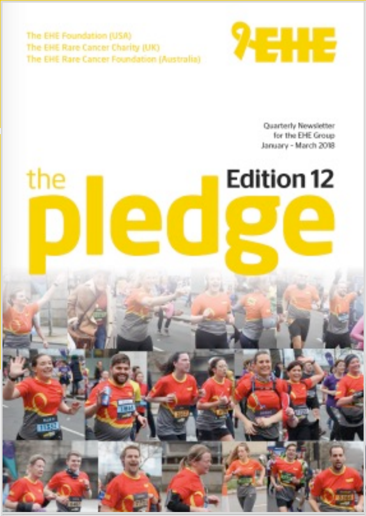
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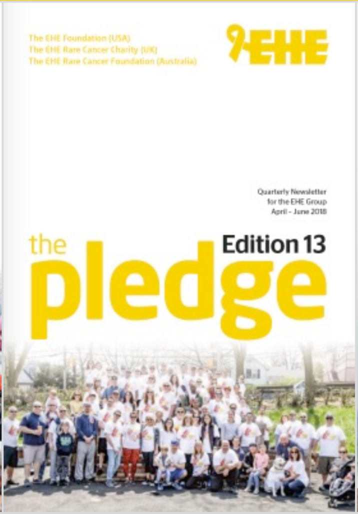
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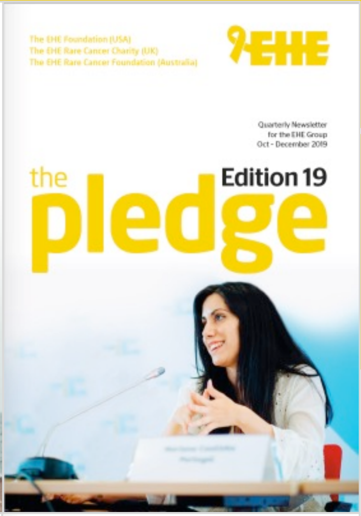
Rowing the Atlantic for EHE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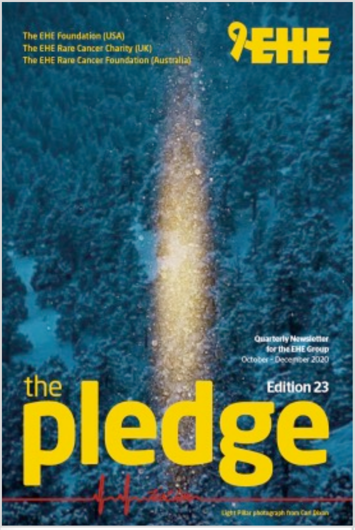
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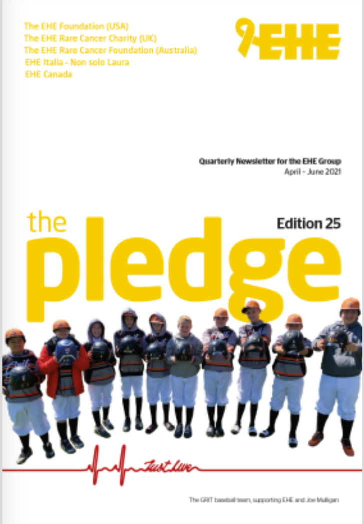
Light Pillar photograph from Carl Dixon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The GRIT baseball team, supporting EHE and Joe Mulligan


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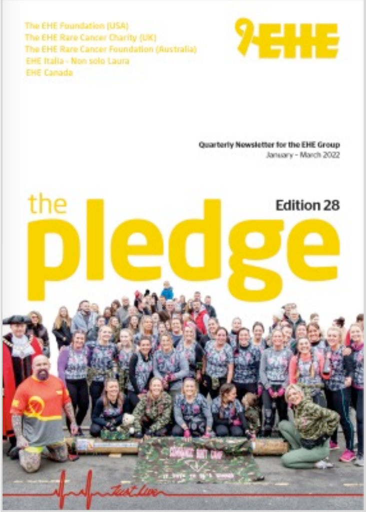
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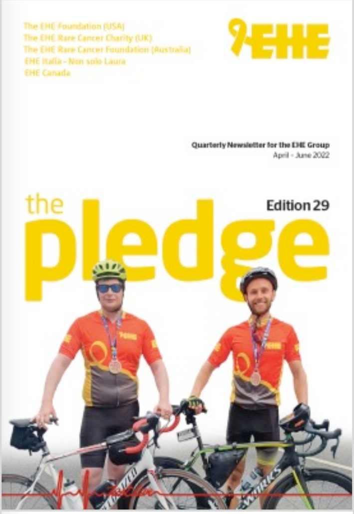
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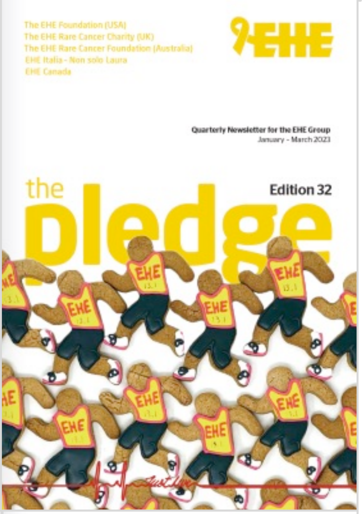
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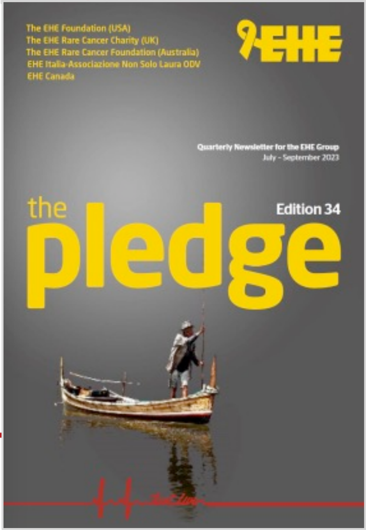
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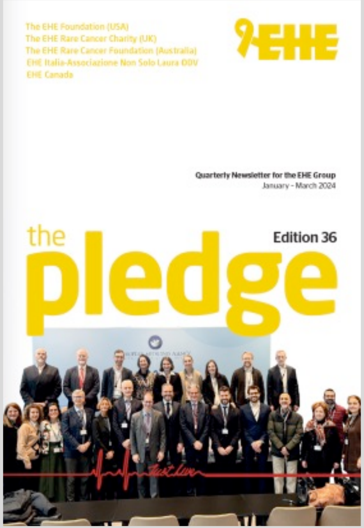
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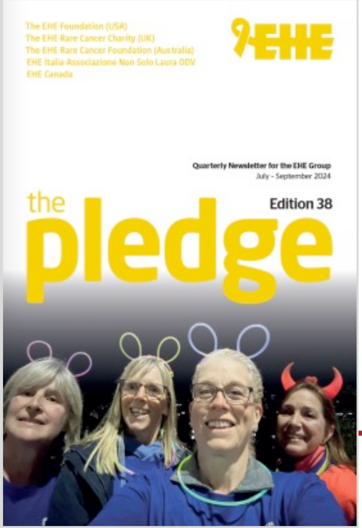
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Welcome

Celebrating 10 years!

We are delighted to issue our 40th edition of **The Pledge,** the quarterly newsletter of the global EHE community and the EHE not-for-profit organisations that work so tirelessly to represent them.

It has been a true honour to document the activities of all those involved over the last ten years and share so many inspirational stories. This edition is no different, and we hope you will enjoy the many stories included in the following pages.. They are shining examples of the group's mantra:

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

Highlights

The EHE Group is celebrating ten years!

The EHE Foundation in the US was established in early 2015. The EHE Rare Cancer Charity (UK) and the EHE Rare Cancer Foundation Australia both followed the same year. So, 2025 will see these founding members of the EHE Group each celebrate their 10th birthdays. Happy birthday guys!

EHE-RCFA represents EHE patients at APOS25

The EHE-Rare Cancer Foundation Australia represented the EHE patient community at the important Australian Precision Oncology Symposium (APOS25), held over two days in Sydney in early March.

EHE Group entities are driving EHE research

The EHE Rare Cancer Charity, The EHE Foundation, and EHE Italia-Associazione Non Solo Laura ODV hosted an EHE research review and strategy meeting in Amsterdam. Key clinicians and researchers from the UK, US, and Italy also gave their time to participate.

Michelle Hughes fundraising juggernaut keeps rolling in Canada

Michelle Hughes's 'My Journey to Just Live' platform launched its 2025 Fun Run campaign and is hoping to better the amazing C$108,000 they raised last year.

