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

Quarterly Newsletter for the EHE Group
July - September 2023

the pledge

Edition 34

Just Live

Contents

Front cover:
Photograph by Carl Dickson

Welcome

Welcome to the **34th edition of The Pledge**, the quarterly newsletter of the EHE Group, for the third quarter of 2023. We hope that you will enjoy and be inspired by the stories in this newsletter which cover the key activities of the global EHE community.

As we do every quarter, we want to say a massive thank you to all our EHE supporters who provide amazing energy, drive, fundraising, time given, and so many other types of support, without which we would have achieved nothing. We all owe them so much. ***"Just Live".***

Highlights

Three-day engagement at INT in Milan

Members of the EHE Rare Cancer Charity (UK), The EHE Foundation in the US, and EHE Italia-Associazione Non Solo Laura ODV attended a three day EHE review in Milan with the Istituto Nazionale dei Tumori and The Institute of Cancer Research.

EHE Global Patient Registry makes a great start

The EHE Global Patient Registry has made an excellent start and will provide critical disease information in the future, but we want more patients to enrol. **Please support this critical initiative.**

New oncology screening platform opens in Australia

Australia has launched another ground-breaking programme, this time offering patients with advanced and/or incurable cancer free access to world-class genomic profiling and matching to the best personalised treatments available, through the new PrOSPeCT platform.

The EHE Foundation reports on US research initiatives

This quarter we are providing an update on some of the excellent EHE research taking places in the US, supported and monitored by The EHE Foundation. See this latest news in our Research section.

Growing participation in clinical trials

It has been exciting to see reports of several EHE patients either on or in discussion about joining different clinical trials, and in particular the phase 1 trials of TEAD inhibitors.

EHE Italia - Associazione Non Solo Laura ODV continues to grow

EHE Italia continues with important initiatives to expand and deepen its activities.

EHE Support Group FaceBook page celebrates its 10th birthday

Jane Gutkovich posted news that the EHE Support Group Facebook page had reached its 10th Birthday. Originally set up by Dawn Scott it is amazing to see over 2,700 patients and supporters now on the page.

Further details on these stories, and much more, can be found in this edition

the pledge **Edition 34**

01 Patient Support and Advocacy

Patient Support and Advocacy are two critical areas of activity of the EHE Group and the worldwide EHE patient community.

Patient support within our global community predominantly comes in the form of advice, support and encouragement provided by EHE patients through the EHE Support Group closed Facebook page, and other EHE social media and patient engagement programmes.

Advocacy focuses on promoting greater awareness of EHE, targeting better care and better outcomes for EHE patients globally. We hope that the following stories will provide an overview of the activities that the patient community and EHE Group are delivering.

EHE Tattoos are out again

The EHE Community has long embraced ***Just Live*** as our rare cancer anthem, even before the EHE not-for-profits were in existence. The motif was originally suggested by Georgiana Trandafir who sadly left us before she was able to get the tattoo herself. Soon afterwards however the first tattoo was posted and the campaign was up and running. Tattoos are worn to show support for loved ones with the disease, and as a sign of support for the whole EHE community. The message is very simple:

> “ we won’t let our cancer define us, we will ***Just Live*** ”

There are wonderful variations, with flowers and butterflies. Whatever the design, we love them.

Diana Axness is Just Living

Diana was diagnosed with EHE in early 2020. She has been through different treatments and in August posted a question about experienced doctors in the Seattle area. Then, as if her challenges were little more than an inconvenience, she finished:

> “In the meantime, I'm following the mantra ***"Just Live"***. Here's a picture of my ponies and I at a combined driving competition this summer.”

Diana, we love your quiet but very clear determination not to let EHE get the better of you; not to stress over dealing with the challenges you face; but most of all your love for life, your ponies and what clearly makes you very happy. ***Just Live*** indeed.

01 Patient Support and Advocacy

EHE is in the Congressional Record

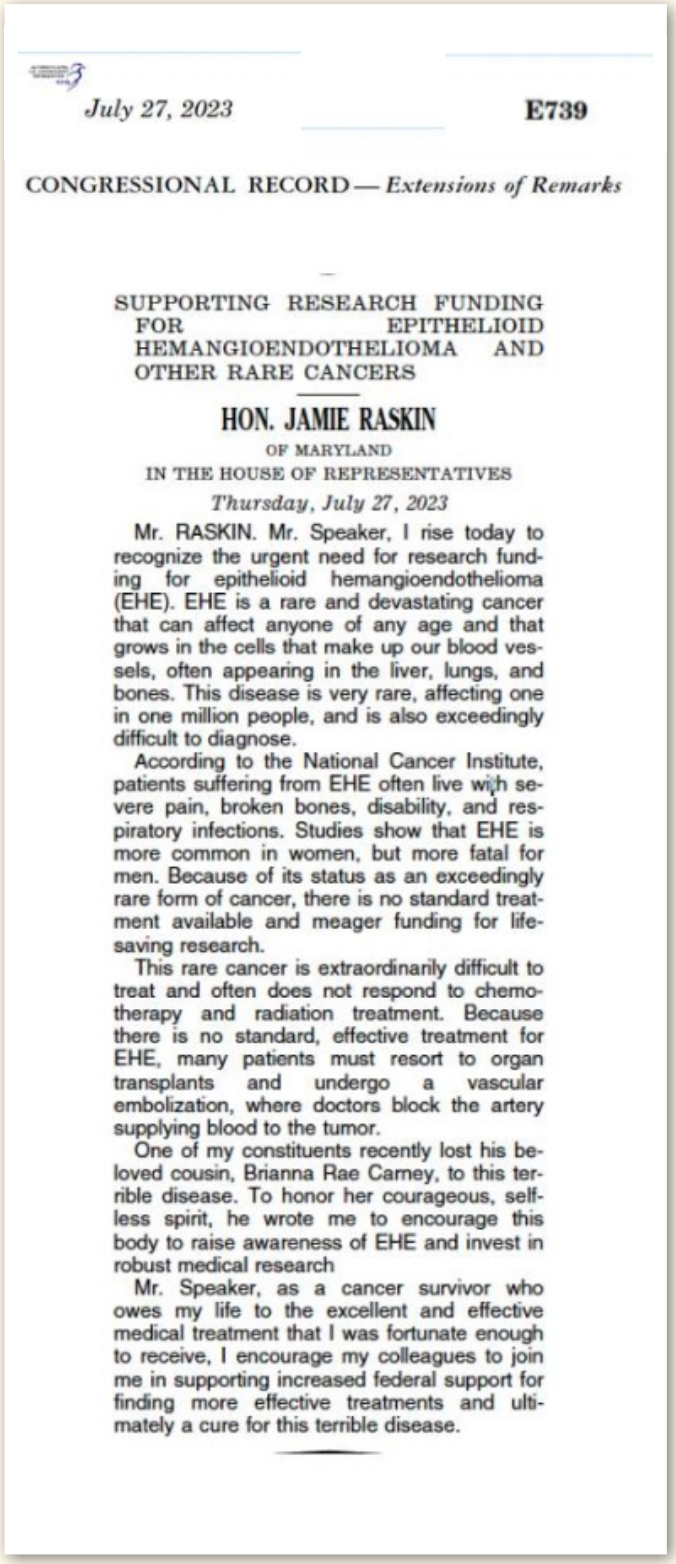
Toni Hightower shared an amazing piece of news during the quarter, involving a statement about EHE in the Congress. Toni explained:

> "For the past several months, our family has been working to raise awareness of EHE and Brianna Carney's memory. Yesterday, Congressman Jamie Raskin (MD-8), entered the following statement into the congressional record. His support for EHE and recognition of her life will be kept forever in the United States House of Representative's records. Rep. Raskin himself is a cancer survivor, and we hope that this is just the beginning of the conversation for bringing increased awareness and federal funding for research into EHE and developing a standard of care for this disease. This was a feel-good moment for our family and is hopefully a step forward in the right direction for EHE research."

The advocacy and discussions of Brianna's family with Congressman Jamie Raskin have led to EHE being discussed in such a prestigious assembly.

Brianna's family celebrated her life by spreading her ashes in a special way while wearing "Shine a Light on EHE" shirts. Brianna wanted her tissue to be studied after her death to help further the understanding of EHE. Her tissue was donated to The EHE Foundation's Biobank (US). Before passing, Brianna said, "Even if it helps one person, it will be worth it."

The EHE Community is grateful for Brianna and her entire family for making a difference, helping to move research forward and for creating awareness in such profound ways. ■



July 27, 2023 E739

CONGRESSIONAL RECORD — *Extensions of Remarks*

SUPPORTING RESEARCH FUNDING FOR EPITHELIOID HEMANGIOENDOTHELIOMA AND OTHER RARE CANCERS

HON. JAMIE RASKIN

OF MARYLAND

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 27, 2023

Mr. RASKIN. Mr. Speaker, I rise today to recognize the urgent need for research funding for epithelioid hemangioendothelioma (EHE). EHE is a rare and devastating cancer that can affect anyone of any age and that grows in the cells that make up our blood vessels, often appearing in the liver, lungs, and bones. This disease is very rare, affecting one in one million people, and is also exceedingly difficult to diagnose.

According to the National Cancer Institute, patients suffering from EHE often live with severe pain, broken bones, disability, and respiratory infections. Studies show that EHE is more common in women, but more fatal for men. Because of its status as an exceedingly rare form of cancer, there is no standard treatment available and meager funding for life-saving research.

This rare cancer is extraordinarily difficult to treat and often does not respond to chemotherapy and radiation treatment. Because there is no standard, effective treatment for EHE, many patients must resort to organ transplants and undergo a vascular embolization, where doctors block the artery supplying blood to the tumor.

One of my constituents recently lost his beloved cousin, Brianna Rae Carney, to this terrible disease. To honor her courageous, selfless spirit, he wrote me to encourage this body to raise awareness of EHE and invest in robust medical research

Mr. Speaker, as a cancer survivor who owes my life to the excellent and effective medical treatment that I was fortunate enough to receive, I encourage my colleagues to join me in supporting increased federal support for finding more effective treatments and ultimately a cure for this terrible disease.

