SMT image
Single TEAD proteins in a single cell nucleus that have been imaged and tracked over time. Most bind DNA so have not moved (spots), whereas others are moving through the nucleus (lines)

Harvey lab SMT image
Single frame of a movie where individual TEAD proteins (purple or yellow) were captured moving in a single cell nucleus (DNA is marked in grey)

Readers may also be interested to see the team's media release (see link below) to learn more about this cutting edge research, and watch an informative video where a member of the research team explains the research with actual video footage of proteins in cells.



https://www.petermac.org/about-us/news-and-events/news/details/revealing-the-hippo-pathway-s-secrets-in-hope-of-new-cancer-treatments

02 EHE Research Continued

EHE Prospective Observational Registry

The need for pan-European registries for rare cancers was recognised by the European Reference Network in Rare Adult Solid Cancers (EURACAN). The STARTER project was therefore established in 2022 on the basis that gathering data on rare cancers will support research, help to develop and/or improve clinical practice guidelines, support multidisciplinary discussion and consultations for patients with rare cancers, and ultimately improve quality of care across Europe.



The Charity was therefore delighted when EHE was selected to be the first rare cancer within this important data-gathering initiative, the first such prospective observational registry for the disease. The registry Principle Investigators (PIs) are Dr Annalisa Trama and Dr Silvia Stacchiotti, from INT in Milan, with Dr Anna Maria Frezza providing clinical support. The registry involves multiple hospitals across Europe. Patient enrolment into the registry started in 2023, with 20 patients enrolled at the end of 2025.



PUSH Platform continues to grow

During 2025, the Charity continued to support the PUSH Platform (**P**ushing **U**ltra-rare **S**arcomas beyond **H**ope). The platform was developed to help address the significant challenges that patients, clinicians and researchers of ultra-rare sarcomas face, such as:

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

PUSH PLATFORM

As reported above, 2025 saw the POEM EHE study expanded and extended under the PUSH umbrella, as part of the PROSPER framework agreement. The POEM study has also been expanded internationally, with a significant number of institutes and academic centres across the globe joining this important initiative. Although our focus remains with EHE, we are also pleased to see other ultra-rare sarcomas now being studied, including Chordoma, Low Grade Fibromyxoid Sarcoma/Sclerosing Epithelioid Fibrosarcoma (LGFMS/SEF) and Adult-type Rhabdomyosarcoma (RMS).

The PUSH Platform will collate data from patients around the world, including real-world data from patient registries such as the EHE Global Patient Registry. This data will in turn be used, with regulatory involvement and input, to define and initiate appropriate new prospective studies and associated analyses to help deliver new treatments for patients in faster, lower-risk, well understood and defined processes. PUSH is particularly important for patients with ultra-rare diseases such as EHE, who face significant unmet needs in terms of the availability of effective treatments.

The PUSH Platform is also a component of the ongoing discussions with the EMA and the USA Food and Drug Administration (FDA) concerning the processes and procedures relating to drug approvals for ultra-rare sarcomas, as reported in the Patient Support and Advocacy section of this report. There is recognition that changes need to be made to reduce the time, risk and costs of such processes, and so encourage pharma involvement in the development of such drugs.

The Charity is actively supporting the PUSH Platform, with Hugh Leonard, and Denise Robinson from the EHE Foundation in the USA, both being members of the PUSH Executive Committee.

Biobanks and registries

In the Patient Support and Advocacy section of this report, *Research Roundtable: advocacy in action,* the importance of disease registries and biobanks was highlighted. One of the most important achievements of the Charity has been the funding of the setting up and ongoing administration of the UK National EHE Biobank at the Royal Marsden biobank facility. This biobank enables the capture of ultra-rare EHE tissue and fluid samples for use in EHE research. For example, tumour tissue donated by patients after surgery has led to the exciting development of both PDX mouse models in Europe and even more importantly, actual EHE cell lines in the USA. These are huge steps forward in terms of EHE research and have only been possible because biobanks were available for patients to donate their biosamples.

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

The EHE community could not be more grateful to all patients who donate their tissue. EHE biospecimens are so rare and therefore unbelievably valuable and critical for EHE research. We would encourage all patients who are having surgery to please contact the Charity or the EHE Biobank directly using the contacts below:

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

ehe Biobank | **The UK National Epithelioid Haemangioendothelioma Biobank**

Equal in importance with EHE biobanks is the EHE Global Patient Registry, which is managed by the EHE Foundation in the USA. This registry is structured to make data entry as simple as possible, and requires a very small time commitment from patients to first enter their data, and then update it every six months. But the value of the data provided cannot be overstated.

Denise Robinson, Executive Director of The EHE Foundation in the USA, who is also the Principle Investigator for the registry, explained:

> ***"Participation in the EHE registry is vital to improve our understanding of the disease, treatments used and how they work, and what long-term living with this ultra-rare sarcoma really looks like. We want to record as many EHE patient journeys as possible. We need as many EHE patients as possible to join the registry and share their experiences. This type of data and experience sharing is so important and will inform doctors and patients, and could give hope to many people newly diagnosed with this disease."***



The Charity therefore encourages any patient living with EHE — whether recently diagnosed or a patient for decades — to join the registry and provide their data. By joining, patients can help provide hope and real-world answers for those newly diagnosed, and their voices can shape the future of EHE care.