EHE Foundation hosts excellent Connect 360+ webinars

The EHE Foundation presented two excellent webinars: one on the use of sirolimus, led by Dr Silvia Stacchiotti, and one on the results of the clinical trial of Trametinib, led by Dr Scott M. Schuetze.

Australia funds cutting-edge microscopy research

The EHE-RCFA provided details of the EHE research it is funding with Professor Kieran Harvey at the University of Melbourne and Peter MacCallum Cancer Centre in Melbourne, and hopes to update the community on initial results in the next edition of The Pledge.

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

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01 Patient Support and Advocacy

Patient support and advocacy are key objectives of the EHE Group. In this section you will find updates on The EHE Group's activities in these key areas. Most of the patient support is provided through the established EHE social media platforms by patients themselves, while advocacy activities are also undertaken by the EHE Group entities in their respective regions. Regardless of the format, the EHE community continues to work to create greater awareness of EHE, improve support for the patients themselves, and achieve greater focus on the research we need to defeat this disease.

Happy 10th Birthday

The first three EHE foundations, in the US, UK, and Australia, were all established in 2015, so this year will see all three celebrating their 10th birthdays.

The first of the three to go live was The EHE Foundation. Jane Gutkovich, one of the driving forces behind the setting up of all three of these foundations, shared news of this milestone on 25 February:

THE EHE FOUNDATION 10 Celebrating Years of Progress

> Happy 10th anniversary to The EHE Foundation!! To celebrate I am sharing the announcement made by the first President of the Foundation, Heidi Tolton Chatterton. The EHE Foundation was born right here, in this group, by its members and it has been supported by this group in every step! It is absolutely astonishing what we have achieved in these 10 years! From the "black hole" EHE was 10 years ago with so little science behind it and no treatments to constantly expanding scientific and clinical research bringing a cure closer every day. Happy Birthday!!!”

Sadly, Heidi left us far too early, but she too was a powerhouse and arch communicator within the EHE community in those early days, along with Jane and Julie Rivers Wahl. Here is that first message shared by Heidi at the time, and mentioned by Jane in her birthday message above:

> Julie Rivers Wahl, Jane Gutkovich, and I have a big announcement!! We have officially created The EHE Foundation!! We have a fledgling corporation, a business license, and we have filed for official IRS 501c3 status to allow us to accept donations tax free for us and the donor. In the near future, we will be working to create our website to make fundraising efforts easier, to house the EHE patient database we are working on, and to provide information and support to patients, caregivers, family, and friends. We are growing our board to include a very diverse group as we want all with a desire to help to be able to join and participate. We are novice foundation creators and are learning as we go but we hope this will lend credibility to our efforts in contacting doctors, researchers, government officials. Once we get our website functional, we will post all group activities, funds raised and how spent, board meeting info, as well as the ability to donate via the website. We are so excited for our baby foundation and can't wait to watch it grow!!”

We have no doubt at all that Heidi is looking down today with great pride on the foundation she helped establish, “Way to go Team. Defeat that disease!” Happy Birthday to The EHE Foundation!

EHE represented at APOS25 in Sydney

Jonathan Granek, Founding Director and Chair of The EHE Rare Cancer Foundation Australia, and Zosia Golebiowski, mother of an EHE patient, both attended and represented the EHE patient community at the important Australian Precision Oncology Symposium (APOS25), hosted by Omico and held over two days in Sydney in early March.

Jonathan Granek explained:

> **APOS brings together around 370 doctors, researchers, scientists, industry experts and patient representatives—both in person and online—to focus on precision oncology. The event highlights the incredible commitment of so many people working together to improve cancer care. Their goal? To bring more targeted, personalised treatments to Australians facing cancer."**

Jonathan and Zosia at APOS25, both seen here with Prof David Thomas

Over the two days, experts explored the latest research, technologies, and treatment approaches, pushing the boundaries of cancer care to make it more precise, more effective, and more hopeful.

Jonathan added:

> **Events like this matter because they turn research into real impact for patients. APOS25 showcased how precision oncology is moving from theory to practice—helping more people get the right treatment at the right time."**

It is so good to see EHE represented at such a prestigious event, and here at The Pledge, it is hard to think of a more important objective than "helping more people get the right treatment at the right time". Thank you Jonathan and Zosia for being there for our community.

Research Roundtable: Advocacy in Action

In January, EHE advocacy leaders from EHE ITALIA Associazione Non Solo LAURA ODV, The EHE Rare Cancer Charity (UK), and The EHE Foundation (US), were pleased to be able to jointly host a meeting in Amsterdam, The Netherlands, with researchers and clinicians from Italy, the United Kingdom, and the United States 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. While much work remains, the EHE Group entities are deeply grateful to everyone who supports the group's mission through these invaluable collaborations..

Andrei Ivanescu, Denise Robinson and Hugh Leonard (L to R) hosted the EHE research roundtable

Ultra-Rare Pushes Forward at the EMA

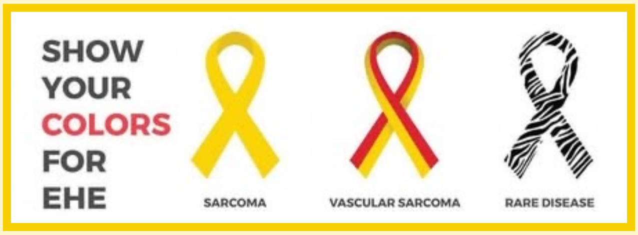
On 31 January, the day after the EHE research roundtable reported above, expert clinicians, researchers, and patient advocacy leaders met in Amsterdam with the European Medicines Agency (EMA) under the auspices of the European Organisation for Research and Treatment of Cancer (EORTC) to explore strategies to develop and obtain approval for new treatments for ultra-rare sarcomas as a model for ultra-rare tumors. 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. The EHE Group entities 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.

Ribbon colours shared

It is now commonly accepted that ribbon motifs denote different cancers, with different coloured ribbons denoting different types of cancer. Some are well recognised, but for ultra rare cancers, the question is often raised as to which colour denotes EHE?

There are in fact several different ribbons that could be used, as shown here. The EHE Group however has adopted the red and yellow ribbon that is associated with vascular sarcomas because EHE tumours form in the lining of blood vessels.

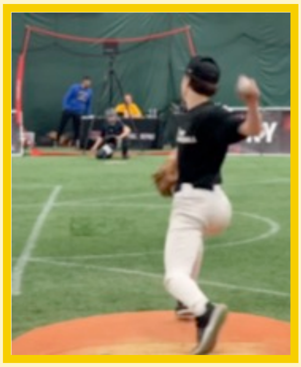


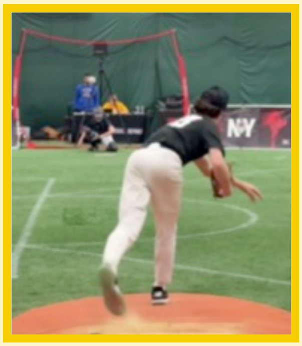
Colin Straub is 'Just Living'

Sasha Straub posted news of her son, Colin, who was diagnosed with EHE three years age:.

> Colin has played baseball since he was a t-baller. With college in sight, a couple weeks back he did his first pitching showcase! I thought I'd share, because he's never been afraid EHE would hold him back from the sports he loves. As a parent I have questioned the perception people have or will have knowing he has EHE. In 2023, he ran into some coaching that questioned his size and strength even though he's always been an efficient pitcher with great command of the mound. Happily, we knew we needed to make a coaching change and allow Colin the time to grow and develop at his pace with high school peers. As a young junior he showed poise and command and is where he needs to be to continue to grow unapologetically! He threw a top of 83 mph with his fast ball as a "slender" left-handed pitcher. I love that for him! Just Live!"

Colin's athletic talents extend beyond baseball. He's also recently qualified for state-level golf competition and will compete this spring. We wish him the best of luck and congratulate Colin on the progress he is making as a pitcher, and for living the "*Just Live*" motto of the EHE community. And we want to thank Sasha for sharing Colin's great story.





International Childhood Cancer Day

Saturday, 15 February, is International Childhood Cancer Day. This is an important day also for the EHE community because although the disease is very rarely seen in children, it sadly does occur. The EHE Foundation supported this special day with great imagery and a simple message to those in our community who might have been affected by EHE in children:

> **EHE in children and young adults is exceedingly rare, and we do not have evidence that the disease behaves differently in young people than in adults. Much more research is needed. What we do know, including treatment considerations, recommended providers, and reference material, is now available on our website: www.FightEHE.org/ehe-in-children ."**

Aimee Ladd also posted news of an event her son, Jasper, and his ice hockey team had been involved in to support childhood cancer awareness, as well as his sister, Veronica, as Aimee explained:

> **Jasper's team and the opposing team wrapped their hockey sticks in lavender for childhood cancer awareness and to support his sister Veronica Graves who was diagnosed at age 12 with EHE!"**

Jasper's team and their opponents can be seen below.