Sarah Bright shares her experience after 7 years

A key component of the EHE patient support page, and why it works so well, is because EHE patients share their stories and information. These can at times be difficult to read, but on other occasions patients can post uplifting and inspiring words as they describe their own EHE journey, and observations they have made on the way. Sarah Bright is just one such person as she celebrated the seventh anniversary of her EHE diagnosis on September 26th:

> "Today marks seven years since diagnosis, and what a ride it has been! I will never forget all the details for where I was when I got "the call" to confirm my worst fear - the many, many lesions in my liver were cancer (and a rare and incurable cancer, at that).
>
> I am astonished at what we as humans can endure. To live with something so traumatic and to thrive (and recover from moments when the bottom drops out). To have the opportunity each day to make "the choice" to ***Just Live***, even though we could just as easily choose to hold the weight of this burden as the most important thing in life. I am amazed, and proud, as I look back at how I've weathered this storm. And I'm grateful for you all and my support network for holding me up in the moments when it was so hard that I couldn't stand on my own. Through it all, we cannot EVER forget our angels for which this disease was swift, furious, and unforgiving. May they and all those that love them rest and be at peace.
>
> My kids were toddlers and in kinder when I was diagnosed. They are thriving as preteen and teenagers now. We meet each day with the awareness that life is a gift. Bless you all! Some recent photos of our family. ***Just Live!***"

We want to join Sarah in remembering and honoring everyone affected by EHE. This quarterly newsletter is called **The Pledge** in recognition of the pledge and commitment we make to ourselves, to each other, and to those who are no longer with us. We will not let EHE define us and we will continue to do all we can and leave no stone unturned until we have answered the questions and found the treatment to initially stabilize and ultimately cure EHE. ■

01 Patient Support and Advocacy

EHE Italia continues to develop

EHE Italia-Associazione Non Solo Laura ODV is the newest of the foundations in the EHE Group, so we are always delighted to report on their growing development and important initiatives to promote and support all aspects of the Group's activities.

Andrei Ivanescu, President of EHE Italia explained:

> "We have two primary goals at the current time. The first is to ensure that EHE Italia is engaging with and supporting all aspects of the EHE Group's activities. The second, and equally important, is to promote and grow the communications with the Italian EHE patients community to ensure they are fully informed about all the great work that is going on, and to provide a focal point for their engagement if they want to help."

Andrei was delighted to be able to highlight a number of important achievements:

> "Providing information about this rare sarcoma is of course key. The ESMO consensus of experts paper published in 2021, and the subsequent patient version of the paper are obviously important documents. However, as both are in English, we wanted to create an Italian version of the patient version for our community. We are proud to have done this for our community with the help of some wonderful Italian clinicians at INT who checked and corrected our final version."

Caterina Colaci has also been working hard on presentation of information:

> "One of the first things we wanted to do was to provide EHE patients in Italy with the locations of sarcoma refence centres to ensure that EHE patients are being seen at the right clinics. We have produced a map showing where all the Italian reference centres are. This can be found on our EHE Italia Facebook page and we hope it will be helpful for those who are diagnosed with EHE."

The foundation has also launched its new website which can be found at **https://www.ehe-italia.it** ...

...and has successfully qualified for the '5x1000' registration, providing Italian donors with the ability to attribute some of their tax to a not-for-profit organisation.

We want to congratulate Andrei and Caterina, and everybody else involved, for their great work in getting their foundation up and running. ■

01 Patient Support and Advocacy

Jane's bracelets get people talking

Advocacy often involves just getting people to engage and talk about EHE. This was Jane Biddlecome's simple idea behind her one-pearl bracelets which she posted form Australia in the summer, as she explained:

> "The bracelet represents "us", our EHE community. The rare PEARL represents the rarity of EHE & sarcoma, and the individuality of a cancer patient. The GOLD BEADS represent the gold ribbon for sarcoma and sarcomas including EHE. I hope that people will buy and wear this bracelet to remind you to talk about sarcoma and EHE with people you meet and remind you that you are not alone."

And the bracelets seem to be working as Jane went on:

> "Wow! What a response! Today, whilst on work errands, I had 5 people comment on my **#wear_rare** bracelet, not one of them had heard of sarcoma. So yes, being the chatterbox I am, I gave them a very quick lesson on what sarcoma is, who it affects and the classic symptoms of sarcoma, and about EHE. I now have 5 new members following our Facebook page, that's 5 more people who can share this important knowledge, and one person realised a friend of hers at school had sarcoma (osteosarcoma)."

The UK loved the bracelets and Sally Baker was happy to coordinate the purchase of 10 for EHE patients who were delighted to share photos of their new sarcoma talking points. We love the idea, and the fact that while these bracelets will promote awareness of EHE and sarcoma, they also raised funds for EHE research.

Sarcoma Awareness Month

July is Sarcoma Awareness Month which the EHE Rare Cancer Foundation Australia recognised through the holding of a Morning Tea event, hosted by Jonathan Granek and Di Hirsch. The event was held both to spread awareness and raise funds for EHE research.

The EHE-RCFA wanted to amplify facts such as the prognosis for many sarcoma patients having changed little over the past 30 years. They also wanted to amplify key objectives to try and move sarcoma treatment forward, such as awareness of the signs, early detection, and the need for research.

AWARENESS + EARLY DETECTION + RESEARCH can save lives.

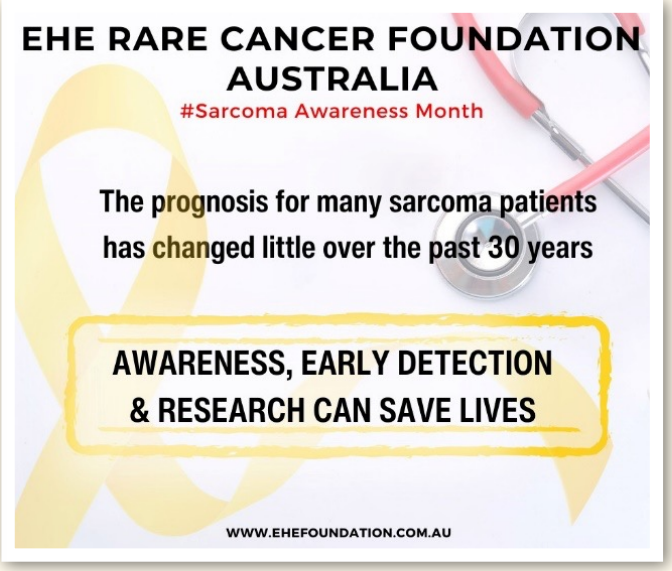
The EHE-RCFA also wanted to send the simple invitation to anybody who is interested in hosting their own event, to visit the EHE-RCFA website or reach out to the team for a Host Pack or ideas on how they can make a difference, using the email address **info@ehefoundation.com.au**

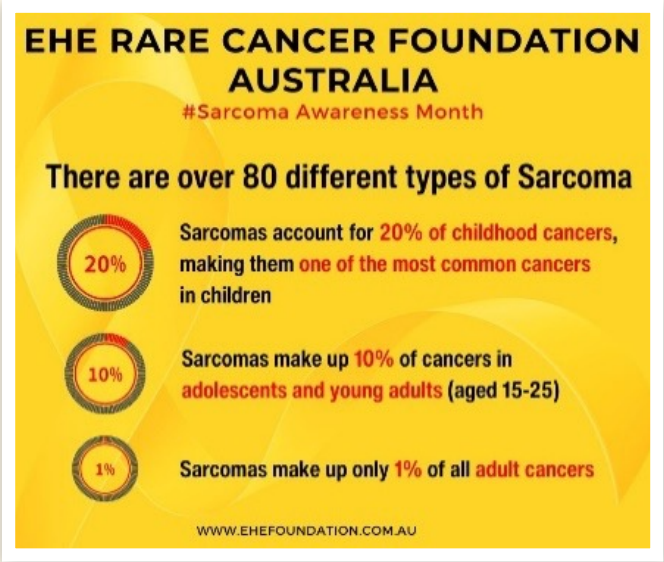
Great campaigns for sarcoma and rare cancers

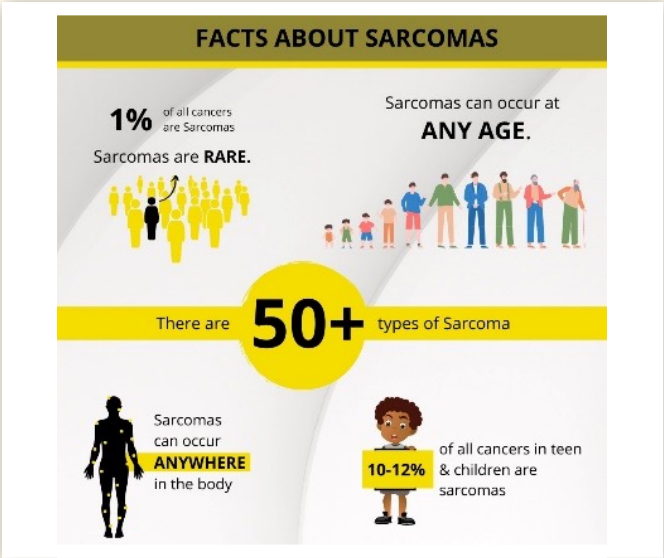
The second quarter started with Sarcoma Awareness Month in July, and finished with Rare Cancer Day on September 30th. In both cases, members of the EHE Group ran robust campaigns with exciting graphics. Check out these campaigns:

Sarcoma Awareness Month (EHE-RCFA)

The EHE-RCFA recognises the urgent need for action for sarcoma patients. Our goals during Sarcoma Awareness Month is to raise awareness of Sarcoma to ensure that people are diagnosed in a timely manner, as well as to raise vital funds to support ground breaking research into Sarcoma. The EHE-RCFA recognises the urgent need for action for sarcoma patients.