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

03 Fundraising and Finance

2025 was an exceptional year in which we enjoyed unbelievable support from our patient members and their supporters as we celebrated our tenth birthday. Together, they once again raised substantial funding for critical EHE research.

In 2025 we received £109,690 from all sources. Of this sum, £6,000 was received from a single donor, specifically for funding our charity running costs. That means that 100% of the remaining sum of £103,690, received from all other sources, is available for EHE research. These funds are critical to our ability to meet our objectives, as we strive to find effective treatments for a disease as rare as EHE. Without this we would not be able to support and contribute to the research that continues to deliver such exciting results.

And it is not just the UK that is enjoying such progress. Our sister foundations in the USA, Canada, Australia and Italy are also making great advances. We cannot thank our supporters across the globe enough for their dedication and wonderful support.



Review by Jeff Collins

"2025 was another year when the EHE patient community and their supporters took up the fundraising challenge with great energy and raised substantial funding for EHE research. Together they delivered more than £103,000 in donations. That support means that we can continue to fund our ongoing research, look at ways to expand it, while also considering new research projects."

In 2025, our grassroots fundraising was excellent, with our supporters engaging with our 10th anniversary celebrations. The 114 runners who took part in our **10 for 10** runs in Bristol, Glasgow, Birmingham, Newcastle, Manchester and London, ran more than 1 million meters in support of those affected by this 1-in-a-million sarcoma!

We saw huge support for Emma, a young mother, championed by her twin sister, Kym, all her family, and so many fantastic friends. The Albion Ale House, run by Emma's parents-in-law, were hugely involved. Collectively, they continued to throw themselves into fundraising for EHE research with amazing support from so many, including her brother Ben who ran the Bath 50 Ultra. Tragically, despite inspirational courage, Emma passed away in 2025. It is for Emma, and others who have left us far too early, that we work so hard to find better treatments for this wretched disease.

Kelly Denton held her annual EHE Quiz Night at the start of the year. Lorraine Faulds and nine other members of her family ran in Glasgow and/or Newcastle in memory of Loraine's mother. Nicola Henderson swam 10km during April, and many of her friends ran a 10K for us. Judith Gordon climbed 10 peaks with her dog Leo, and was joined for parts of her campaign by friends and family in Scotland, and her son Connor also took on the Three Peaks Challenge.

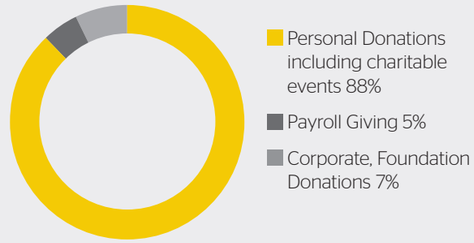
As 2025 drew to a close, Luke Harrison, who had already made substantial donations to the Charity for EHE research, announced that he and his family were taking on a 430kms hike in the Vosges mountains in France over the next year, again to raise research funding. We wish Luke and Melissa, and their two children Rohan and Zahra, and their Cockapoo, Marley, safe travels and great hiking.

Key objectives

In the 2025 calendar year our supporters raised a total of £109,690 for the charity's key objectives. The sources of these funds are summarised on the pie chart shown here.

During 2025 we provided research funding of £85,259. This included the EHE National Biobank and Tissue Manager at the Royal Marsden. We also provided funding for the pan-European EHE Prospective Registry. Together with EHE Italia and the EHE Foundation, we jointly funded the collaborative research project involving INT in Milan and the ICR and RMH in London. We also jointly funded Professor Kieran Harvey's research at the Peter MacCallum Cancer Center in Melbourne Australia.

Source of funds



Administration/business running costs

In 2025, we once again received the generous support of a single donor who funded 100% of the charity running costs. As in all previous years, we segregated these funds, donated for administration purposes, from those received from all other sources, which can therefore be allocated to fund our key objectives, in particular, EHE research. It is the intention of the Trustees that the same will be true in 2026.

The charity received additional funding of £6,000 for its administration and business running costs account. During 2025, £7,109 of expenses were incurred, which included the fees associated with fundraising events conducted in 2025, design and publishing costs, and expenditures associated with ongoing website maintenance.

*"Every year we are so grateful to our patient community, their supporters, and the corporate groups and foundations who supported us through the year. A particular and huge thanks must go to every single person who took up our **10 for 10** challenge. We are also grateful to all those who helped us and volunteered, keeping our charity running costs as low as possible, and to all the companies and service providers who have supported us with their services, often provided at no or reduced cost.*

We had hoped that 2025, being our 10th anniversary, would create extra focus and support. We were not disappointed, and it is thanks to our amazing patient community and their wonderful supporters that we once again received substantial funds for the Charity, for which we are hugely grateful. We will however continue to ensure that we already hold the funds for any funding commitments we enter into. We will also continue to manage all funds with the utmost care to ensure that we get the maximum benefit from every pound that we have so generously received."

Jeff Collins

Wonderful support for the Charity in 2025

The following pages highlight some of the amazing fundraising events that raised funds for the Charity in 2025.