Thank you, Aimee, for sharing this fantastic photo, and thank you to all who support International Childhood Cancer Day.

ISG meets with Patients

The Italian Sarcoma Group (ISG), led by Dr Silvia Stacchiotti, is a scientific association with the goal of improving the research and treatment for patients diagnosed with sarcoma. ISG met with Patients and Family Members on the evening of 16 January under the theme of 'FOLLOW-UP' in a virtual meeting organized thanks to the support of Patient Associations that actively collaborate with ISG and who also participated in the event.

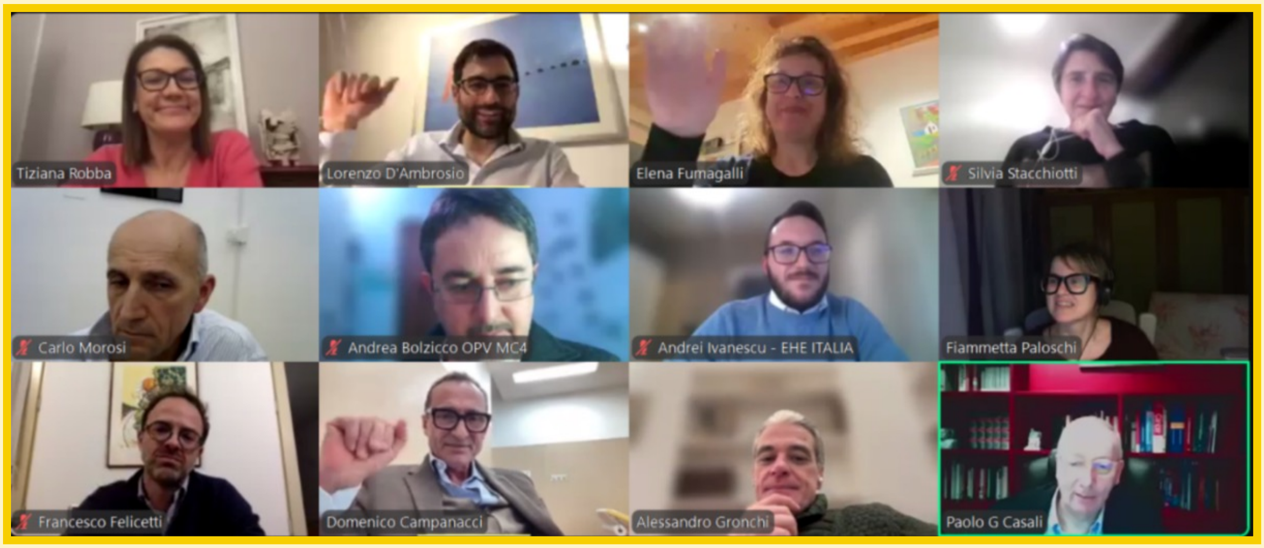
The following topics, involving different histologies (and thus including all sarcomas), were discussed::

- The purpose of 'follow-up' (Prof. Paolo Casali, National Cancer Institute, Milan, Italy)
- Guidelines on sarcomas and GISTs (Dr. Lorenzo D'Ambrosio, San Luigi Hospital, Orbassano)
- Choice of follow-up examinations (Dr. Tiziana Robba, Orthopedic Trauma Center, Turin, Italy)
- Survivorship (Dr. Francesco Felicetti, Molinette Hospital, Turin, Italy).

Andrei Ivanescu explained:

> **During the event, participants had the pleasure of hearing speeches from distinguished physicians such as Dr. Stacchiotti, Prof. Casali, Dr. D'Ambrosio, Dr. Robba and Dr. Felicetti, as well as other experts who participated in the discussion. We would like to sincerely thank all the patients in the EHE group who actively participated. For those who could not be present, we invite you to watch the video, as it was really interesting and full of valuable information, thanks also to the answers to the questions posed by the Patient Association representatives."**

The video can be accessed using this link: https://www.youtube.com/watch?v=pHituWaaf4E&t=1s



A special person remembered

There is nothing sadder for the EHE community than when somebody posts the tragic news that a loved one has passed. The sadness and loss will be overpowering for those who knew and loved them, yet over time, while the loss is never forgotten, we hope that the sadness will be tempered by the treasured memories that EHE can never take away.

We were moved, therefore, by Jillian Harrington sharing her story about events involving her wonderful father, which had provided her with more great shared memories of him. Jillian explained:

> “Hi friends. My late father, Richard Harrington's lovely wife recommended last Father's Day that my siblings and I gift him a journal subscription. I consider it now to be one of the greatest gifts anyone has ever given me. The subscription emails the writer a question prompt about their life over the course of a year. My dad unfortunately didn't make it through the year but we are lucky enough that he was able to complete as many prompts as he did. I wrote his obituary using stories from his subscription. I feel like I got to know my dad better. He and I were very close. I would recommend it to anyone, and especially anyone who is suffering with EHE. The subscription we used was Storyworth, but I'm sure there are many others.”

We think this is a really tremendous idea. It actually struck us that this would be a great thing for anybody to do with elderly parents, regardless of whether they are diagnosed with a life-threatening disease or not. Thank you so much, Jillian, for sharing this wonderful idea and reminding us all of your wonderful father. He certainly embodied our *Just Live* motto.

National Days Celebrated

The EHE Foundation in the US always supports national days of celebration that are important to the EHE community. This quarter saw two such days, National Caregivers Day and National Doctors Day, both celebrating key members of our communities.

Maggie Cameron, Director of Development and Communications at The EHE Foundation, explained:

> “On this National Caregivers Day, we extend our gratitude to the amazing caregivers in the EHE community! Your selflessness, compassion, and dedication make a world of difference in the lives of people living with EHE. Thank you for your tireless efforts and unwavering commitment to providing comfort and support each day.”

Denise Robinson, Executive Director and Director of Research at The EHE Foundation, wanted to recognise the extraordinary contribution made by doctors::

> **National Doctors' Day is a time to recognize and celebrate physicians who dedicate their lives to healing and saving others. The EHE Foundation extends our deepest gratitude to the EHE doctors around the world who are advancing our understanding of this rare disease and providing compassionate, expert care to those living with EHE. We are especially thankful for the members of our Scientific and Medical Advisory Board, whose time, dedication, and guidance continue to shape the future of EHE research and treatment."**

These heartfelt messages of thanks and support were also shared by the global EHE Group, comprising EHE foundations in Canada, Australia, Italy, and the UK, and of course the global EHE patient community, wherever they live.

We at The Pledge want to add our support and heartfelt thanks to Caregivers and Doctors everywhere. It is impossible to overstate the importance and value of your contribution to our patient community. Thank you!

EHE Italia's 2025 membership campaign

EHE Italia's 2025 membership campaign launched with a summary of key achievements and significant milestones from 2024, which included:

- The donation of €17,000 to the Italian Sarcoma Group (ISG), contributing to research on Epithelioid Haemangioendothelioma (EHE);
- The organization of numerous medical and fundraising events, which involved the community and raised awareness of our cause;
- The ongoing support of patients and caregivers through dedicated meetings and activities.
- The raising of more than 50,000€ to fund new projects for EHE, for which there will be more news soon.

Andrei Ivanescu added:

> **These achievements were only possible thanks to your generosity. To continue to make a difference, we need your support in**

2025. Becoming a member means joining a community of people committed to improving the lives of those affected by EHE and promoting research to find new treatments. The membership fee is €20, with people able to become new members using either of the following two procedures*:

1. Fill out the online form found on our website at www.ehe-italia.it/diventa-socio; or
2. Download and fill out the paper form found on our website at www.ehe-italia.it/diventa-socio and send it to info@ehe-italia.it"

*Note that for those who were members in 2024, the forms do not need to be completed. Only payment of the membership fee is required.

Payment can be made directly from the EHE Italia website using the following link: https://www.ehe-italia.it//_paylink/AZQPBgpC, including the reference '**For 2025 membership**'.

Bank details can also be provided by the Association and can be obtained by contacting the Association at *info@ehe-italia.it*

The Association wants to thank everybody who does join for their wonderful support which is so important.

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 effecting 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, but at The Pledge, 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!

Unity Makes Strength!

During the first quarter, Andrei Ivanescu from EHE Italia-Non Solo Laura ODV had the pleasure of meeting with Fiammetta, representative of the Italian GIST Foundation and contact person of the Italian Sarcoma Group working party of patient associations dealing with sarcomas.