01 Patient Support and Advocacy

Rare Cancer Day (EHEF)

Epithelioid Hemangioendothelioma (EHE) is an ultra **#rarecancer**. The EHE Foundation is committed to working with NORD and other rare disease organizations to find treatments and eventually a cure for EHE. Patients are at the heart of everything we do, and we remain dedicated to research, collaboration, and advocacy. Our resources connect patients to experts and bring research directly to patients.

We are proud to stand with organizations like NORD on **#RareCancerDay**, Sat, Sep 30th, in fighting rare cancer. Join us in spreading awareness. Alone we are rare. Together we are strongl.

Assistance so generously given

Gemma Huang posted news in August of how she was trying to help fellow EHE patients in China who are grappling with the disease like so many of our members, but also having to deal with limited access to information and the challenges of not speaking English. Gemma explained:

> **"Hi EHE family, I am in a Chinese EHE group, which has 137 patients (not including their family members), they are not able to access Facebook so can't ask questions or review information by themselves. As myself has no too much experience in EHE, so I am helping them with forwarding their questions. I will later share your answers back to them. Please feel free to give responses. Thank you in advance for any assistance you will provide."**

Gemma then posted two questions about EHE for her fellow patients in China.

It is hard to think of a better or more powerful example of patient support and love within our community than those who translate for their fellow countrymen to try and help them gain the knowledge they so desperately want and need. Gemma is not the first of course. Pia Marie in Germany is another, but I think Pia would admit she has never faced coping with 137 patients.

Gemma, we love what you are doing. Please let us know if there is anything we can do to help.

Brian Rubin really is wonderful

On September 18th Hugh Leonard finally had the real privilege of spending a whole evening having dinner with Prof Brian Rubin in London:

> "Last week I spent 3 days in Milan visiting the INT Team. Tonight, after 8 years of emails, zoom calls, video conferences etc I finally had the privilege of meeting Prof Brian Rubin in person during his visit to London. This man is a true champion of our cause and it was really awesome to catch up on what is happening in EHE research over a very nice meal. He was also really interested in our EHE research strategy that we started to discuss last week in Italy, and is keen to help. Thank you Brian for all you and your team do."

Hugh is also excited by how excited Prof Rubin is about the ongoing development of TEAD inhibitors, and amazed at the range of different collaborations he has ongoing with different experts in so many fields.

We want to join Hugh in congratulating Prof Brian Rubin on all he is doing to move the treatment and understanding of EHE forward, for all EHE patients. ■

Support Group Celebrates 10 years

On 23 September Jane Gutkovich reminded as all that it was the 10th anniversary of the EHE Support Group Facebook Page:

> "Today is a 10 year anniversary of our wonderful group. First of all, many thanks to Dawn R. Scott for creating this bottomless well of support and information for EHE patients around the globe.
> It is incredible what this community has achieved! EHE was a "black hole" 10 years ago; no knowledge; no research; no treatment protocols.
> **Happy anniversary dear family!**" ■

02 EHE Research

We will ultimately find new ways to treat and manage EHE because of the ongoing research programmes that we are supporting today, and the research that we will promote and fund in the future.

This section of the newsletter provides an update on our EHE research.

We hope you will be inspired by the work taking place and the dedication and skill of the researchers that are delivering it.

New oncology screening platform opens in Australia

In late August Jonathan Granek posted news that Australians with advanced or incurable cancers, such as EHE, will have access to PrOSPeCT (Precision Oncology Screening Platform Enabling Clinical Trials).

23,000 Australians, no matter what their location, with advanced or incurable cancers will have free access to world-class genomic profiling and matching to the best personalised treatments available.

To check eligibility for free genomic screening, Australians should speak with their treating doctors, and if you need assistance, please reach out to the team at the EHE-RCFA.

Professor David Thomas spoke at the launch of the platform:

> **"We are heartened by the response to our recent PrOSPeCT launch and are thankful to all our partners who are making this program possible. But we're only just getting started.**
>
> **PrOSPeCT provides free access to genomic testing, helping match you or your loved one with advanced or incurable cancer to the best advanced personalised treatments."**

Ask your cancer doctor about accessing free genomic testing or learn more here: https://www.omico.com.au/patients-and-families/

02 EHE Research

EHE Group Meet-up in Milan

With the launch of the new pan-European observational study in Milan tabled for mid-September, Hugh Leonard from the EHE Rare Cancer Charity (UK) saw a golden opportunity to combine this with other important EHE initiatives and activities while at the same time involving representatives of other EHE entities to help foster global cooperation and collaboration in their EHE programmes. Hugh was therefore delighted when Denise Robinson, Director of Research at The EHE Foundation in the USA and Andrei Ivanescu, President of EHE Italia- Associazione Non Solo Laura ODV, were both able to attend the three day programme. ■

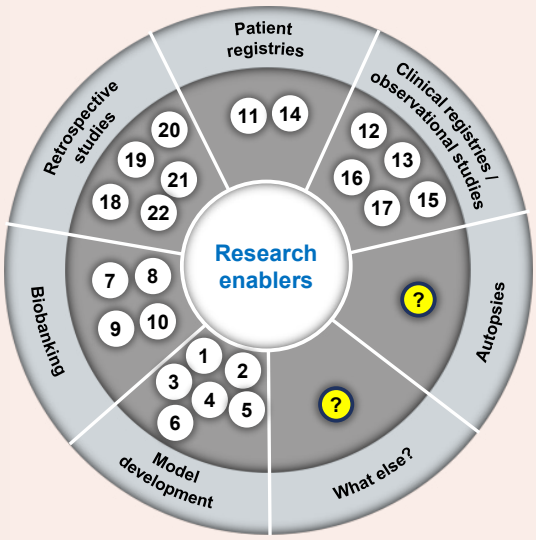
Building an EHE Research Strategy

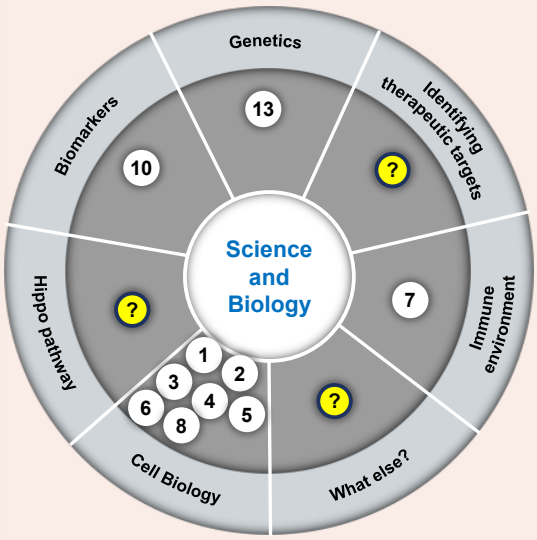
Part of the time spent in Milan was focused on discussing the need for a research strategy for EHE. Hugh Leonard explained:

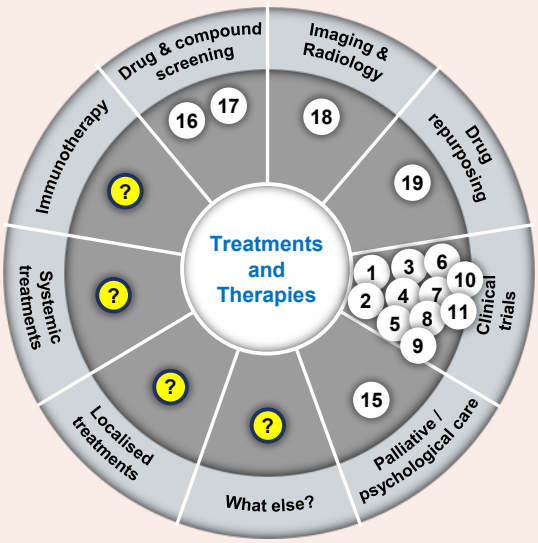
> "The EHE global community has done an extraordinary job of promoting research into EHE and getting an exciting portfolio of EHE research up and running. This of course has only been possible because of major donations and the amazing grassroots fundraising effort of so many in our global patient community and their supporters.
>
> With continued successful fundraising, it is imperative that we develop a pro-active research agenda that prioritises areas where there are gaps in our knowledge, to bring forth critical data and advances in the development of treatments for EHE. This will also allow us to develop and promote a coherent multi-year research programme and associated budgets which we hope will in turn allow us to engage with larger sources of funding."

Denise Robinson, Director of Research for The EHE Foundation is also working actively to help develop the strategy. Denise commented:

> "Our goal is to produce a research strategy that will guide our research planning and help us collectively achieve our research goals – to find effective treatments for EHE. To date, we have funded amazing projects that have advanced knowledge in EHE; now is an appropriate time to assess the gaps in knowledge that need to be addressed in order to accelerate research that ultimately will improve the lives of people diagnosed and living with EHE. We can start to assess the gaps by simply mapping our research projects against different research subjects and objectives."







These strategic discussions in Milan enabled the EHE Group to engage with clinicians and researchers who are actively working with EHE to seek their input and direction, for which the EHE Group are extremely appreciative, as Andrei highlighted:

> "We could not be more grateful to Drs Stacchiotti, Frezza, Zaffaroni, Pasquali (all INT) and Huang (ICR) for giving us a whole afternoon to discuss and review our EHE research needs. They helped us clarify and identify key steps in identifying and prioritising EHE research objectives that will then allow us to build an overall EHE strategy."

However, it is not just the opinions of clinicians and researchers that the EHE Group want to hear, as Hugh, Denise and Andrei all note:

> "It is so important that we engage with our global patient community and also seek their input to this research process. The patients' view is very powerful when collectively voiced, and there is no group more vested in achieving positive outcomes than the global EHE community. So we will ensure that they are involved."