'10 for 10', our 10K challenge

As many of our readers know, 2025 was the 10th anniversary of the establishment of the first three EHE foundations in the UK, the USA, and Australia. To celebrate this fact, and of course raise funds for EHE research, the UK charity decided to launch its **10 for 10** challenge, asking its supporters to do something involving the number 10 to raise funds for EHE research. This included supporters taking on a 10K run during the year for EHE patients everywhere.

Hugh Leonard, Chair of Trustees, explained:

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

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



Sally Baker was delighted to be able to report that the Charity's target of getting 100 runners to participate had been achieved:

"Once again, our supporters stepped up for the challenge - when have they ever not? We had 114 runners participate across all the runs, which is so awesome. Most ran 10K but several chose to run half marathons where they were available, so we exceeded our target of 1,000,000 metres run for EHE by some margin."

The UK Charity could not be more grateful, as Hugh and Sally made clear:

"We are just so grateful for the unbelievable support we get from so many people, including our brilliant runners. We just want to thank each and every one of them for all they are doing to raise critical funds for EHE research, and in support of EHE patients, wherever they are in the world."

And here is a small collection of photos of our runners from around the country.



03 Fundraising and Finance Continued

Amazing support for Emma

When Kym's sister, Emma, was diagnosed with EHE in 2024, the whole family were of course devastated. But alongside that devastation came a burning desire to support Emma in every way possible, together with a determination to fight back. Kym immediately understood the challenges faced by those with such a rare disease. Mobilising her entire family and their unbelievable friends and supporters, and following Kym's call-to-arms, Team Emma engaged in a dynamic and sustained fundraising campaign that started in 2024 and continued into 2025. Tragically, and despite her inspirational courage, Emma passed away in 2025. But that does not diminish for one minute the fantastic support and wonderful events that Team Emma held during 2025 to help raise funding for EHE research. Below are just some of their stories. We know that Emma was very proud and also hugely grateful for all that they did.



Riotous race night at the Rafa!

On 15 March, Kym and Emma's Dad, Daryl, and their step-mother Elaine, organised a riotous race night at the Rafa Club Leyland Branch. All agreed it was a fantastic night, and although described as a race night, there was clearly a lot of dancing and partying going on too.

Daryl and Elaine were thrilled with the result:

"Thank you to everyone who came to the race night last week! What a fantastic night it was and we raised £1,500 for the charity... which is amazing!! Special thanks to Rafa Club Leyland Branch, Kelly and the team at the club, Geoff and Logan for the music and compering and local businesses including Wardrobe Leyland, Leyland Market, Heaven on Earth Hair & Beauty Spa Leyland, Lauren Gooch, Tan's Tasty Treats & Annie's Kitchen amongst many others for the raffle prizes!"



Ben takes on the Bath 50 Ultra

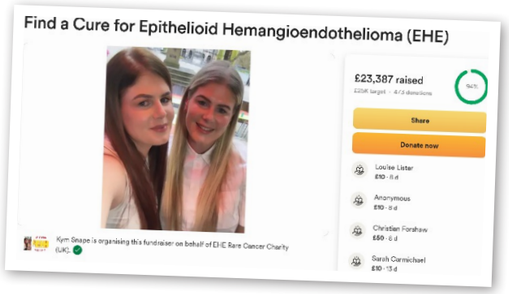
Ben Snape, Emma's brother, ran the Lancashire Loop Trail Run half marathon towards the end of 2024, supporting Emma but also supporting Kym, who was also running the half marathon. For most people that would have been enough. But Ben wanted to do more for Emma, and wanted to raise more funding for EHE research. So with those goals, Ben decided to take on The Bath 50 Ultra Challenge:

"My sister Kym gave me the idea to do something for charity. After swearing never to do another marathon again I decided to go one further and do a 50km ultra marathon. This will be a big challenge for me and all for an extremely good cause."



Ben's family were super proud of what Ben was taking on, as Kym explained:

"On Saturday, my brother Ben will be running his Ultra Marathon to raise money for the EHE Rare Cancer Charity UK, who are supporting our sister in her journey against this terrible disease! Ben has worked so hard for this and we're super proud of him. Looking forward to being there to support him on race day (and his birthday)."



We also want to thank Kym and everybody in Team Emma for their brilliant and passionate support. Their fundraising page reached a staggering £23,387, with more events planned!

The amazing Albion Ale House

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

Then in July Becs and Kevin organised a 'Bangers and Smashed' event. We loved the idea, and the red and yellow bunting, giving the venue a real EHE vibe.

Thank you Becs and Kevin for all your great events and thank you also to your brilliant customers who were so generous with both their time and funding.



A feeling-great fundraiser!

Fundraising comes in many different forms. Some are endurance events, some are riotous, some involve making things, but it is not often that we see a fundraising event that is dedicated to pampering those taking part, and making them feel great. We love it!

The organiser of this special evening in February, the lovely Gill, also loved it:

"So last Friday I was privileged to host a Tropic guided pamper fundraiser event for this AMAZING lady! With the aim of raising awareness of the EHE Rare Cancer Charity UK and providing Emma with some well-deserved pampering, the event was a huge success and I'd like to thank everyone who donated in support of it. Emma is an absolute inspiration and supporting her was what the event was all about."