Andrei commented:

> “It was an important opportunity to talk about the projects currently underway, analysing the progress and results achieved so far. Collaborating all together allows us to join forces and expertise, creating a greater and more meaningful impact. The evening was not only a demonstration of support and determination, but also an opportunity to strengthen the bond between the associations. We are full of hope and motivation for the next initiatives!”

A coffee shared with fellow patients

With a disease as rare as EHE, the likelihood of having a fellow EHE patient living within 10 miles of you is very low. The likelihood of having two is infinitesimal. Yet that is exactly what has happened to Jenni Kovach, President of The EHE Foundation. And when that happens, a patient get-together, something that we always celebrate, becomes a lot easier.

Jenni was delighted to post news of such a meeting:

> **“Unbelievable! Coffee this morning with three EHE patients who all live within 10 miles of each other. Hadden, on my left, was diagnosed with EHE in 1990 and had a liver transplant. Dave, on my right, was diagnosed this past October. It was amazing to get to know these two!”**

Thank you Jenni, Dave and Hadden! We love news about EHE patients getting together.

Benefit Performance: I Barroccini di Via dell'Ariento

VENERDI 21 MARZO 2025

ORE 21:30

BARBERINO TAVARNELLE

I RAMPANTI

Compagnia di Prosa e Canto

TORNANO AL CIRCOLO LA RAMPA CON

I BARROCCINI DI VIA DELL'ARIENTO

Con:

Antonio Mulas, Franco Castrucci, Paola Canocchi, Anzio Giannetti, Laura Lombardini, Monica Gheri, Franca Rossetti, Claudia Ceccherini, David Baroncelli, Paola Lazzeri, Andrea Massetani, Gianni Bucciarelli, Giuseppina Brogi, Alessandra Corti, Maria Cristina Galletti, Alessandro Mori

Regia di Sergio Berti

SERATA DI BENEFICENZA A FAVORE DI

EHE ITALIA

ASSOCIAZIONE NON SOLO LAURA ODV

ASSOCIAZIONE CHE SI OCCUPA DI
L'EMANGIOENDOTELIOMA EPITELIOIDE (EHE)
UN SARCOMA VASCOLARE ULTRA-RARO

The weekend of 21 March provided the EHE Italian community with some very special moments in Tavarnelle Val di Pesa, where the charity play, promoted with great enthusiasm by our wonderful associate Paola, was held.

Caterina Colaci from EHE Italia-Non Solo Laura said:

> Thanks to Paola's efforts and collaboration with the I Rampanti Company, we witnessed a unique show: hilarious and engaging, capable of making us laugh and, at the same time, touching the deepest chords of our emotions. During the evening, Andrei Ivanescu, had the honor of introducing the association to everyone present."

Caterina Colaci continued:

> In addition, we organized a small meal with little items and informational materials to let people know about our mission and projects. Special thanks also go to Anna, the president of Circolo La Rampa in Tavarnelle, for her valuable support and for making this wonderful initiative possible."

> We would also like to express our deep gratitude to Dr. Giacomo Giulio Baldi and Dr. Serena Bazzurri, who joined us from Prato to participate in this event and share these wonderful moments with us. Their presence was very important to all of us."

Both Andrei and Caterina agreed:

> It was wonderful to share these moments, to be together, if only for a while, and to feel the warmth of a community united by a common purpose. These moments remind us of the importance of networking and cultivating human connection, elements that are fundamental to our journey.
>
> In addition to the wonderful production, fantastic time spent with so many special people, and the inspirational support we received, we also want to say a thank you to all those who helped us raise an impressive €1374, funds that will all go to driving EHE Italia projects. This achievement is proof that great things can be done together."

Andrei and Caterina wanted to thank everybody who had helped make the weekend so special:

> We want to say a huge THANK YOU to Circolo La Rampa in Tavarnelle, Val di Pesa and the theatre group I Rampanti for their extraordinary support! Also, a huge thank you to all who attended the charity play they organized. This special evening was made possible thanks to the great efforts of Paola and the invaluable support of Anna,

President of the Circolo La Rampa in Tavarnelle. The association is dedicated to three basic goals: providing support to Patients, supporting research, and promoting fundraising initiatives to improve the future of those in need. Thank you for sharing with us this extraordinary opportunity for solidarity. We think this whole weekend personifies our EHE Group moto: **Alone we are RARE, TOGETHER we are STRONG!"**

Patients coming together

While the wonderful weekend in Tavarnelle was coordinated around Paola's spectacular production, it also provided a wonderful opportunity for some of the Italian EHE patient community to get together, which is always special, as Andrei explained:

> "
>
> After a long time, we were able to get together with some other associates during the theatre weekend in Tavarnelle. It was so special for Caterina and me to have the chance to meet Paola, Nicoletta and Noemi, and share a weekend full of pleasant and meaningful moments. Our Patients' Association is also this: spending time together in light heartedness, listening to each other's stories and giving each other support and a few laughs. We hope to see even more of us on future occasions, to continue to strengthen our ties and share such precious moments."

EHE 360 Global Patient Conference is on the horizon

One of the biggest events in the EHE global calendar is the EHE 360 Global Patient Conference, planned and presented by The EHE Foundation early in the year. The 2025 EHE 360 event was scheduled for the 10 and 11 of April, as explained by The Foundation:

> **“The 2025 EHE 360 Global Patient Conference is April 10th-11th, where global expert clinicians and scientists will share the latest news about EHE research and clinical care. Don't miss this important opportunity to inform your EHE journey.”**

The EHE Foundation were also pleased to be able to announce that the conference would include a keynote presentation by Professor Brian Rubin from the Cleveland Clinic, and one of the world’s leading EHE experts:

> **“Brian Rubin, MD, PhD, from the Cleveland Clinic, will give the keynote address, "Reflection on 10 Years of Discovery & Future Perspectives." His presentation will trace EHE research progress from its beginnings to the goals scientists have for its future. Dr. Rubin is a long-time EHE Champion whose work is foundational to understanding the disease.”**

In past years, feedback from participants has repeatedly identified the ‘Ask the Experts’ Q&A session as a highlight of the conference. The Foundation were pleased, therefore, to confirm that the 2025 conference would close with the same format, with another expert panel answering questions posed through the conference platform’s Q&A function:

> **“Once again, we are excited to facilitate the "Ask the Expert" panel discussion, where leading medical experts answer your questions about #EHE. We encourage you to submit questions that could be helpful to our community. The panel cannot answer questions about an individual patient's diagnosis or treatment.”**

02 Research

This section of The Pledge includes information relating to EHE research and our understanding of the disease. Much of this work is supported by our global patient community and funded by the EHE Group entities. It is this research that will ultimately help the EHE Group find new ways to treat and manage EHE. We also include information and updates on clinical treatment and advances in disease management. We hope you will be inspired by the work taking place and the dedication and skill of the researchers and clinicians that are delivering it. Together with our patient community, the researchers and clinicians are at the heart of everything we do.

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

2024 was the first year of a two-year research project 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. The project was proposed to, approved, and funded by the EHE Rare Cancer Foundation Australia (EHE-RCFA).

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, 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 components which 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, including poromas and meningiomas.

Prof Kieran Harvey

Jonathan Granek, Founding Director and Chairperson of the EHE-RCFA, explained:

> **“Given that both YAP-TFE3 and TAZ-CAMTA1 also form a physical interaction with TEADs, and this is important for their tumour-promoting ability, TEAD inhibitors have the potential to be the first effective medical oncology therapies for EHE. It is because of the involvement of YAP/TAZ and TEAD-binding in EHE that the recent ongoing development of TEAD inhibitors is so important for EHE patients.**
>
> **While the development is ongoing, however, there is still a lot we don’t know about EHE biology and that is why Professor Harvey’s research proposal was so interesting.”**

Multiple companies and academic groups have reported the identification of TEAD inhibitors. There are two main types of TEAD inhibitors, both of which bind to the TEAD proteins and are predicted to prevent the EHE fusion proteins from binding to TEADs, and thus block their ability to influence transcription in the EHE cells. These compounds have reported potent anti-proliferation properties in cancer cell lines that harbour Hippo pathway mutations, as well as cell lines and patient-derived tumour xenografts grown in mice. These include Hippo pathway mutant cancers such as mesothelioma, cancers with NF2 mutations, and in some cases, cancers with YAP or TAZ fusion genes, including EHE.