The team hope to be reaching out to patients in the very near future as they move forward with building the research strategy. Watch out for their communications. We would like to congratulate them on progressing this important work and we look forward to posting updates in future editions of **The Pledge.** ■

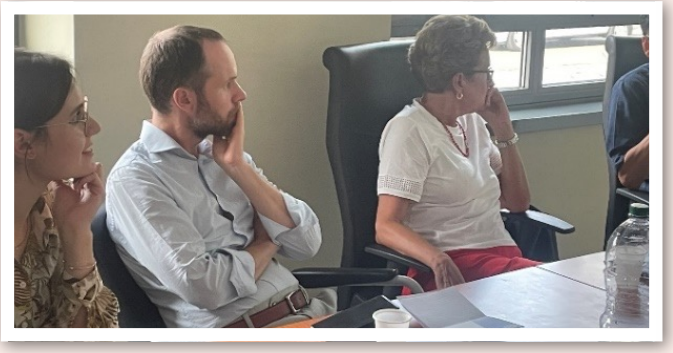
02 EHE Research

Research Review: Evaluation of cytokines and hormones as biomarkers for EHE

A significant collaborative research project funded jointly by the EHE Rare Cancer Charity UK and The EHE Foundation (US) includes the Instituto Nazionale dei Tumori (INT) based in Milan, and the Institute of Cancer Research (ICR) / Royal Marsden Hospital (RMH) based in London. Key researchers in the project include Dr Nadia Zaffaroni (PI) and Dr Sandro Pasquali from INT, and Dr Paul Huang (PI) from ICR/RMH. Members of the research team all gathered in mid-September in Milan to review progress on the project and discuss future perspectives.

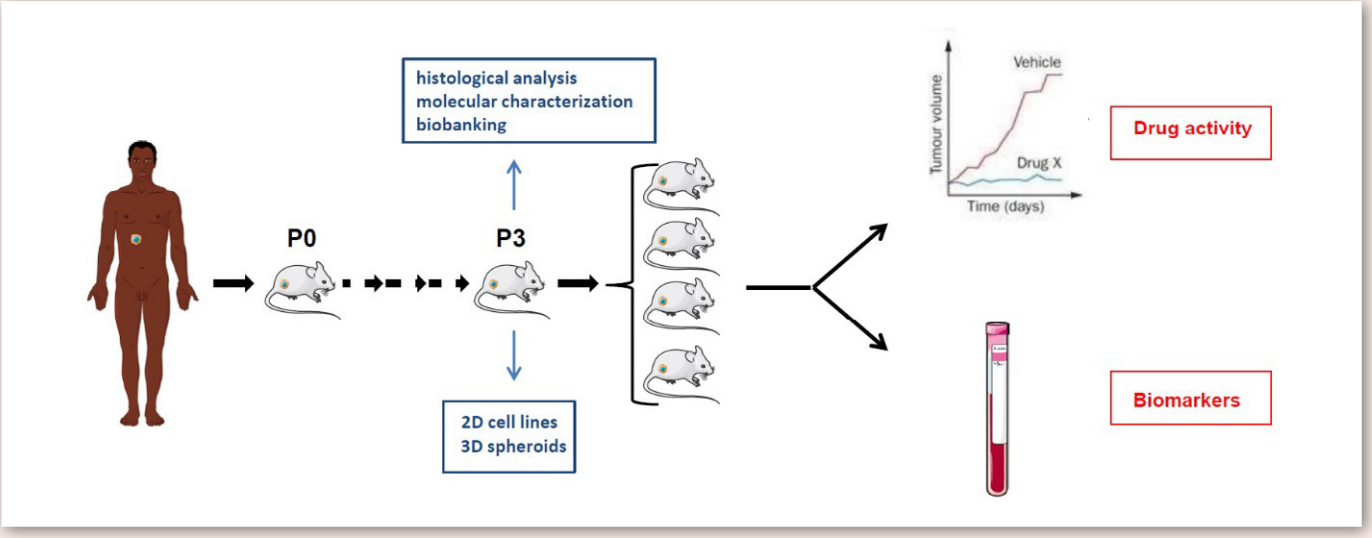
The EHE Group were delighted to see the good progress being made on core elements of the project. Underpinning the research is the ongoing enrolment of a prospective observational study, including tissue and blood sample collection and recording of disease progress and treatments over time. At the time of the review a total of 40 patients had been enrolled in this project, 35 in Milan and 5 in London.

These patient samples and detailed clinical observations are being used to support the research programme, including the identification of new biomarkers which can help with patient management, providing a tool to help with more accurate prognosis, identify possible therapeutic targets, and assessment of responses to different drugs.



In summary, progress highlights from this research are:

- The study has enrolled 40 patients as of September (35 at INT, 5 at RM)
- A small number of cytokines involved with inflammation have been identified that are found to be differentially expressed in EHE patients. Currently, the research continues to evaluate a potential biomarker for EHE, Growth and Differentiation Factor-15 (GDF-15), which plays multiple roles in a wide variety of cellular processes.
- The team looked at the concentration of circulating GDF-15 in a retrospective series of 23 EHE patients and observed a statistically significant association of GDF-15 levels with EHE aggressiveness. This result was confirmed in a second cohort of 21 EHE patients prospectively collected within the currently-ongoing observational study.
- The team are also now analysing miRNAs as possible biomarkers, with early results looking positive.
- Research looking at hormones has also started.
- The team also hope to start research into tissue-based biomarkers.



Another key component of the research programme is to develop disease models of EHE, in this case the study aims to make Patient Derived Xenografts (PDXs) of EHE. PDX models involve mice into which human EHE tumour tissue is implanted to keep it alive and allow it to grow. If successful, samples of the tumour tissue from the first mouse are then transferred to additional mice to accommodate further growth. Tissue samples may then also be used to create EHE cells lines where the EHE cells are grown in petri dishes, providing another type of EHE model that is critical for research – an EHE cell line. Disease models like cell lines and PDX can then be used in ongoing biomarker and drug screening studies.

To date, INT have generated one PDX model which has been validated and reproduces all the key characteristics of the original human EHE tumour. The PDX is currently being used to assess the activity of other drugs.

Andrei Ivanescu who was attending the first such research overview was excited:

> "It was amazing for me to see and hear all that the team at INT are doing to help us find ways to better treat this disease. There is so much going on, and so many positive results being reported. I was also delighted to see the level of collaboration that is already taking place between the EHE Group advocates and the researchers and clinicians in Italy, the UK and Canada. I am convinced that with this high level of international collaboration between all the EHE stake-holders we are already making significant progress in understanding this disease and will bring forward the day when we can genuinely manage and treat the disease"

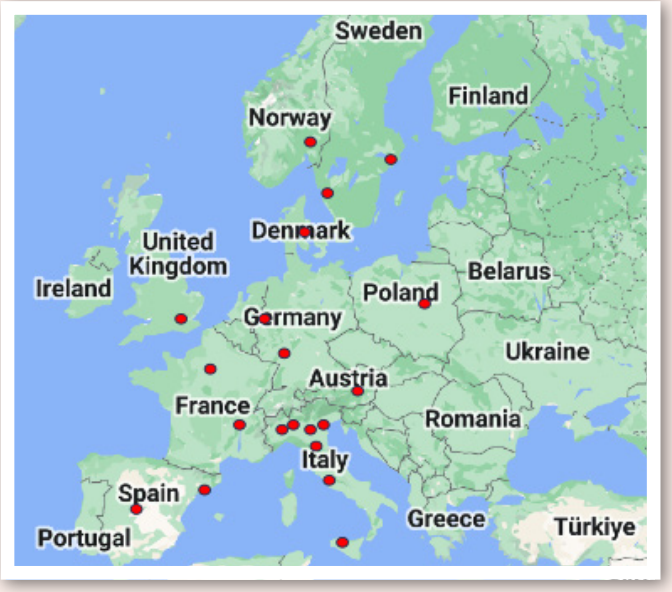
None of the above work could have been completed without the successful development of INT's EHE PDX model and cell line, which could not have been achieved without the donation of patients' surgical tissue samples. It is almost impossible to overstate the critical value of live EHE tissue for ongoing EHE research. It is also why the EHE Group continues to advocate for and encourage the capture and donation of all forms of EHE biospecimens to EHE dedicated biobanks. ■

Pan-European EHE Prospective Observational Registry is launched

The third day of the EHE Group's visit to INT was entirely focused on the launch of the world's first ever multi-centre prospective registry for EHE. This EHE registry is being coordinated by the INT team within the STARTER project, a major data gathering initiative developed under the auspices of EURACAN.

There was a lot of excitement as the INT team has been working hard over an extended period to develop the registry. This had not been easy due to the heterogenous nature of EHE providing a major challenge to all involved in creating the appropriate data capture infrastructure. Hugh Leonard was also thrilled to see the large number of institutes that had joined the project:

> "Joining the project is not compulsory. Each institute that is eligible has to make its own decision as to whether to join the registry or not, so we were delighted to see that 22 hospitals had already joined the project. The registry team hope to add more hospital in the future, including international centres who have expressed interest, but the immediate focus will be on getting the project up and running first with the 22 initial participating institutions."



Andrei Ivanescu was also present at the launch and was pleased to see INT leading this important project:

> "This world-first registry will start to collect clinician-entered data from EHE patients across Europe, and hopefully over time will allow us to gain a greater understanding of the disease. It will also begin to standardise clinical practices and treatment of the disease as participating centres follow the study protocols. That too will be of significant benefit in managing and understanding EHE."

It is important to keep in mind that there are different types of patient registries. This registry includes people enrolled by their physician, with data entered into the study by the physician, including information about symptoms, disease presentation, treatments and outcomes. Another type of patient registry includes data entered by patients directly about their disease journey. Together, these data provide the most comprehensive history of EHE.