Gill had indeed created a wonderful evening. We know that everybody there had a brilliant time and did indeed come away feeling very pampered. And to add something really special, Emma drew the winners LIVE on Facebook during the event!



03 Fundraising and Finance Continued

Kelly's Quiz Night is another great success

One of the EHE Rare Cancer Charity's super supporters, Kelly Denton, organised her first EHE quiz night in 2022 in support of the Charity and her daughter who has EHE. Kelly's EHE quiz night has now become an annual event in the EHE calendar, held at the Bridge House Pub in Penge in South London.



The 2025 event, Kelly's fourth, was held in March and once again saw fantastic turnout and great support. Kelly was particularly delighted that Liam Conlon, Member of Parliament for Beckenham and Penge, joined the quiz night and also spoke, supporting the EHERCC and what it is doing.

Hugh Leonard, Chair of Trustees of the Charity, was delighted to be able to give a talk at the midpoint - just to update all those present regarding the research into the disease that their funds from previous events had helped pay for.

Everybody agreed that the evening was wonderful, raising nearly £2,000.

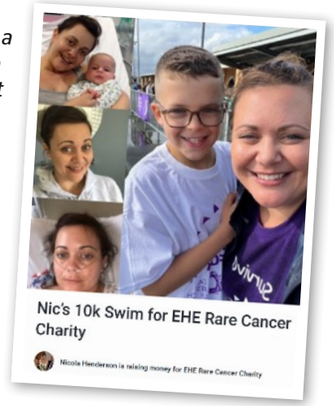


Nicola's 10K swim challenge for EHERCC

Nicola was diagnosed with EHE in 2014 and subsequently had a liver transplant, a process that is incredibly gruelling, taking a huge toll both physically and mentally. But Nicola, like so many other EHE patients, is a fighter and is determined not to let her EHE define her or limit what she does and can achieve. So when the **10 for 10** challenge was launched, Nicola was there for the fight, together with her huge group of wonderful supporters!

Nicola had the great idea of completing her 10K in the pool, setting out to swim 400 lengths of her local pool during the months of March and April, as she explained:

"I'm taking on a huge personal challenge to swim 10 kilometres—400 lengths of a 25-meter pool (not in one go!) but hope to complete it within 1 month over various sessions in the pool!!! I want to raise awareness and funds for EHE (Epithelioid Hemangioendothelioma), a rare cancer that myself and others live with every day.

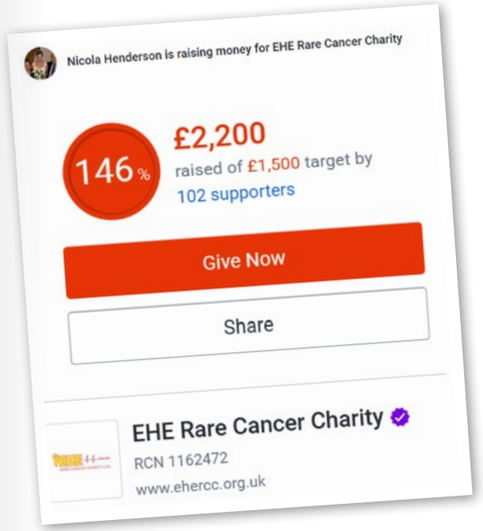


Why am I swimming? Swimming 10 kilometres is a massive physical challenge for me. Since my transplant I suffer with low energy, fatigue and medication side-effects every day. The mental toll of living with a rare and incurable cancer is extreme. This challenge will be a test of endurance, strength, and mental resilience. It's a way for me to channel the energy and focus I need while I wait for my next scan on April 22nd. EHE is always on my mind, and this swim is my way of taking control and turning my emotions into something meaningful. It's also a way for me to push myself and see what my post-transplant body can do. I also hope to raise much-needed funds for a cause that I believe deserves far more attention."

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

"I just completed my 10K swim challenge! 400 lengths done! Feel so proud of myself!!! Raised £1,765 so far! Hoping when I add that I've completed I can get to a bit more!!!! And I thought of all my fellow EHE patients today in the pool."

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



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 that same year. To mark the 1st anniversary of her death, Irene's daughter, Lorraine, together with Irene's nine grandchildren, Laura, Louise, Lisa, Aaron, Finlay, Leah, Lana, Wallace and Hazel, ran in the Great Scottish Run 10K in Glasgow. The youngest two actually did 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 run that Lorraine and the other nine in her group achieved. 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.

Well done Lorriane, and Irene's nine grandchildren for such an amazing contribution, not only raising funds but introducing EHE to a whole new audience. We are sure that Irene was very proud of you all.