Jonathan Granek continued:

> **“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 understand how EHE oncoproteins induce and sustain cancer, and how we can target them for therapeutic benefit.”**

The key objectives of Professor Harvey’s research are listed below:

Year 1:

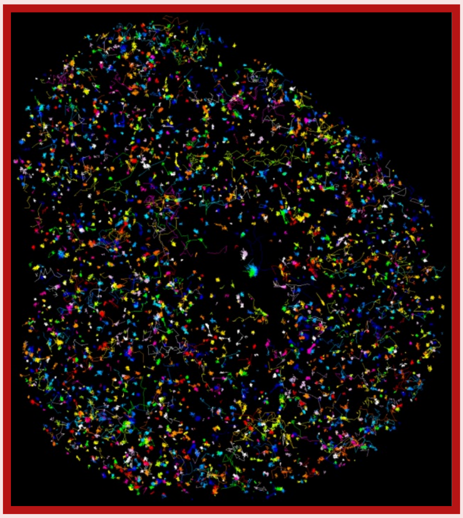
1. To analyse key proteins (TEAD1; YAP; TAZ, TFE3; CAMTA1; YAP-TFE3; and TAZ-CAMTA1) in non-tumorigenic epithelial (MCF10A) cells using HiLo microscopy (a system which is established and currently working) in the presence and absence of different types of TEAD inhibitors.

2. To analyse any unexpected variants in behaviour observed in MCF10A cells in an additional cell line, e.g., an endothelial cell line such as HUVECs.

Year 2 (subject to variation and funding approval):

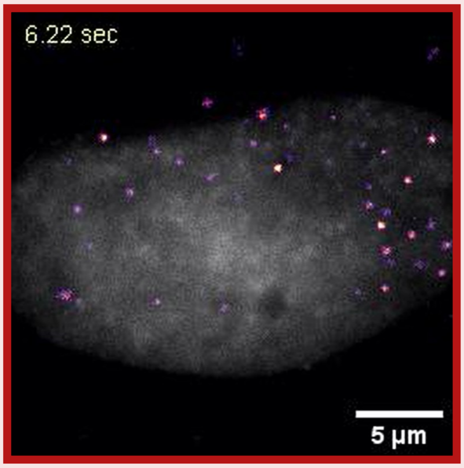
1. To analyse the proteins listed above in MCF10A cells using Fluorescence fluctuation microscopy in the presence and absence of different TEAD inhibitors.
2. To analyse the proteins listed above using HiLo microscopy and Fluorescence fluctuation microscopy in the presence and absence of a MEK inhibitor, as well as a combination of MEK inhibitor and TEAD inhibitor.
3. If a human EHE cell line(s) becomes available, to analyse YAP/TAZ cancer fusion protein behaviours in it.
4. To determine the impact of different TEAD inhibitors and a MEK inhibitor (alone and in combination) on YAP-TFE3, TAZ-CAMPTA1 and TEADs.

At the core of the project is a completely different approach to gain new insights into EHE biology and treatment which utilises a powerful combination of high-resolution microscopy and computational methodologies. The research team will 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.



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), whilst others are moving through the nucleus (lines)

They will also assess the impact of different drugs on these proteins. The approaches they will use have never been used to study EHE proteins.



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)

Jonathan Granek concluded:

> **“We have a lot of excellent EHE research taking place around the globe, looking into drug screening, biomarkers and other aspects of EHE biology, and establishing large scale EHE registries and observation studies. However, the work proposed by Professor Harvey is genuinely cutting-edge, with the ability to potentially show how different proteins and fusion proteins are physically moving within EHE cells and interacting with cell biology, which in turn could open up whole new areas of understanding about how EHE works with associated therapeutic possibilities. For these reasons we felt it was research we should fund. We look forward to sharing preliminary results in the near future.”**

Sirolimus for EHE explained

Many of our global EHE community are aware that with a limited set of data, a drug called sirolimus has produced positive results for patients with progressive disease, stabilising their EHE, in some cases for several years. However, sirolimus is not appropriate for all people with progressive EHE, and it is not an easy drug. The rate of uptake into a patient’s bloodstream varies individually and is affected by a wide range of dietary and other factors. One of the world’s leading authorities on the use of sirolimus for the treatment of EHE is Dr. Silvia Stacchiotti from Istituto Nazionale dei Tumori (INT) in Milan, Italy. Dr. Stacchiotti has led pioneering work on the use of sirolimus over the past decade, with the INT team publishing several important papers highlighting the effectiveness of the drug. These publications contributed to the experts’ consensus on the management of EHE, which describes sirolimus as the leading known agent effective in progressive EHE. The EHE Foundation were therefore thrilled when Dr. Stacchiotti accepted the Foundation’s invitation to participate in a global patient webinar to talk about sirolimus and share important information with the EHE community.

The webinar, held in late January, was well attended and hugely successful. The EHE Foundation explained:

> **Dr. Silvia Stacchiotti highlighted the limited data currently available on the use of sirolimus to treat EHE as compared to other systemic therapies. She also answered questions about therapeutic levels, dosage, food and drug interactions, side effects, and more."**

There was unanimous agreement amongst those who attended that this was a very important presentation, with the following Q&A session particularly informative.

Under Dr. Stacchiotti's leadership, a long-term observational study of EHE patients, including those treated with sirolimus is underway, with funding contributed by The EHE Foundation and The EHE Rare Cancer Charity (UK). Data from this study will be invaluable to inform clinical practice and treatment of EHE patients. We look forward to sharing findings from this research in the future.

The EHE Group and the entire EHE community could not be more grateful to Dr. Stacchiotti for so generously giving her time to provide patients with the data and experience learned from clinical practice regarding sirolimus. The Pledge also wants to join in thanking Dr. Stacchiotti, and indeed her whole team at INT, for all that they do to help improve our understanding of the disease and deliver better treatment options.

The webinar was recorded as not all patients could attend on the day, and can be viewed through The EHE Foundation website using the link below:

https://youtu.be/azDB-qAyA6Y

Trametinib trial findings explained

In mid-February, The EHE Foundation was delighted to welcome Dr. Scott M. Schuetze to their EHE 360 Connect program.:

> **Dr. Scott M. Schuetze, University of Michigan, Rogel Cancer Center, will provide an overview of the rationale for treatment of EHE with trametinib, an oral inhibitor of the MEK kinase; the trial design of 10015/SARC033; and the results of the primary and secondary study endpoints. The presentation will also include an update on exploratory investigation of blood-based biomarkers including hemoglobin, C-reactive protein, and connective tissue growth factor as prognostic and predictive factors in the patients with EHE who participated in the clinical trial. There will also be a Q&A session to follow where patients can submit questions."**

In addition to the trial itself, Jane Gutkovich wanted to share a positive aspect about the trial relating to the challenge of recruiting meaningful numbers of patients with such a rare disease:

> **When Dr. Brian Rubin proposed this clinical trial to confirm the results of his research at the Cleveland Clinic, the proposal was met with a lot of scepticism as no one really believed that it would be possible to enrol enough patients with such a rare cancer. No one, except us ...this very group. We voiced our support for the trial and demonstrated our commitment to help with recruitment. Eventually, the trial was approved with the condition of enrolling at least 13 EHE patients.**

> By spreading the word, by talking about Dr. Rubin's work, by sharing information about first experiences we helped to ultimately enrol more than 40 patients into the trial! This made quite ‘a splash’ in the sarcoma community.”

Results of a Phase 2 Trial of Trametinib in Advanced EHE

Scott M. Schuetze, MD, PhD
University of Michigan,
Rogel Cancer Center

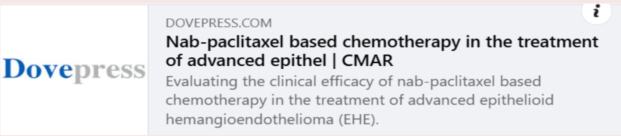
EHE 360 connect+
EDUCATIONAL WEBINAR

PRESENTED BY THE EHE FOUNDATION

Those attending found Dr. Schuetze’s presentation to be very informative, providing valuable insight not only to the drug and the trial results, but also to the clinical trial process. The presentation was recorded for those who could not attend the recording and can be viewed on The EHE Foundation website at the link below:.

https://fightehe.org/ehe-360-connect/results-of-a-phase-2-trial-of-trametinib-in-advanced-ehe/

Interesting nab-paclitaxel results from China



DOVEPRESS.COM
Nab-paclitaxel based chemotherapy in the treatment of advanced epithel | CMAR
Evaluating the clinical efficacy of nab-paclitaxel based chemotherapy in the treatment of advanced epithelioid hemangioendothelioma (EHE).

Jane Gutkovich posted news of a new study published from China involving patients with aggressive EHE:

> Attention patients with aggressive EHE! A new study just came out of China demonstrating favourable outcomes in some patients with aggressive EHE using nab-paclitaxel based chemotherapy therapy (a newer form of paclitaxel, the well-known chemo drug). The study looked at two combination treatments, one with nab-paclitaxel and bevacizumab, and another with nab-paclitaxel and sirolimus. Neither combination showed 100% response, but it seems that in this particular, very hard to treat type of EHE, the results are better than in previously reported studies.”