Denise Robinson was also excited to see the launch of this new registry:

> **"A key challenge in understanding ultra-rare diseases is the tiny number of highly-dispersed patients which makes gathering clinical and patient information very difficult. The EHE Group has been working hard on these issues and is now addressing both these limitations. Prospective clinical data will be captured through the STARTER registry in Europe which we hope to see grow over time, while patient contributed data will be captured by the EHE Global Patient Registry, coordinated by The EHE Foundation, which was also launched this year and is now gathering data from the global patient community."**

Hugh echoed these comments about the importance of data capture:

> **"Capturing this data is so important as the design focuses on EHE, and over time the study will provide high-quality valuable data important for generating hypothesis and further interrogation of disease treatments. This was why we did not hesitate to provide funding to INT for the registry when we were approached."**

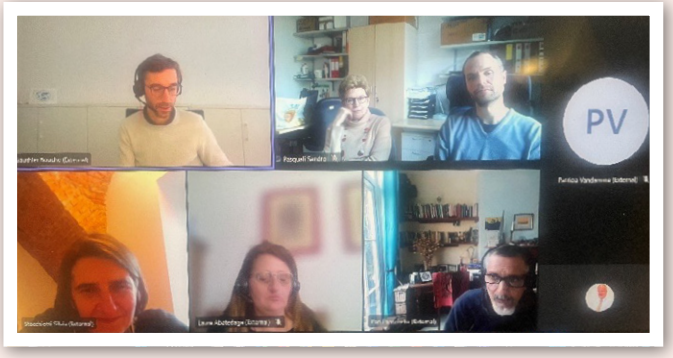
We want to congratulate the INT team for their dedication and hard work in getting the EHE Prospective Registry up and running. We are confident that this study will play an important part in the future development of the understanding and treatment of EHE. ■

Drug Repurposing: Seeking approval for sirolimus for EHE

Regular readers of **The Pledge** will know that the EHE Group is engaged with EORTC and the AntiCancer Fund in Europe in seeking an extension of the marketing authorisation of sirolimus to include EHE. Hugh Leonard explained:

> **"Sirolimus, marketed by Pfizer as Rapamune®, is widely used as an immunosuppressant after organ transplant. It is one of a class of drugs known as mTOR inhibitors. The drug however has never been approved specifically for the treatment of EHE. From 2015 onwards however, thanks to initial work done by Dr Silvia Stacchiotti, and subsequently followed by other leading sarcoma clinicians, there has been a growing body of evidence that strongly indicates that sirolimus is more active against EHE than any of the drugs currently approved for general sarcoma use."**

So when the EMA announced that they were setting up a pilot scheme to explore ways to repurpose drugs for rare diseases, the Anticancer Fund, based in Belgium, in collaboration with Dr Stacchiotti, submitted the use of sirolimus for EHE as a potential candidate, and were pleased when the EMA accepted the proposal. The Anticancer Fund then engaged with the EHE Rare Cancer Charity (UK) to bring in the EHE patient voice, and initiated engagement with the regulator, The European Medicines Agency (EMA).



Hugh Leonard summarised the process so far:

> “Dr Stacchiotti’s team collated all available data relating to the use of sirolimus and its effect on EHE, and were able to generate an extensive description of all this work and the appropriate conclusions. At the same time, the EHE Rare Cancer UK and The EHE Foundation sought to reach out to the EHE global patient community with a survey relating to their lived experiences of sirolimus, which was analysed, and key results documented. This whole package was submitted to the EMA under their Scientific Advice procedure and has led to the exchange of several emails and one video-conference call between the two teams. The EMA’s standard process has taken some time but we are now exploring an ‘Exceptional Circumstances Authorisation’ procedure as directed by the EMA. We hope that this may allow us to move forward with an approval for sirolimus, but there is likely to be more work and therefore more time required. This is frustrating but we need to continue to push and stay focused on getting the approval we need to help patients everywhere access this important drug.”

Results of the EHE Patient Survey relating to sirolimus can be seen in our 32nd edition (Q1 2023) of **The Pledge.** We hope that we can report a positive outcome in future editions of **The Pledge**. In the meantime, we want to thank Dr Stacchiotti, EORTC, the Anticancer Fund and our own EHE patient community for the time and dedication given to this important issue. ■

Ikena Phase I Clinical Trial Continues Enrollment

Alkena Oncology continues to enroll patients in their Phase I study of IK-930, a novel TEAD inhibitor targeting the Hippo signalling pathway. IK-930 binds to TEAD and prevents transcription of multiple genes that drive cancer progression. The study is investigating IK-930 in patients with advanced solid tumors including EHE.

See below the centres that are enrolling EHE patients currently, additional study centres will be opening in the future - please watch for updates at fightehe.org.

IK-930 centres enrolling EHE patients:

- Massachusetts General Hospital - Boston, MA - Dr. Greg Cote
- MD Anderson Cancer Center - Houston, TX - Dr. Vinod Ravi
- Memorial Sloan Kettering Cancer Center - New York, NY - Dr. Mrinal Gounder

For contact information for these centres and to learn more about this study go to: https://clinicaltrials.gov/study/NCT05228015.

Phase I studies primarily test safety, side effects, and the best dose of a potential new treatment. Some study participants may benefit from the drug candidate being tested; however, disease response is not the primary purpose of a Phase I study. Read more about TEAD inhibitors from AACR ’23: https://ir.ikenaoncology.com/news-releases/news-release-details/ikena-oncology-shares-differentiation-profile-ik-930-novel-hippo.

If you have questions about this or other clinical trials, email: research@fightehe.org. ■

Spotlight on the Lamar Lab at Albany Medical Center – a Translational Research Partnership

Jane Gutkovich is a long-time supporter of John Lamar, PhD and in late September, Jane had the opportunity to visit the Lamar Lab. Jane commented:

> "I spent a day at Albany Medical Center with the team of Dr. John Lamar. His lab is intensely studying EHE thanks to the support of the EHE community. Dr Lamar is a firework of ideas."

In 2019 The EHE Foundation (US), EHE Rare Cancer Charity UK, and EHE Rare Cancer Foundation Australia collaborated to fund a modest $50,000 seed grant to Dr. Lamar. This funding enabled Dr. Lamar to grow his team and expand his research to collaborate with the Rubin Lab at Cleveland Clinic. Fast forward to 2021, The EHE Foundation awarded another 3-year grant award to study **"TAZ-CAMTA1 Regulation by the Calcium Sensor Calmodulin",** and in 2022 a new 3-year grant was awarded to investigate the **"Use of multiplexed tumor growth assays and pre-clinical EHE models to identify drugs that can treat EHE."**

Denise Robinson, Director of Research at The EHE Foundation added:

> "Dr. Lamar and his team are working to significantly advance knowledge in EHE research to find effective treatment options for this disease. Dr. Lamar is an inspiring collaborator, and we are grateful for the opportunity to support the expansion of EHE research in his lab. We are eternally grateful to donors whose generous contributions enable our awarding these grants to Dr. Lamar." ■

The EHE Foundation Championing Drug Repurposing for EHE

Denise Robinson, The EHE Foundation's Director of Research and member of the CURE Drug Repurposing Collaboratory (CDRC) Rare Coordinating Committee, talked about the importance of drug repurposing in a rare cancer, like EHE, at C-Path's 2023 CDRC Annual Meeting. Denise explained the importance of partnerships, like The EHE Foundation's with CDRC, in supporting the EHE Group's mission to find effective treatments for EHE patients. You can see Denise's comments on YouTube. https://www.youtube.com/watch?v=fdyDCWGyEvY

What is drug repurposing?

Drug repurposing aims to find new purposes, or indications, for preapproved or existing drugs. Drugs that have already been proven to be safe in humans for other diseases can more efficiently be tested in patients for a new disease. Such drugs are sometimes already being prescribed 'off label', which means for a use not included under the current authorisation of the drug. Drug repurposing holds promise for systematic and possibly faster and less expensive methods to find new treatments for EHE, as compared to the traditional drug development cycle. Rich, quality data sources are a key in the drug repurposing cycle – something that The EHE Group is working to bring forward for researchers.

What is C-Path?

Critical Path Institute (C-Path) is an independent, non-profit organization established in 2005 as a public and private partnership. C-Path's mission is to catalyse the development of new approaches that advance medical innovation and regulatory science, accelerating the path to a healthier world. ■

The EHE Foundation – Research Roundup

Each edition of The Pledge this year is focusing on key research taking place in different regions of the world. Our Q1 edition was focused on the UK, while Q2 was focused on Europe. This edition is focused on research taking place in the US and coordinated by The EHE Foundation.

Lamar Project Update: Use of pre-clinical EHE models to identify druggable pathways to treat EHE

Dr. Lamar's research entitled **"Use of multiplexed tumor growth assays and pre-clinical EHE models to identify drugs that can treat EHE"** aims to identify FDA-approved drugs that inhibit EHE cell growth, and then test them in pre-clinical mouse models for the treatment of EHE.

What does this mean for patients?

This could mean a shorter path to an FDA-approved treatment for EHE, since these drugs have been tested and proven safe for other diseases.

Dr. Lamar reports that they made significant progress in their first year of funding:

"Shortly after the project was funded the first EHE cell lines were established by Dr Brian Rubin's lab. In collaboration with Dr. Rubin, we have been working with these cell lines and have completed the extensive characterization and optimization necessary to effectively use these cells in assays required for this project. We have also demonstrated that inhibition of TAZ-CAMTA1-TEAD activity blocks the growth of these cells, indicating that targeting TAZ-CAMTA, TEADs, or other pathways that regulate them is a good therapeutic approach for EHE.

In addition, we have established pre-clinical tumor models of EHE in mice using these cells. This was important as it will allow us to perform preclinical experiments mentioned above. With all optimizations nearly complete we are in the process of performing a small drug screen that has the potential to identify compounds that could block EHE cell growth, but also serves as a proof-of-concept experiment to demonstrate that our screening approach will work on a larger scale.