03 Fundraising and Finance Continued

Climbing 10 mountains for EHE research

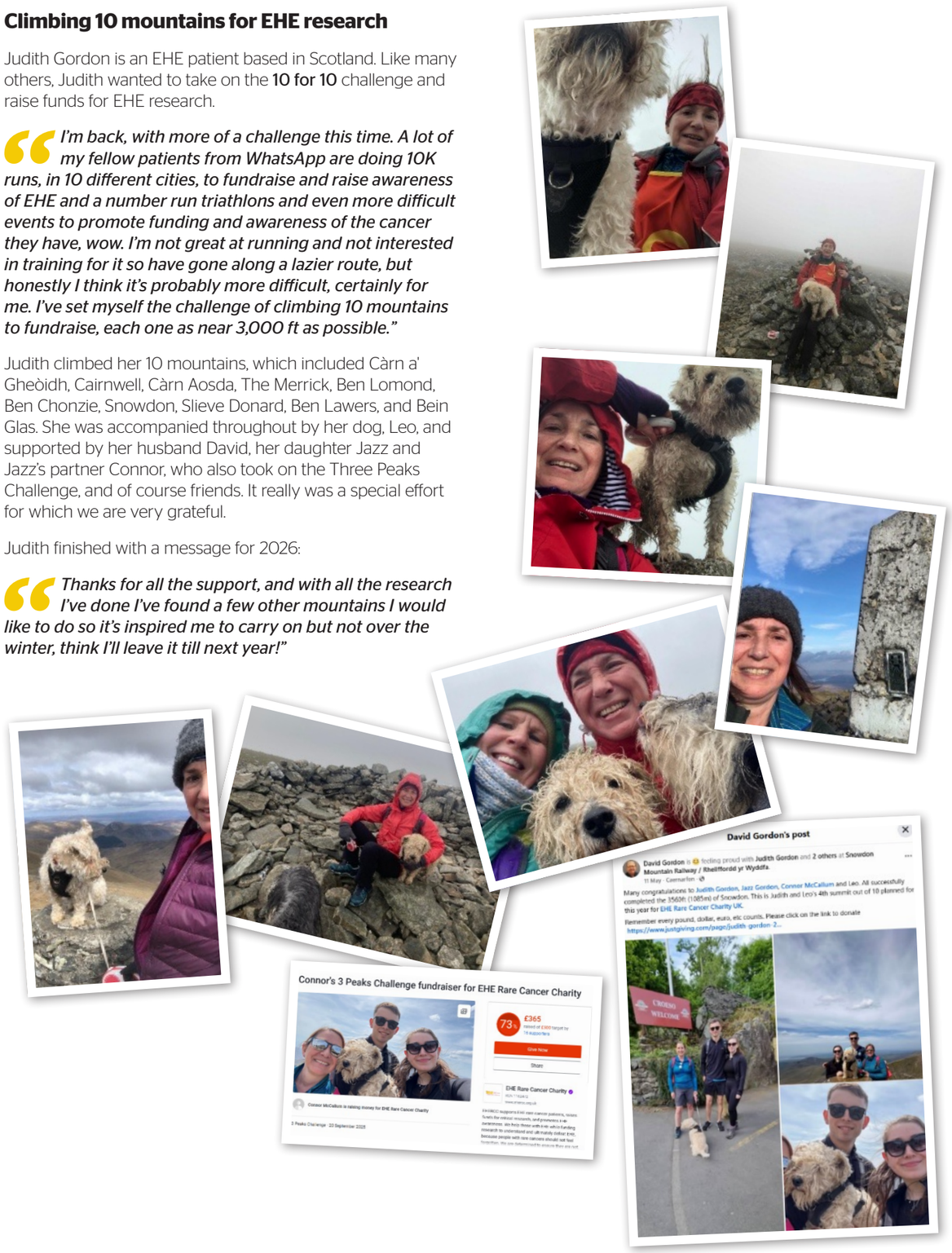
Judith Gordon is an EHE patient based in Scotland. Like many others, Judith wanted to take on the **10 for 10** challenge and raise funds for EHE research.

"I'm back, with more of a challenge this time. A lot of my fellow patients from WhatsApp are doing 10K runs, in 10 different cities, to fundraise and raise awareness of EHE and a number run triathlons and even more difficult events to promote funding and awareness of the cancer they have, wow. I'm not great at running and not interested in training for it so have gone along a lazier route, but honestly I think it's probably more difficult, certainly for me. I've set myself the challenge of climbing 10 mountains to fundraise, each one as near 3,000 ft as possible."

Judith climbed her 10 mountains, which included Càrn a' Gheòidh, Cairnwell, Càrn Aosda, The Merrick, Ben Lomond, Ben Chonzie, Snowdon, Slieve Donard, Ben Lawers, and Bein Glas. She was accompanied throughout by her dog, Leo, and supported by her husband David, her daughter Jazz and Jazz's partner Connor, who also took on the Three Peaks Challenge, and of course friends. It really was a special effort for which we are very grateful.

Judith finished with a message for 2026:

"Thanks for all the support, and with all the research I've done I've found a few other mountains I would like to do so it's inspired me to carry on but not over the winter, think I'll leave it till next year!"



Luke and family take on huge trek 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 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. 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.



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."



We want to say a huge thank you to Rohan and Zahra for having such an inspiring idea, and to the whole Harrison family, including Marley, for their amazing effort in support of the Charity and EHE research. We look forward to providing a full update about their trek in our 2026 Annual Report.