Denise Robinson, Director of Research of The EHE Foundation commented:

> This study concluded that nab-paclitaxel based chemotherapy may offer an effective treatment option for patients with advanced EHE who have adverse prognostic factors such as rapid tumor progression, severe tumor-related symptoms such as pain, fever, and shortness of breath, or serosal effusion. However, it is important to highlight that further studies are needed to determine whether the observed treatment effects are primarily due to nab-paclitaxel or the result of its combination with sirolimus or bevacizumab.”

This publication can be found in the EHE Library and using this link:

https://www.dovepress.com/nab-paclitaxel-based-chemotherapy-in-the-treatment-of-advanced-epithel

03 Fundraising

Fundraising is so critical for ultra-rare diseases. Without it, our other activities could not progress. That is why we are so grateful for the amazing effort, organisation and generosity of so many people, which has enabled us to raise the funds we need to drive EHE research. Here are highlights of some of the fundraising undertaken by our supporters. Whether you are a fundraiser, a donor, or a supporter, we want you to know that we are deeply grateful for all you have done.

Arelene Sutton's Birthday Garden Party

Arlene Sutton lives in Australia and wanted to celebrate her birthday while supporting the EHE Rare Cancer Foundation Australia (EHE RCFA) and honouring her friend Rebecca Sherman. Arlene achieved both goals by generously holding a fantastic EHE Garden Party.

Everybody agreed that it was a very special event, combining great company, great weather, great food and a spectacular garden that came alive at night with its wonderful glass sculptures and brilliant lighting.

Jonathan Granek, Chairperson of the EHE-RCFA, confirmed that 100% of the amazing $2,265.78 raised by Arlene's event had been earmarked to help advance frontline research and achieve transformational breakthroughs for those affected by Epithelioid Hemangioendothelioma (EHE) – including cutting-edge research being undertaken by world-renowned researcher, Professor Kieran Harvey, at the Peter MacCallum Cancer Centre, Parkville, Victoria. Jonathan Granek wanted to thank Arlene for hosting such a special event:

> **“On behalf of the EHE Rare Cancer Foundation Australia, we would like to both congratulate and thank you for hosting such a successful fundraising event on the occasion of your birthday and in honour of your friend. We think Rebecca would have been very pleased and proud of what you achieved.”**

The Pledge agrees Jonathan. What a great event, and we love the coloured glass sculptures too. Awesome. Thank you, Arelene for your great support.

Just Live Fun Run preparations underway

Michelle Lynn posted news this quarter about her 3rd Annual Just Live Fun Run that will take place on Prince Edward Island in Canada on 24 August. Michelle explained:

> **Hey Everyone! We are gearing up for our Just Live Fun Run this August 24th here in PEI, Canada. Last year we had thousands come together to raise $108,000 thanks to the Sarcoma Foundation of Canada matching each donation. We offer in-person and virtual sub-events, and we can even send you event race kits if you want to "host" your own run. We provide shirts, medals, bibs, etc. Registration doesn't open until next week and I'll post the link then, but I'm coming to you with a big ask instead of just talking about registration!"**

This year Michelle wants to do something different, broadening the scope and focus of the event:

> **This year I want to make this event about all of you! I would love if you'd be open to sharing a photo, AND a 1 minute video we can use to educate others about the different faces of EHE around the world. You can submit yourself, or your beloved (if they have passed away). We are open to all EHE members, past or present."**

Michelle has two plans for this content. The first is to create social media content (reels/posts) using these videos and photos under her event's 'EHE Champions' highlight. Secondly, Michelle wants to line the race route with these photos so the people participating remember who they are raising funds for. Michelle went on:

> **If any of you are open to participating, then please submit a photo & a 1-minute video telling us:**
>
> - **a little about yourself;**
> - **when you were diagnosed with EHE;**
> - **what the fundraising dollars from this event mean to you; and**
> - **submit your video by email to the wonderful Brittany at justlivesocials@gmail.com , but if for any reason you feel more comfortable, send it to me at Michelle@myjourneytojustlive.com .**
>
> **Your story could motivate runners, donors, and supporters to make a difference in the fight against EHE! Let's do this, together!!!"**

Michelle is setting a HUGE GOAL this year for the event. All proceeds will go to the PRO CARE EHE Research Team at the Princess Margaret Cancer Centre in Toronto, Ontario, which is wonderful. Here at The Pledge, we want to support Michelle and her '*Just Live*' team as much as possible, and so encourage all EHE patients, wherever you live, to join the event and provide these photos and videos.

Running shirt being updated

Michelle Lynn, based in Prince Edward Island in Canada, has possibly the best EHE running gear anywhere in the world. Michelle explained the back story:

> **“One of our members had a wonderful shirt made for the marathon she was running which carried on the back of it many names of fellow EHE patients. I loved the idea, and did the same, for my race shirt when I was featured in my first documentary. I then did an update last year, as we filmed our second documentary for my half distance triathlon.”**

Michelle posted an image of all the names she previously included, as well as a graphic of her amazing 2024 tri-suit created by Betty Designs.

> **“Hey EHE Community, I have another big favour to ask. We are filming another documentary this year for a Hyrox competition in New York. Puma is partnering with us and making custom gear, and I’d love to add your names again, so I want to update the names of our EHE community members who'd like to be included on my newest race shirt. It is a gift I can do what I do with my body, and carrying you all along with me, is the beautiful reminder I need on my race days.”**

We love this story, Michelle, and we love that you carry so many of your fellow EHE patients with you as you take on these amazing challenges. Everybody at The Pledge sends you their very best wishes for all that you are taking on in 2025.

STAGE 4 INCURABLE CANCER THRIVER

I CAN so I WILL

I RUN FOR ME FOR THEM

Lisa De Young
Tennille Steinbrock
Diana Axness
Douglas Duckworth
Jeff Leighton
Leah Heinrich
Jack Hurley
Robert Liddell
Marcey Flood
Zebrina Lauridsen
Marta Iglesias
Tammy D
Jane Biddlecombe
Gabriella Corral
Janet Matthys
Mariana Coutinho
George M Page
Georgiana Trandafir
Jon Oogjen
Rav De Castro
Adina Biro
Charleen Dardinski
Penelope Foster
Graham Haber
Nicola Henderson
Tonja Pektas
Carl Dickson
Otto Schönebaum
Tracy Bomback Grunewald
Lisa Sendukas
Shari Walker
Amelie Bemard
Emilia Tzunum
Hannah Kiner
Malcolm Barrah
David Poulin
Veronica Flores
Steve Campbell
Paul Dean

Melissa McPherson
Cameron Voly
Steven Lal
Dana Levanto
Delaney Wahl
Amanda Holland
John Lamb
Lily Dickens
Dawn Scott-Benson
Shelley Thomas
Tara Watson
Mia Newman
Kimberly Young
Lynne Gentle
Fiona Ross
Catherine Olsen
Bec Sherman
Justin Herald
Terry Neugeboren
Carol Spence
Adrianna Graca
Colton Williford
Gabriella Corral
Olga Deriabina
Natalia Antonova
Debra Taylor
Kathryn DeJean
Howard
Susan Dick
Shannon Estrem
Randee Peled
Reid Zupanc
Kathy Field
Stacey Stefan
Amanda Roach
Richard Mason
Theresa Marion
Heidi Littlefield

Andrea Bresnick
Debraoh M LeJeune
Linda MacDonald
Timothy Webb
Jillian Aylott
Karen Workenaour
Ronda Johnson
Kyle Reitz
Sarah Welock
Mia Newman
Keren Stern
Amy Baghdadi
Rebecca Zekants
Stanley Jeynes
Lindsey Williams
Isabelle Miller
Ralph
Alicia Ann Thomason
Megan Buntin
Nadine Nicely
Maria Kirsten
Brian Frank
Tiffani Dial
Tracy Hoefling
Sandrine Cadot
Michelle Hughes
Barbara O'Connor
Cara Ryan
Caroline Flamand
Jan Courtoreille
Denise Zufelt
Jason Park
Kim Alexander-Bird
Jennifer Ness
Michaela Walker
Mona Turley
Justin Darragh
Ashley Quehe

Neil Toering
Mary Ann Jamgochian
Alison Hughes
Claudia Pereira
Paula Mason
Mimi Irene Gonzales
John Tirabassi
Alan Wood
Joseph Sassone
Thomas Gagliardi
Barbara Vance
Nancy Woods
Veronika Drsková
Christine Church
Natalie Pizzimenti
Nancy Ellis Woods
Cindy Donitzen
Amelie Flecken
Linda Lewis
David Andrew Lence
Malda Sherikeh
Aliviah Keeris
Debbie Kinsey
Rionna Jones
Natalie Pearce
Nikki Walters-Penrose
Lisa Smith
Jacob Latch
Shane Hennessee
Tim Peer
Bruce Niermeyer
Christina Robb
Gert du Plessis
Graeme Norwood
Francois Levesque
Jim Greubel
Harry Medwin
Jennifer San
Allana Parker

I CAN.
I WILL.