The drug screen is ongoing, but preliminary results suggest we have identified some compounds that block EHE cell growth. These drugs will be evaluated further and if they remain promising, we will test them in our pre-clinical mouse models of EHE. In addition, these results show that our screening approach works well so we are preparing to do the larger RNAi screen that we proposed." ■

02 EHE Research

EHE Foundation Funded Research Project Report: Repurposing an FDA-approved Drug for EHE Treatment

Investigator: Ajaybabu Pobbati, PhD, Cleveland Clinic – Lerner Research Institute

In 2022, The EHE Foundation funded a grant to Dr. Pobbati for research that looks at a library of current FDA-approved drugs that act as TAZ-CAMTA1 (TC) or TEAD inhibitors, for use in EHE.

What does this mean for patients? This could mean a shorter path to an FDA-approved treatment for EHE, since these drugs have been tested and proven safe for other diseases.

Dr. Pobbati has provided a report on his team's progress:

"Epithelioid hemangioendothelioma (EHE) is caused by an unusual chromosomal rearrangement that causes the abnormal joining of two genes, generating the cancer-causing TAZ(WWTR1)-CAMTA1 (TC) fusion gene, which is the defining feature of EHE. TC is predominantly found in the nucleus, and its nuclear location plays a key role in causing EHE. We performed a screen on EHE cells grown in dishes using ~4000 compounds that included ~2000 FDA-approved drugs to identify those that regulate the location of TC within the cell and those that cause it to be unstable. We identified drugs that could drive TC out of the nucleus and ultimately destabilize it, causing it to degrade and disappear. Currently, experiments are being designed to understand the underlying reasons for this. One of the potent drugs uncovered in our study was FDA-approved and has already been shown to have a good safety profile. Ultimately, our aim is to evaluate whether it could be used to treat unresectable aggressive EHE.

Another aspect of our research is to understand why EHE has an indolent or aggressive course. We have EHE cells that grow in dishes that model aggressive disease, but not indolent or less aggressive disease. The EHE cell lines that we have developed facilitate robust hypothesis testing, as they can be easily manipulated using genetic and pharmacological tools, and indolent cell lines will complement mechanism-based studies and studies that uncover therapeutic vulnerabilities. We plan to introduce clinically relevant tumor suppressor genes into aggressive EHE cells to investigate the possibility of generating EHE cell models for indolent/less-aggressive EHE." ■

The Telluride YAP/TAZ and TEAD Workshop: A Small Meeting with a Big Impact

The EHE Foundation celebrated dedicated EHE researcher, John Lamar, PhD, Albany Medical College and clinician-scientist, and long-time EHE patient advocate, Dr. Guy Weinberg, CRAVAT Foundation and their colleagues for highlighting the success of their annual science workshop, **"YAP/TAZ and TEAD: At the crossroads of cancer"** in their recent **publication**.

Annually, a global group of researchers meet in Telluride, Colorado, US to discuss Hippo signalling and ways to potentially regulate YAP/TAZ-TEAD activity, which is important to the development of treatments for EHE and other cancers.

While the meeting is not solely focused on science and collaboration to advance EHE research, there have been several notable studies, projects and advancements in drug development directly resulting from the meeting's collaborative environment that have directly benefited EHE awareness and funding of basic science - advancing our mission to find treatments for EHE.

Generous contributions from the EHE community have helped to fund travel grants for young investigators to present at this workshop. ■

02 EHE Research

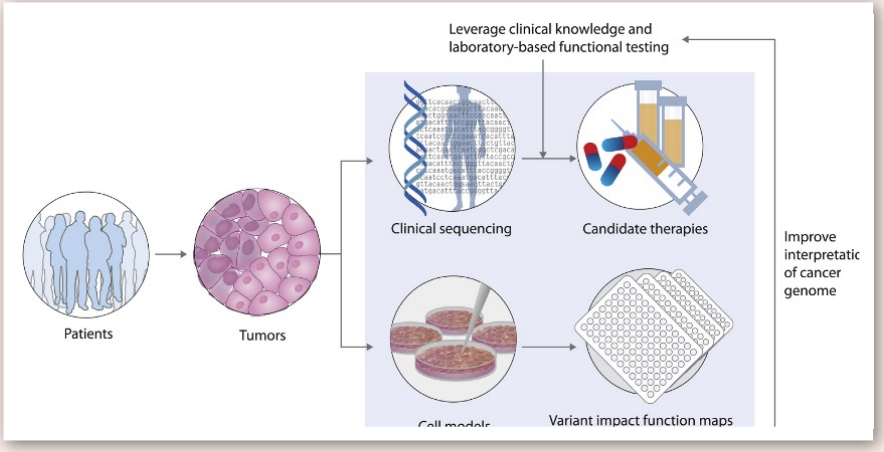
The EHE Foundation Partners with Boehm Lab – a Patient-Partnered Platform for Rare Sarcoma Discovery

Jess Boehm, PhD, Principal Investigator at the Boehm Lab at the Koch Institute for Integrative Cancer Research at MIT was awarded a 3-year grant through the Department of Defense Rare Cancers Research Program Resource Community Development Award. This novel project aims to harness the power of patient-partnered research towards creating a platform for rare cancer drug target discovery. The key to its success is patient-donated tumor tissue from people living with EHE.

Through partnership with The EHE Foundation, Rare Cancer Research Foundation, and other advocates, the Boehm lab can receive tumor tissue specimens from patients and grow the tumor tissue in the lab, turning tumor specimens into cell models. Newly created models are then subjected to CRISPR genome engineering technology to find the best therapeutic options to treat the disease.

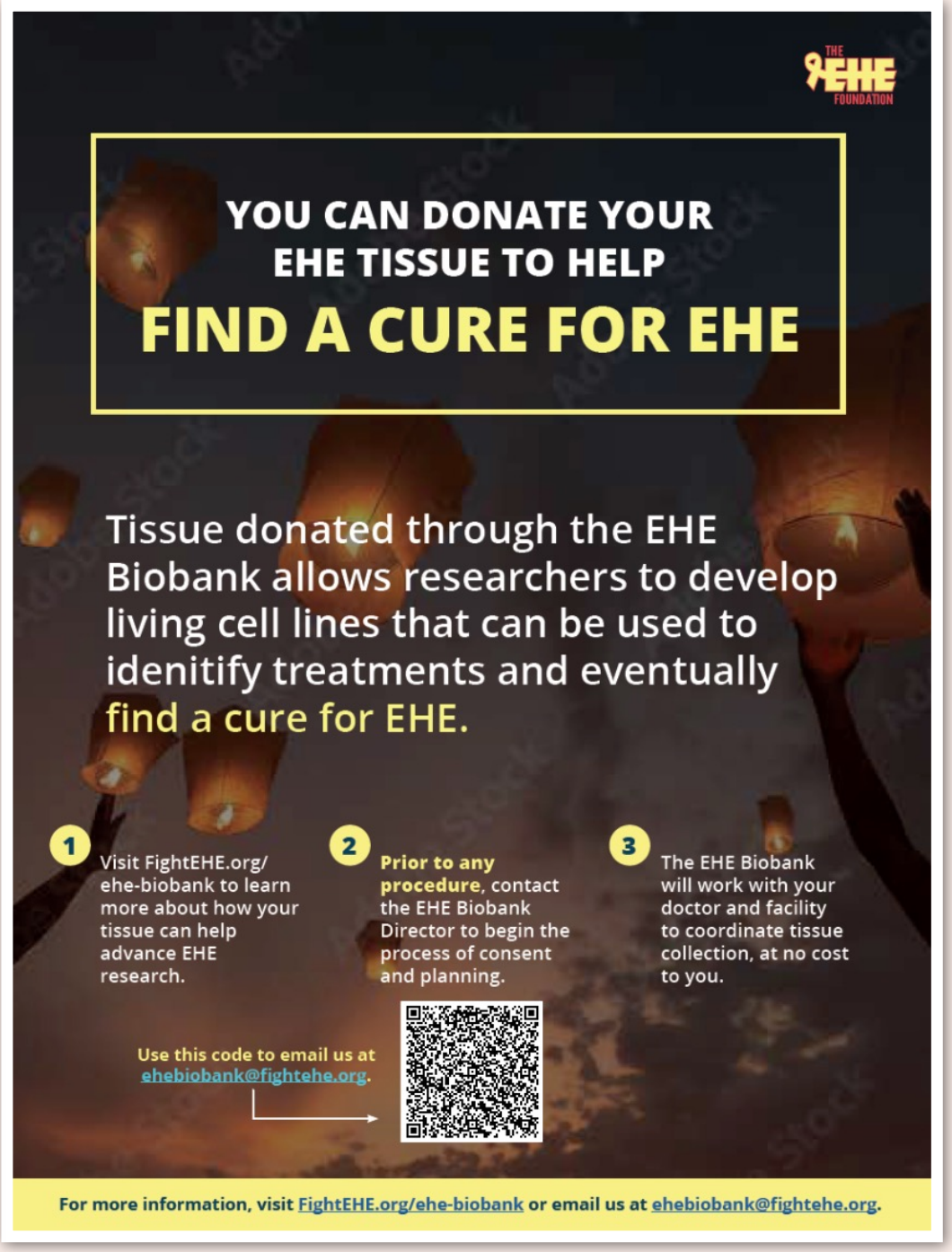
Denise Robinson, Director of Research at The EHE Foundation said:

> "we are thrilled to continue our partnership with the Boehm Lab and to work collaboratively with other rare sarcoma patient organizations to advance the use of this innovative technology approach to identify effective treatments for EHE. This is one example of how patients can donate EHE tumor tissue to the EHE Biobank and have a direct impact to advance science today." ■



EHE Research is Powered by People with EHE

Patient participation through tumor tissue donation to the EHE biobanks or by sharing data (information) about their disease in the Global Patient Registry is critical to advancing EHE research. Your participation can advance understanding of this disease and progress toward finding treatments and a cure.