Darran takes on the Sodbury Slog

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"



Huge thanks to the Geoff Payne Friends & Family Charity

At the start of 2025, the Charity was really thrilled to receive a donation of £3,000 from the Geoff Payne Friends &Family Charity. The Charity had been introduced to the Geoff Payne Friends &Family Charity by David Iddiols, a friend of Hugh Leonard. David was pleased to report that the Trustees had approved a donation to the EHE Rare Cancer Charity, as Hugh Leonard explained:

"David was happy to introduce us to the Geoff Payne Friends &Family Charity as he had successfully fought his own battle against another rare sarcoma. Nothing was promised, of course, so we were thrilled when David rang us to say that the EHE Charity had been selected to receive a £3,000 donation. The excitement did not stop there, however, as shortly afterwards, David informed us that the Trustees had agreed to increase the donation to £5,000. We could not be more grateful, with the £5,000 being used to fund a large part of the EHE Biobank costs for the year. It is wonderful to think that critically important EHE tissue samples will be captured for future research, thanks to this amazing gift".

EHE Rare Cancer Charity UK

Financial Accounts for 2025

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EHE Rare Cancer Charity (UK)
Independent examiner's report

Independent examiner's report to the trustees of EHE Rare Cancer Charity (UK)

I report to the charity trustees on my examination of the accounts of EHE Rare Cancer Charity (UK) (the Charity) for the year ended 31 December 2025.

Responsibilities and basis of report

As the trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

(signed) "RJP LLP"

Michael Blay FCCA
RJP LLP
Ground Floor
Egerton House
68 Baker Street
Weybridge
Surrey
KT13 8AL

Date: 18 August 2026

EHE Rare Cancer Charity (UK)
Statement of Financial Activities
for the period ended 31 December 2025

	Notes	Unrestricted funds £	Restricted funds £	**Total 2025 £**	Total 2024 £
Incoming resources:					
Donations	2	103,690	6,000	**109,690**	132,868
Total incoming resources		**103,690**	**6,000**	**109,690**	138,868
Resources expended:					
Costs of generating donations		2,074	562	**2,636**	5,081
Charitable activities		85,259	-	**85,259**	41,580
Governance costs		-	-	**-**	1,200
Other administrative costs		144	6,547	**6,691**	5,649
Total resources expended	3	**87,477**	**7,109**	**94,586**	53,510
Net surplus/(deficit) for the year		**16,213**	**(1,109)**	**15,104**	79,358
Transfer between funds		**-**	**-**	**-**	-
Balance brought forward		242,027	9,087	**251,114**	171,756
Funds carried forward	8	**258,240**	**7,978**	**266,218**	251,114

Funds carried forward for 2025 £266,218

EHE Rare Cancer Charity (UK)
Balance Sheet
as at 31 December 2025

	Notes	Unrestricted funds £	Restricted funds £	**Total 2025 £**	Total 2024 £
Current assets					
Debtors	5,9	68,463	5,610	**74,073**	86,723
Cash at bank and in hand		289,678	6,088	**295,766**	223,341
Total current assets		**358,141**	**11,698**	**369,839**	310,064
Creditors: amounts falling due within one year	6,9	(86,429)	(3,720)	**(90,149)**	(53,610)
Net current assets (liabilities)		**271,712**	**7,978**	**279,690**	256,454
Creditors: amounts falling due after one year	7,9	**(13,472)**	**-**	**(13,472)**	(5,340)
Net assets (liabilities)		**258,240**	**7,978**	**266,218**	251,114
Funds carried forward					
Unrestricted funds		258,240	-	**258,240**	242,027
Restricted funds		-	7,978	**7,978**	9,087
Total funds	8	**258,240**	**7,978**	**266,218**	251,114

The Charities Act 2011 requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity at the year end and of the surplus or deficit for the year then ended.

In preparing these financial statements, the trustees are required to select suitable accounting policies, and then apply them on a consistent basis, making judgements and estimates that are prudent and reasonable. The trustees must also prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure the financial statements comply with the Charities Act 2011. The trustees are also responsible for safeguarding the assets of the charity and hence taking reasonable steps for the prevention and detection of fraud and other irregularities.

These accounts were approved by the trustees committee on 17 August 2026 and signed on its behalf by:

(signed) "Hugh Leonard"

Hugh Leonard
Chairperson

EHE Rare Cancer Charity (UK)
Notes to the Accounts
for the period ended 31 December 2025

1 Accounting Policies

Basis of preparation
The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Incoming resources

Recognition of incoming resources
These are included in the Statement of Financial Activities when:

- The charity becomes entitled to the resources;
- The trustees are virtually certain that they will receive the resources; and
- The monetary value can be measured with sufficient reliability.

Deferred income
Where grants are received in advance and specified by the donor as relating to specific accounting periods, these are deferred on an accruals basis to the period to which they relate.

Tax reclaims on donations and gifts
Incoming resources from tax reclaims are included in the Statement of Financial Activities at the same time as the gift to which they relate.

Incoming resources with related expenditure
Where incoming resources have related expenditure, the incoming resources and related expenditure are reported gross in the Statement of Financial Activities.

Volunteer help
The value of any volunteer help is not included in the accounts.

Investment income
Investment income is included in the accounts when receivable.

Expenditure and liabilities

Resources expended are inclusive of VAT where applicable which cannot be recovered.

Liability recognition
Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.

Costs of charitable activities
A research grant is recognised when the Charity formally notifies the recipient of the award following scientific review. The liability is measured as the total of expected payments for the award. Grant payments that are contingent on a successful outcome of and payable after a future scientific review are disclosed as commitments. Liabilities for awards payable more than one year after the balance sheet date are recorded at the value the Charity expects to settle the grant or award.