CANADIAN
EHE
RESEARCH

@MYJOURNEYTOJUSTLIVE

Amazing support from Team 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 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 fund-raising campaign. We reported several of these in the last edition of The Pledge. Below is a summary of the wonderful events they held in the first quarter of 2025, all of which have added to their amazing fundraising total for EHE research which is now over £23,000.

Riotous race night at the Rafa!

On the 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 £1500 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!"

And here at The Pledge we also want to send a huge thank you to Daryl and Elaine for organising such a great event, and for all those who supported it.

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:

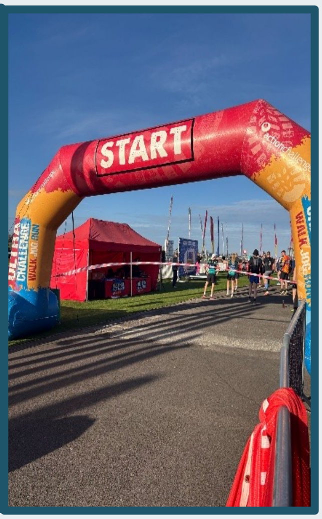
> “My sister Kym gave me the idea to do something for charity and she herself is running a half marathon to raise money to go towards further research into EHE not only to help Emma but to help anybody else who may suffer in the future. I couldn't ask people to sponsor me to run a half marathon or even a full marathon as I didn't think it was right for me to do so. But after swearing never to do another marathon again I decided I needed to go one further and do a 50km marathon next year. Yes, I'm a fit person but this will be a big challenge for me and all for an extremely good cause. Please donate as much or as little as you can so Emma and others who have this rare disease can benefit.”

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

> “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)”

Ben has so far raised a staggering £6,430 for EHE research, and to support Emma. What a fantastic birthday present! Thank you Ben for your brilliant support, and we hope you had a great birthday.

We also want to thank Kym and everybody in Team Emma for their brilliant and ongoing support. Their fundraising page has now reached a staggering **£23,387**, and they have more events planned!



Thanks, INARCA

Andrei Ivanescu, on behalf of everybody at, and represented by, EHE Italia-Non Solo Laura ODV wanted to express his sincere and heartfelt thanks to Nicoletta Piovesan and Inarca SpA, a leading company in the design and development of electrical terminals and connectors:

> “We are so grateful to Nicoletta and Inarca SpA, for choosing to support our cause with their wonderfully generous donation of €1500. Their support represents a significant contribution that allows us to continue carrying out initiatives dedicated to our patients and the community.
> This collaboration, initially born in a professional context, has become a valuable opportunity to share the activities and projects that our Association is diligently pursuing. Receiving such substantial support is a wonderful act of support but also provides a powerful message of hope for all those who face complex challenges daily. Thank you from the bottom of our hearts for your compassion and generosity: gestures like this truly make a difference and motivate us to keep working for the wellbeing of our patients and a better future.”

The Pledge wants to whole-heartedly endorse Andrei’s comments and of course pass on our “thank you” too to Nicoletta and everybody at Inarca!

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 on 28 February, the lovely Gill, was also thrilled:

> **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. The Tropic fundraiser stands at £935 but people can still donate. I'll be topping up Emma's well-deserved Tropic pamper bundle with extra goodies ... the more donations we get this weekend, the more I'll add to Emma's pamper."**

As part of this event there was a raffle that was open to everyone, with amazing Tropics products up for grabs. These included: £100 Tropic Voucher; a Discovery Skincare bundle worth £34; a Luxury leather 'Tropic exclusive' toiletry bag; and a Tropic Exclusive Stanley cup. To add something really special, Emma drew the winners LIVE on Facebook during the event!

Thank you Gill for this wonderful evening. We know that everybody there had a brilliant time and did indeed come away feeling very pampered. Awesome

Days of international recognition celebrated

Every year, there is a wide range of internationally recognised days dedicated to different causes, and the EHE Group likes to support and recognise those that relate to the EHE patient community. Two such days, occurring in February, were celebrated by EHE Italia-Non Solo Laura ODV, and used to drive their latest fundraising campaign.

World Cancer Day

La lotta contro il cancro richiede un impegno costante e coordinato a livello globale e l'Associazione EHE Italia si impegna a fare la propria parte per aiutare a raggiungere questo obiettivo.

The fight against cancer is a challenge that requires a continuous and shared global effort. The Associazione EHE ITALIA Non Solo Laura ODV is deeply dedicated to helping to achieve this goal.

> **If you would like to support us, you can participate in our February fundraiser. This collection starts today, on World Cancer Day, 4 February, and will end on 28 February, on World Rare Disease Day. Every small gesture makes a difference, and your support will allow us to keep making progress against this disease"**

World Rare Disease Day

World Rare Disease Day is celebrated on 28 February each year to raise public and institutional awareness of the challenges faced by, and to give a voice to, an estimated 300 million people worldwide who suffer from rare diseases, defined as conditions that affect less than one in 2,000 people, and who face many challenges. EHE Italia explained:

> **Let's join hands and hearts to spread awareness, empathy and support. Every story is unique, but together we can make a difference. We share knowledge, embrace diversity, and work together for a future where no one has to face the struggle alone. The Associazione EHE ITALIA Non Solo Laura ODV, fights every day to raise awareness and shine a light on the ultra-rare cancer called Epithelioid Haemangioendothelioma."**

Thank you to our amazing supporters!

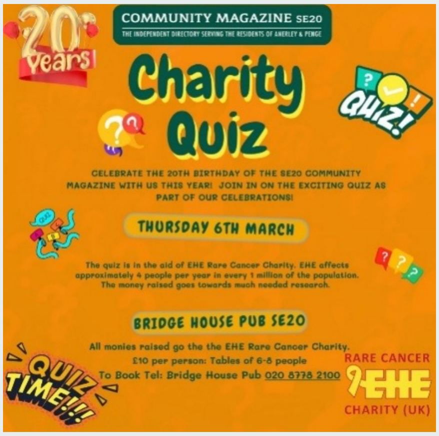
And the Italian EHE community did indeed support their cause, as Andrei Ivanescu explained:

> **We are overjoyed to announce that, thanks to your incredible generosity, we were able to raise €1200 during our February fundraising campaign. We set a goal of 1000€, and you have exceeded all expectations! Your critical contributions continue to support our mission and our ability to implement new projects that will make a difference. Thank you all so much for your continued support and for believing in EHE ITALIA."**

Here at The Pledge, we want to also add our thanks and congratulations to EHE Italia Non Solo Laura ODV and the whole Italian EHE community for another great campaign.

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.



COMMUNITY MAGAZINE SE20

THE INDEPENDENT DIRECTORY SERVING THE RESIDENTS OF ANERLEY & PENGE

Charity Quiz

CELEBRATE THE 20TH BIRTHDAY OF THE SE20 COMMUNITY MAGAZINE WITH US THIS YEAR! JOIN IN ON THE EXCITING QUIZ AS PART OF OUR CELEBRATIONS!

THURSDAY 6TH MARCH

The quiz is in the aid of EHE Rare Cancer Charity. EHE affects approximately 4 people per year in every 1 million of the population. The money raised goes towards much needed research.

BRIDGE HOUSE PUB SE20

All monies raised go the the EHE Rare Cancer Charity.
£10 per person: Tables of 6-8 people
To Book Tel: Bridge House Pub 020 8778 2100

The 2025 event, Kelly’s fourth, was held in March and once again saw fantastic turnout and great support. Kelly had organised a full evening, including the quiz, a great raffle, and fundraising games such as ‘heads and tails’, all with the sole goal of raising funds for EHE research. 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 was 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 close to £2,000. We want to thank Kelly and the Bridge House Pub for putting on another fantastic event. We are already looking forward to the 2026 event!