EHE Global Patient Registry
EHEregistry.iamrare.
JOIN TODAY
EHE Research - Powered by YOU
You can participate in vital Epithelioid Hemangioendothelioma (EHE) research by joining the EHE Global Patient Registry and detailing your unique experience in a natural history study of EHE.
Because EHE is so incredibly rare, this is a powerful opportunity for you to directly impact EHE research to improve understanding of this ultra-rare cancer and accelerate research toward improved treatments and ultimately a cure.
Who can join the Registry?
Anyone diagnosed with EHE anywhere in the world, including:
✓ Adults
✓ Children or minors (represented by a parent or guardian)
✓ Deceased persons (included by a legal adult representative)
How to Join
1. Visit EHEregistry.iamrare.org to create your profile.
2. Consent to provide your information to the registry.
3. Answer questions about your EHE experience, such as symptoms, diagnosis and treatment.
JOIN TODAY
EHEregistry.iamrare.org
THE EHE FOUNDATION
The EHE Global Patient Registry is hosted by the National Organization for Rare Disorders (NORD®) on the IAMRARE® secure platform, and is sponsored by The EHE Foundation, a 501(c)(3) organization dedicated to pursuing effective treatments for EHE and supporting patients and their families. To learn more visit fightEHE.org.

Spotlight on Young Investigator Nicholas Scalora, Advancing the Science Behind EHE

The EHE Foundation is proud to have awarded the 2023 Fellowship Travel Grant to Nicholas (Nick) Scalora, a 5th year graduate research assistant in **the pathology lab of Dr. Munir Tanas** at the University of Iowa. Dr. Tanas is an expert pathologist and researcher, was first author of **"Identification of a disease-defining gene fusion in epithelioid hemangioendothelioma,"** a foundational publication for EHE research.

In June 2023, Nick attended the **"YAP/TAZ and TEAD: at the crossroads of cancer"** workshop at the Telluride Science Research Center (TSRC), in Telluride, Colorado. Annually, prominent scientists and several promising young researchers from around the world have the opportunity to come together to discuss Hippo signalling and ways to potentially regulate YAP/TAZ-TEAD activity. While the meeting is not solely focused on science and collaboration to advance EHE research, there have been several notable studies, projects and advancements in drug development resulting from the meeting's collaborative environment that have directly benefited EHE awareness and funding of basic science - advancing our mission to find treatments for EHE.

Nick's presentation at the meeting was entitled **Towards Targeted Therapy of EHE.** In the Tanas lab, Nick's research is focused broadly on the Hippo signalling pathway which is known to be important in many types of cancer, especially sarcoma. Importantly in EHE, the end effectors of the Hippo pathway, TAZ and YAP, are involved in chromosomal translocations that drive EHE. Recently, the lab completed a high-throughput drug screen against cells engineered to express an EHE fusion protein. Following up on the results of this screen will lead to better therapeutic options for EHE patients.

Nick is also leading a second project where he and his team are focused on the development of disease models from patients' donated tumor tissue which are critical tools for developing new treatments for EHE. Nick and the Tanas lab team are eager to advance EHE research through their partnership with the EHE Biobank on this project, hopefully leading to human cell lines of EHE in the future.

As a grantee of The EHE Foundation, Nick provided a post-meeting report sharing:

> **"I walked away from the meeting with new experiments to consider, and helpful insights for sharing my data in future presentations and publications. It was great to have the opportunity to get to interact with leaders in the (Hippo) field and hear more about their research. I tried to soak in as much knowledge as possible from pioneers of the Hippo and EHE field. One of the key takeaways I had was how collaborative the meeting was, both during and after the scheduled presentations with the end goal being better outcomes for EHE patients."**

Here's a small piece about Nick and how he came to the Tanas Lab. Nick tells us:

> **"While earning my undergraduate degree from Doane University, I became very interested in understanding mechanisms of gene regulation, which propelled my interest in research and subsequent application to the University of Iowa for graduate school. My current career goals are to work at a primarily teaching focused institution, but still run a lab and push science forward. I really enjoy the teaching and mentorship aspect of science, so I hope to be able to highlight and emphasize that at my next position. Outside of the lab, I enjoy watching and playing soccer, as well as walking with my fiancée and dog!"**

The EHE Foundation is fortunate to have the opportunity to collaborate with the Tanas Lab to ultimately help people with EHE. To learn more about the TSRC "**YAP/TAZ and TEAD: at the crossroads of cancer**" workshop, go to **https://www.mdpi.com/2072-6694/15/19/4717** ■

03 EHE Fundraising

Highlights of some of the fundraising activities that our supporters are delivering can be found in this section of our newsletter.

This fundraising is key to our success. It is the 'life blood' of our EHE Group. We thank every single person who has organised a fundraiser of some variety, supported fundraising in any way they can, or has donated to these event. We could not have achieved the progress we have without your wonderful contributions.

A stunning evening

Kelly Denton's family have been brilliant supporters of the EHE cause ever since her daughter Neve was diagnosed with EHE. So we were not surprised when Neve's cousin, Hannah, held a small and intimate concert in central London one Sunday night to raise funds for The EHE Rare Cancer Charity and for EHE Research. Hannah had previously participated in and done very well on The Voice, a prime time music talent show, so those present were not surprised to be blown away by her phenomenal voice. Hannah was brilliantly supported by two other young singers, as well as her husband and brother, both talented musicians.

It was also great as there were four EHE patients present on the night, Sally Baker, Kim Alexander-Bird, Michaela Murphy, and Kelly's daughter Neve. All agreed that is was lovely to be able meet each other and their lovely respective partners.

Hugh Leonard also had the chance to say a few words about EHE and the Charity at the start of the concert. At the end of the night Hannah had raised over £1,000, an amazing achievement.

We want to thank Kelly and Hannah for organising this great event. Our community motto is ***Just Live,*** something that those present on the night very definitely lived up to. ■

Dave Thomas runs in memory of Janet

We always find it moving to see people taking on a fundraising event in memory of somebody who has lost their life to EHE. In mid-September, Colin Griffiths posted news of Darren Thomas's Swansea Bay 10k run in memory of Colin's wife, Janet, who passed away at the end of 2022.:

> "As many of you know, Jan lost her brave fight with EHE Cancer in December 2022. In January 2023, 6 of our fittest lads (Dai, Darren, Scott, Stephen, Colin and Simon) started training for the Swansea Bay 10k to raise funds and awareness for this rare cancer. Unfortunately over the training period, injuries led to 5 having to drop out leaving just 1 - well done Darren! Darren will be taking part in the Swansea Bay 10k on Sunday 17th September to raise funds and awareness for The EHE Rare Cancer Charity UK. We as a family are greatly appreciative and if you would also like to support Darren and provide much needed funds for this charity please use the just giving page."

Darren has already raised nearly £1,000 for EHE research. We want to congratulate Darren for this fantastic effort. We are sure that Janet was watching and willing you on. Well done indeed. ■

03 EHE Fundraising

A 100 km trek for cancer research

Caroline Flamand is a Canadian EHE patient. Like many members of our patient community, she is determined that cancer will not define her. In May 2024, Caroline will be participating in the Challenge Against Cancer organised by the Cancer Research Society where she will complete a 100KM trek to raise $9500 for cancer research. Caroline has already started to raise funds with different fundraisers including selling ***Just Live*** bumper stickers and small keychains. We want to congratulate Caroline on this endeavour and amplify her closing message **"Many thanks and long life to all of us."**

To order, go to: https://undoigtdhonneur.etsy.com/ ■

In memory of a special person

It is heartbreaking that we continue to lose cherished EHE family members to this terrible disease. They will always be remembered, and never more so than when friends or family celebrate their lives with an event in their memory.

Bill Desjardins shared news of just such an event in memory of his late wife Tammy, when her very good friend, Priscilla D'Amico Dineen, decided to host an EHE Fundraiser in her memory.

Thank you, Priscilla, for remembering Tammy, and supporting a group who was important to her. We think she would have been proud of you and your desire to help EHE patients everywhere. ■

An unstoppable force

Michelle Hughes lives in Canada and was diagnosed with grade 4 EHE just over two years ago. Ever since then, Michelle has been the powerhouse behind her growing advocacy, awareness and fundraising campaigns.

September was no different. Michelle underwent additional scans due to some change to her symptoms, and was delighted to be able to report that her EHE was still stable. Yet, even while posting news of this and footage of her scan, she was far keener to update the community about her EHE activities:

> "I'm still working out final numbers from my ***Just Live Fun Run,*** a run that had 800 participants come together to celebrate my 2 years since diagnosis. It's looking like we will come close to $60k with the help of the Sarcoma Cancer Foundation of Canada matching every dollar!
>
> My fall line of ***Just Live*** Merch is coming available in a few days, with Canadian, US and international options for shipping - so stay tuned!!
>
> Oh, and one more thing! I'm running my first half marathon in 4 weeks in Niagara Falls, Canada. If it goes well, I'm making the trip to London England to join the EHE team there and run in the London Landmarks Half Marathon."

Keep going Michelle. We love the drive and determination to never give in to your EHE! ■

The Big 4-0 down under

The EHE Rare Cancer Foundation Australia posted a huge thank you to Maggie for her fantastic fundraising in September:

> "Thank you to Maggie for choosing the EHE Rare Cancer Foundation Australia as her charity of choice to support her very special milestone birthday, raising over $1600.00 in lieu of presents. We could not be more grateful. The EHE-RCFA relies on support of people like Maggie who know that 100% of her fundraising goes directly to frontline research and, more importantly, raising awareness of rare cancers like EHE in the wider community."

Thank you Maggie, and we hope you had a brilliant birthday. ■

03 EHE Fundraising

It's the Brisbane Challenge

The annual 10K Bridge to Brisbane Challenge will be held in October and for the first time, the EHE-RCFA is on the Charity Register. Jane Biddlecombe posted a call to arms, asking anybody who was interested to enter as an individual, a team, or VIRTUALLY, and set a small fundraising target and dedicate it to EHE front line research. ■

Congratulations to two great teams

The EHE Foundation celebrated the achievements of two great teams who had both provided wonderful support to members of our EHE community.