Governance costs
These include the costs of preparation and examination of statutory accounts, the costs of any general meetings and the costs of any legal advice to trustees on governance or constitutional matters.

Administrative fund

This fund has been established by the trustees to fund all governance and administrative costs and is funded by a single donor for these restricted purposes.

2 Analysis of incoming resources

Donation income:	2025 £	2024 £
Unrestricted funds:		
Personal donations including fundraising events	**98,530**	116,634
Corporate and Foundation donations	**5,160**	1,234
	103,690	117,868
Restricted funds:		
Administration fund	**6,000**	15,000
	6,000	15,000

3 Analysis of resources expended

	Unrestricted funds £	Restricted funds £	**Total 2025 £**	Total 2024 £
Costs of generating donations:				
Just giving fees	528	-	**528**	560
Fundraising event entry and other fundraising fees	-	562	**562**	3,150
Credit card and other processing fees	1,546	-	**1,546**	1,371
	2,074	**562**	**2,636**	5,081
Costs of charitable activities:				
Peter MacCallum Cancer Centre, The University of Melbourne	14,264	-	**14,264**	-
Royal Marsden Biobank	20,507	-	**20,507**	18,089
Zebrafish Study University of Sheffield	-	-	**-**	(14,970)
Fondazione IRCCS and ICR Biomarkers	39,759	-	**39,759**	13,595
Fondazione IRCCS and ICR Observational Study	10,729	-	**10,729**	-
Fondazione Prospective Study	-	-	**-**	24,866
	85,259	**-**	**85,259**	41,580
Governance costs:				
Independent examiners' fee	-	-	**-**	1,200
	-	**-**	**-**	1,200
Other administrative costs:				
Design and publishing	-	5,611	**5,611**	4,400
Website maintenance	-	864	**864**	1,164
Bank fees	144	72	**216**	85
	144	**6,547**	**6,691**	5,649

Trustees' expenses
No expenses were incurred by trustees during the period and reimbursed by the Charity (2024 – £4,269).

4 Taxation

The Charity is exempt from Corporation Tax on its charitable activities.

EHE Rare Cancer Charity (UK)
Notes to the Accounts (continued)
for the period ended 31 December 2025

5 Debtors

	Unrestricted funds £	Restricted funds £	**Total 2025 £**	Total 2024 £
Prepayment to Royal Marsden	8,528	-	**8,528**	25,847
Prepayment to Fondazione IRCSS Istituto Nazionale Dei Tumori	31,407	-	**31,407**	12,395
Peter MacCallum Cancer Centre, The University of Melbourne	28,528	-	**28,528**	-
Refund due from the University of Sheffield	-	-	**-**	44,351
Other debtors	4,463	5,610	**10,073**	4,130
	68,463	**5,610**	**74,073**	86,723

Included within the debtors figures above are amounts of £13,473 (2023 – £5,340) due after more than one year.

6 Creditors: amounts falling due within one year

	Unrestricted funds £	Restricted funds £	**Total 2025 £**	Total 2024 £
Peter MacCallum Cancer Centre, The University of Melbourne	14,264	-	**14,264**	-
Royal Marsden	14,814	-	**14,814**	26,107
Fondazione IRCSS Istituto Nazionale Dei Tumori	57,351	-	**57,351**	24,753
Accrued independent examiners'	-	1,200	**1,200**	2,400
Other creditors	-	2,520	**2,520**	350
	86,429	**3,720**	**90,149**	53,610

7 Creditors: amounts falling due after one year

	Unrestricted funds £	Restricted funds £	**Total 2025 £**	Total 2024 £
Fondazione IRCSS Istituto Nazionale Dei Tumori	13,473	-	**13,473**	-
Royal Marsden	-	-	**-**	5,340
	13,473	**-**	**13,473**	5,340

8 Details of funds

Administrative Fund

This fund has been established by the trustees to fund all governance and administrative costs and is funded by a single donor for these restricted purposes.

9 Commitments and contingencies

In March 2021, the Charity agreed to fund costs associated with the establishment and administration of an EHE Biobank and the provision of a Tissue Manager with the **Royal Marsden Cancer Charity and the Royal Marsden NHS Foundation Trust** with an estimated total cost of £85,150 over five years commencing in April 2021 (four years commencing April 2022 regarding the Tissue manager). In 2025, £16,632 of payments were made (2024 – £18,255) and £20,507 recorded as charitable activity cost (2024 – £18,089). The amounts committed to for future years have been included within Debtors and Creditors as appropriate.

In June 2022, the Charity agreed to expand the project contracted with the **Fondazione IRCCS Istituto Nazionale Dei Tumori in Italy** and the **Institute of Cancer Research, UK** and **Royal Marsden Cancer Hospital, UK** to find novel biomarkers for EHE, to develop additional PDX models of different variants of EHE, and to continue to expand the EHE non-interventional prospective observational study. Total costs of the expansion over the two years of the project are estimated at £117,396 with costs funded 50% by the Charity and 50% by the EHE Foundation in the United States. The project was expanded for one additional year, in 2025 payments of £Nil were made and £24,423 was recorded as charitable activity cost (2024 – payments of £20,760 were made and £13,595 was recorded as charitable activity cost). The remaining amounts payable by the Charity have been included in Debtors and Creditors as appropriate. This one-year extension was jointly funded by the Charity, The EHE Foundation (based in the United States of America) and EHE Italia, the new Italian EHE Foundation. Under this funding arrangement, EHE Italy contributed €30,000 and the Charity and the EHE Foundation shared equally the remaining funding.