Nicola’s 10K Swim Challenge for EHERCC

Nicola Henderson and her huge group of supporters are another team that have been incredibly supportive of EHERCC. They have organised a huge number of events; none of us will forget their ‘positive-pants’ campaign! Many of them have participated in our previous half marathons, and this year several of them will again be helping us celebrate the charity’s tenth birthday by running in the Bristol 10k. Nicola wanted to participate too, and had the great idea of completing her 10K in the pool, setting out to swim 400 lengths of her local pool during the month of April, as she explained:

> “
>
> I’m taking on a huge personal challenge to swim 10 kilometers—400 lengths of a 25-meter pool (not in one go!) but hope to complete it within 1 month over various sessions in the pool!!! I want to raise awareness and funds for EHE (Epithelioid Hemangioendothelioma), a rare cancer that myself and others live with every day. EHE is an ultra-rare form of cancer, and those diagnosed often face an uncertain future with no support from government for funding and research. Fundraising is down to patients and their families, making it harder for families and patients to get the support they need. My goal is to change that, to raise awareness, and to push for more research and resources so that others don’t feel as alone as many of us do.”
>
> Why am I swimming? Swimming 10 kilometers is a massive physical challenge for me. Since my transplant I suffer with low energy, fatigue and medication side-affects 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.”

By the end of the March, Nicola had completed 250 lengths of her 400 lengths target, swimming 6.25K. She was of course being supported by family and friends, and her fundraising page was seeing great contributions. We look forward to updating everybody on the final outcome in the next edition of The Pledge. We do however also want to say a huge thankyou to Nicola for what she has already achieved and congratulate her on taking on this personal challenge. You are a star Nic!

Nic’s 10k Swim for EHE Rare Cancer Charity

Nicola Henderson is raising money for EHE Rare Cancer Charity

In memory of Steve

It is always with sadness that we share news of donations that are tied to the passing of a member of our EHE community. In November, last year, Fran Jones informed us of the passing of her beloved husband, Steve, who had been fighting aggressive EHE for some months. Everybody was devastated of course.
Steve was a very skilful blacksmith, creating wonderful art and sculptures as well as many more practical items. His website says 'maker', creating "staircases, pedal powered equipment, big things-small things, post boxes, wood burners, heating systems, engineering projects, metal corsetry, love tokens, garden supports, architectural systems, hooks, cutlery, vessels, bowls, vehicles, items for film, circus props...." He was truly talented, and he and Fran had designed together for 20 years. Here is just a tiny example of their work.

Part of his tool kit was a small-but-big heavy industrial power hammer. Fran organised the return of this to the original provider and then amazed us all by donating the £600 refund to The EHE Rare Cancer Charity. It was such a special gesture.

The UK EHE WhatsApp group are really happy that Fran has continued as a member of the group after Steve's passing. They all hope that she will stay with the group, but will also respect whatever decisions Fran makes in the future. We think Steve would like her to stay as long as she wants, knowing she will always have a special place.

Bournemouth Students running for EHE

Late in 2024, the EHE Rare Cancer Charity was approached by a group of TV Production degree students from Bournemouth University in southern England with a proposal. As part of the third and final year of their course, they had to produce a TV production. Their proposal was to do this in the form of a live-stream event to promote the charity, spread awareness of EHE, and raise funds for EHE research. They had heard about the charity, and EHE, through a family link of Hugh Leonard's. The charity thought this was an extraordinary idea and of course jumped at the chance.

At the end of the first quarter plans were in full swing with the live stream tabled for 25 April. But as part of the preparation, some of the students were already engaging in fundraising events, as Sally Baker explained:

> **This is Hugh's nephew and his girlfriend Reannah, heading off to do the Bournemouth 10k. It's Reannah who is involved with the Livestream event in April for EHE, as her final degree course assignment, raising funds and awareness of EHE. There will be six or seven of them running in the Bournemouth 5K and 10K events this weekend. We wish them well, and hope that people will support them.**

We love this story, and cannot wait to update our readers on the actual Live Stream

CBS Party

The Christmas party organized by Cegeka Business Solutions was held in Milan on 16 December and was an extraordinary event filled with strong feelings of solidarity and togetherness. During the evening, Andrei Ivanescu had the honor of introducing the Associazione EHE ITALIA, raising awareness about the work they carry out every day to support the EHE patient community and promote research. Andrei said:

> “
>
> **A heartfelt thank you goes to CBS and its incredible employees for the warmth and enthusiasm they showed. Through their support, from the solidarity gifts like our handmade angels to the exciting lottery draws, we managed to raise €1,000. This amount represents much more than just a figure—it's a symbol of generosity and hope that will help us pursue our mission with even greater determination. The participation and engagement of each one of you reminds us of the power of coming together for a common cause.”**

Here at The Pledge, we want to join EHE Italia in thanking CBS for helping create what was clearly a very special and unforgettable evening and for your wonderful support, which truly makes a difference.

2025 EHE Fun Run & Walk Launched

Each year, The EHE Foundation holds its EHE Fun Run and Walk event to raise awareness, create community, and fundraise for EHE research, as The Foundation explains:

> “The EHE Fun Run & Walk is a flexible and inclusive event where participants register online and complete the run or walk on their own schedule and in their preferred location. Whether you choose to run, walk, or simply gather with friends and family, this event is all about coming together to support a shared cause. There is no set event date! However, many participants choose to form teams and organize local, in-person events to make the experience even more meaningful. It's an event where everyone can participate in their own way, united by a common goal, no matter where they are.
>
> This is our most anticipated awareness and fundraising event of the year and brings communities together to support patients, raise awareness about EHE, and generate critical funds for advancing EHE research. Last year, the 8th Annual EHE Fun Run & Walk welcomed more than 1,380 participants and raised nearly $80,000 toward impactful EHE research.”

As in previous years, The Foundation has included its popular Team Incentives programme, encouraging people to form team events:

> “Creating a team can be an empowering way to connect with your community. Bring your family, friends, neighbors, and co-workers into our virtual event and make it your own. Together, awareness is raised and critical research is funded as we imagine a bright future for everyone affected by EHE.”

Registration for the 2025 Fun Run and Walk is open, with details of the event and a registration link included on The Foundation website at https://fightehe.org/fun-run/

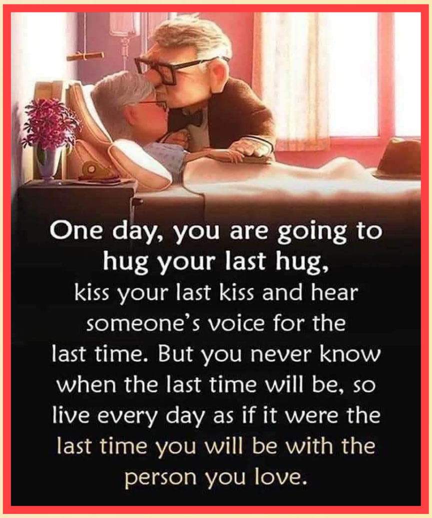
04

And in other news…

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

As he does every quarter, Carl Dickson posted an array of poignant photos and messages, some of which we have shared with readers here.

> Everyone should live life following this advice because you just never know and those of us on this page know just how important the wisdom of this advice is. Just Live my friends.

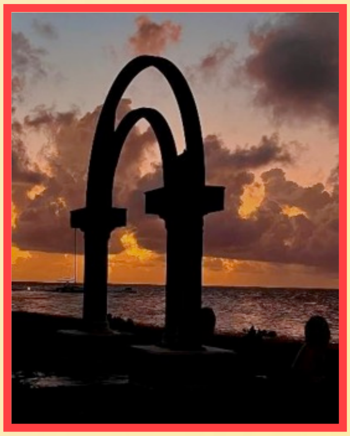


One day, you are going to hug your last hug, kiss your last kiss and hear someone's voice for the last time. But you never know when the last time will be, so live every day as if it were the last time you will be with the person you love.

> EHE many times may feel as though it is a trek filled with insurmountable odds. Even though it is a trek we did not choose, it is one we can not turn away from. We must all dig deep and summon the courage to take it one step at a time in order to live the best life we can during this struggle. JUST LIVE my friends.

The past year has been a struggle but you only win if you keep moving forward.

> Live each day as full as you can and be sure to share it with whomever you can. Be sure to share as many sunrises and sunsets with the one you love for you never know when that last one will be. Here are a couple I got to share with my wife.



Stephanie Kennedy is another regular contributor to the EHE Patient Support Facebook page:

> I've been having so many ups and downs ,we are really fighting every day to be present...
>
> ...but I am thankful to see my oldest granddaughter turn 16.

Meanwhile, Masiel Alejandra Gonzalez Montenegro shared news of her visit to Rapa nui (Easter Island):

> ***Just live!!!*** Ever since I knew my diagnosis and had met this group, I learned to take chances in life and make the most of it. So I just took a flight and came to this magical island... Greetings from Rapa nui, Chile !!! From where our Rapamune (sirolimus) was born!! The journey of my life and my dreams!

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