The first huge thank you went to Aimee Liebert and her family and friends for supporting her as she lives with EHE. This summer Aimee rallied support from her friends, family, and coworkers and hosted events to benefit The EHE Foundation. Whether they were gathering for a walk or run, at a Brewer game, or meeting for food and camaraderie, her circle of support continued to show up in full force. Aimee said:

> "Everyone has made me feel so supported and I am grateful. People don't understand how I can run with this rare cancer diagnosis, but EHE is incredibly unique and running is a passion and a huge stress reliever to me. EHE has many hidden symptoms and can turn aggressive very quickly. I can't wait for my 2nd annual event next year!"

The second huge thank you and **CONGRATULATIONS** went to the top team from the EHE Foundation's 2023 EHE Fun Run and Walk. Jennifer Ness was recently diagnosed with EHE. Even while navigating her new diagnosis and managing day-to-day life including two active children, she rallied an amazing team of nearly 350 nationwide supporters and raised just shy of $16,000!

More than 300 people also joined her local event in June, as we reported in the last edition of the **The Pledge**. The event featured a 5K run or a 1K walk, which concluded at a local NJ brewery, Kings Road Brewery. Friends and family enjoyed a DJ and brunch in the outdoor space. Brunch was donated by a local restaurant, Café Lift. Supporters could register for the EHE Fun Run and Walk, but also have the option to enjoy a beer, brunch, and a cookie for a suggested donation of $20 per person. Jennifer said:

> **"The event was a tremendous success and I'm so lucky to live in an incredibly supportive community! A special thanks to my walk organizer, Jill Lloyd, and fundraiser coordinator and sponsor, Lindsey Watson-McCarthy."** ■

Let's discuss fundraising

Fundraising is the lifeblood of any patient community that wants to drive research for their disease. But fundraising is not easy, and people need and want help and advice. There is also comfort in numbers, being able to talk to others who are doing the same.

The EHE Foundation recently focused one of its Community Connections sessions on **"Championing Our Cause: How Patients Support Fundraising."** The objective was to discuss the impact community fundraising has on supporting research and to highlight inspirational fundraisers.

The discussion was very positive and offered new ideas and inspiration. A new fundraising toolkit (available on **The EHE Foundation's website**) was designed to spark ideas and help you plan your own fundraising activity. The session was recorded and is available on The EHE Foundations Youtube channel at: **https://youtu.be/9zTcQ0tPuOM** ■

03 EHE Fundraising

Employee matching is so valuable

Did you know that many companies support causes that are important to their employees by matching their charitable contributions. This is such a valuable source of funding. And if you are able to get the matching to apply to a fundraising that you are organizing, it can also be hugely motivating for those who join or contribute to the event, knowing that every pound, dollar, or euro they contribute will be doubled.

If you do discover that matched funding is possible, then please don't hesitate to contact your local EHE entity to discuss ways they can help you to access these funds. ■

Regular Giving

Fundraising comes in many forms, and the best fundraising organizations will have many strings to their 'fundraising bow'. The EHE Foundation is a good example, and as part of their ongoing focus on fundraising, have raised and promoted regular giving to their members and setting themselves a goal of adding ten new regular donors to their cause. Regular giving on a monthly basis is hugely valuable, helping to provide the Foundation with regular and reliable income.

In August, thanks to the generosity of the EHE community, The Foundation were able to post that they had nearly met their target, having had eight generous supporters sign up to monthly giving:

> "We have almost reached our goal of 10 new recurring donors in our EHE Circle of Friends. We need just two more donors this week. Could you be the hero that pushes us over the top?" ■

We thank you all for your amazing fundraising and donations. We could not have achieved the progress we have without your wonderful contributions.

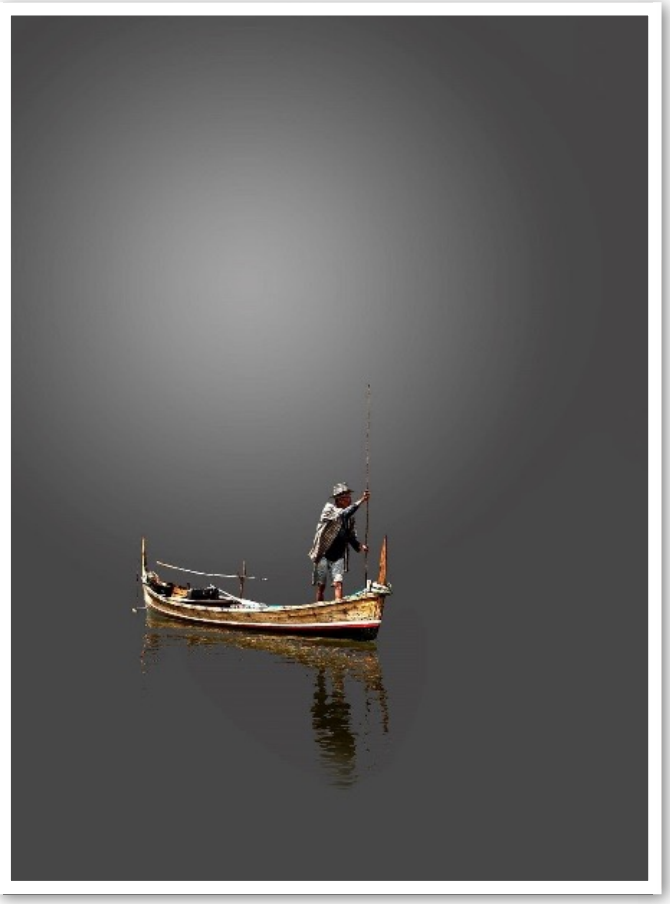
04 And in other news...

In this section as always we include some examples of great stories that may not directly fit the main sections of The Pledge, but which we feel are positive, supportive and/or fun. We hope you enjoy them too

Empowering messages of love and hope

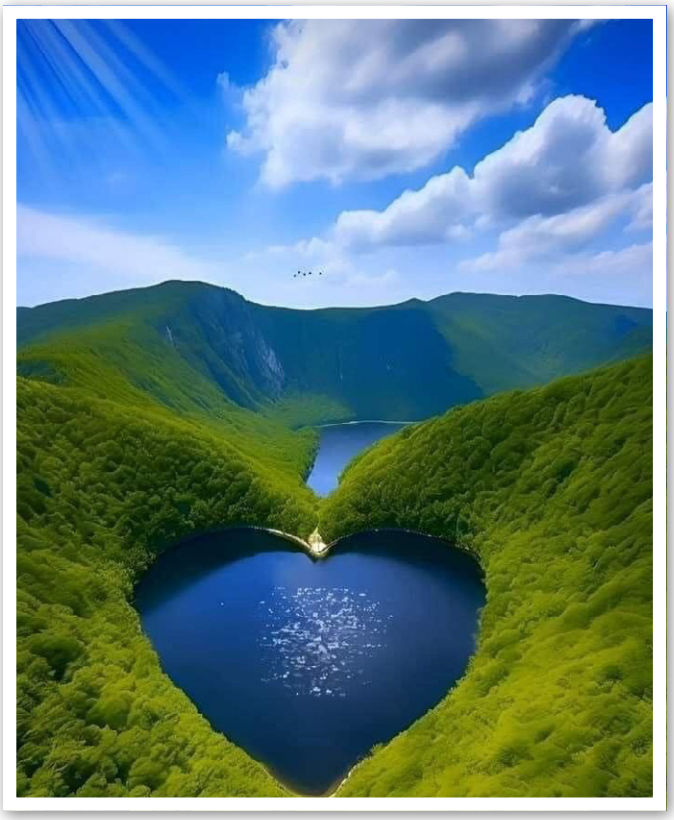
Seen on the front cover of this edition of **The Pledge**, this evocative photograph was posted by regular contributor to **The Pledge**, Carl Dickson:

> "Sometimes this is how I feel living with EHE. Over the past 24 years there have been moments when it feels as though there is no end in sight. But then as I sit and I really look at the situation I'm in, I realize I'm still here. I am still here to decide another course of action.
>
> I hope everyone here is doing well these days. Yesterday is over, tomorrow is but a dream so live for today."

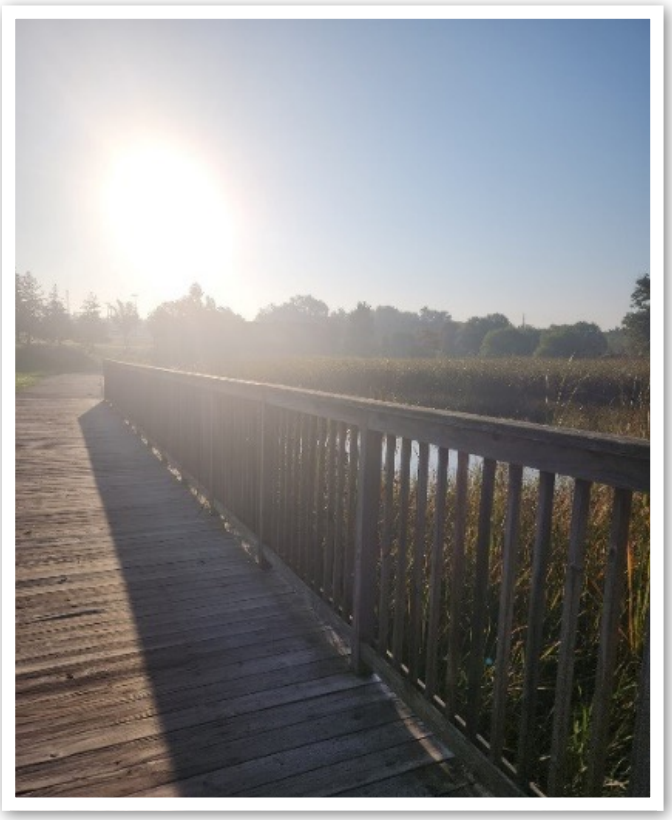


Stephanie Kennedy posted two lovely photos with simple messages for the global community:

“ Good morning beautiful warriors ”



“ Beautiful morning ”



The EHE Foundation (USA)
www.fightehe.org

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

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

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

EHE Canada
website not yet available