In December 2022, the Charity contracted with the **Fondazione IRCCS Istituto Nazionale Dei Tumori in Italy** to fund costs associated with a prospective registry aiming to provide a description of the population affected by EHE, giving an insight into the natural history of the disease and its variants, leading to the possible identification of clinical and biochemical prognostic and predictive factors. Total costs of the project are €91,500. In 2025, payments of £19,096 were made and £15,337 was recorded as charitable activity cost (2024 – payments of £17,200 were made and £24,866 was recorded as charitable activity cost). The remaining amounts payable by the Charity have been included in Debtors and Creditors as appropriate.

In 2025, the Charity contracted with **Fondazione IRCCS Istituto Nazionale Dei Tumori** in Italy, the **Institute of Cancer Research, UK** and **Royal Marsden Cancer Hospital, UK** to fund a further 3 -year expansion of the EHE non-interventional prospective observational study in order to expand the patient cohort from 50 patients to 100 patients to provide a greater data base of EHE patient data and information. In 2025, no payments were made and £10,729 was recorded as charitable activity cost (2024 - £Nil and £Nil). The remaining amounts payable by the Charity have been included in Debtors and Creditors as appropriate. This three-year extension was jointly funded by the Charity, The EHE Foundation and EHE Italia. Under this funding arrangement, EHE Italy will contribute €10,000 per annum and the Charity and the EHE Foundation will share equally the remaining funding.

In November 2025, the Charity contracted with EHE Rare Cancer Foundation (Australia) to provide funding in support of Professor Kieran Harvey, Group Leader and Head of the Organogenesis and Cancer Program at The Sir Peter MacCallum Department of Oncology, based within Peter MacCallum Cancer Centre, The University of Melbourne for research entitled: "Defining the biophysical behaviour of EHE oncoproteins and how they are affected by potential EHE therapies". The commitment is for 50% of one-year of funding, the remaining 50% being funded by the EHE Rare Cancer Foundation Australia. During 2025, payments of £28,528 were made and £14,264 was recorded as charitable activity cost (2024 - £Nil and £Nil). The remaining amounts payable by the Charity have been included in Debtors and Creditors as appropriate.

Trustees' Declaration

As Trustees of the EHE Rare Cancer Charity (UK), the undersigned have fully reviewed the content of this Report of the Trustees and confirm that they each consider it to be a true and fair reflection of the Charity's activities and operations for the year ending 31st December 2025. They each confirm that there are, to the best of their knowledge, no exceptional or special events that have occurred or that should be reported.

The Trustees also confirm that they have undertaken their respective roles and responsibilities with due regard to the public benefit requirements of the charity, and have taken into account the Charity Commission's public benefit guidance when making any decision and producing any reports relating to the Charity's charitable objects and its associated activities.

Signed this 9th day of October, 2026

(signed) "Hugh Leonard"
Hugh Leonard Chair of Trustees

(signed) "Jeff Collins"
Jeff Collins Trustee

(signed) "Kate Hooper"
Kate Hooper Trustee

(signed) "Oliver Pearce"
Oliver Pearce Trustee

(signed) "Sally Baker"
Sally Baker Trustee

Charity Information

Charity Name:
The EHE Rare Cancer Charity (UK),
A Charitable Incorporated Organisation (CIO)

Also known as:
Also known by its acronym, EHERCC

Charity number:
1162472

Web address:
www.ehercc.org.uk

Registered address:
23 Geneva Road, Kingston Upon Thames,
Surrey, KT1 2TW

Charity Trustees:
Mr Hugh Leonard (Chair)
Mr Jeffery Collins
Dr Katharine Hooper
Dr Oliver Pearce
Ms Sally Baker

Established in 2015.

Also working closely with EHE foundations in USA, Australia, Canada and Italy.

Managed and run by volunteers.

All running costs funded by single donor.

100% of all donations received therefore available to deliver core objectives.

The Pledge

The Pledge is the quarterly newsletter of the EHE group of foundations. It is produced in London and provides details of the group's worldwide activities in their key areas of advocacy and patient support, research, fundraising, and any other stories of interest. If you would like to be added to the distribution list to receive a copy of ***The Pledge*** each quarter, please contact the Charity.



EHE Rare Cancer Charity (UK)
23 Geneva Road
Kingston-Upon-Thames
Surrey
KT1 2TW

www.ehercc.org.uk

contactus@ehercc.co.uk
Registered charity: 1162472

A huge thank you to eightcreate.co.uk for the graphics and design work in producing this report and all editions of ***The Pledge***

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Front cover images

Single TEAD proteins in a single cell nucleus that have been imaged and tracked over time. Most bind DNA so have not moved (spots), whereas others are moving through the nucleus (lines). *(A Harvey lab SMT image).*

and

Gingers Fitness runners prepare for Saucony London 10K.