

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



Quarterly Newsletter for the EHE Group
July - September 2022

the pledge

Edition 30



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Welcome

Welcome to “**The Pledge**”, our quarterly newsletter covering the activities of the EHE Group. This is our 30th edition, for the third quarter of 2022. We hope that you enjoy reading it, and are inspired by the stories included within it. As always we want to say a massive thank you to all our supporters for their contributions. Regardless of what type or magnitude of support and contribution you provide, they are all critical to our success and ability to manage and ultimately defeat EHE.



Highlights

\$1 million EHE research grant made in Canada

Sarcoma Cancer Foundation of Canada announced the largest ever investment in Canadian EHE sarcoma cancer research, with a private donor gifting \$1 million for EHE research. The grant will be used to allow Canada to join and collaborate with major European EHE research.

The EHE patient community is represented at ESMO 2022

Hugh Leonard from the EHE Rare Cancer Charity (UK) presented at the ESMO 2022 conference on the subject of advocating for a very rare cancer. The panel also included Dr Silvia Stacchiotti whose team at INT in Milan is undertaking important EHE research funded by the EHE Group.

The EHE Foundation makes three new grant awards

The EHE Foundation (US) has announced the results of its 2022 call for grant applications. See the story in the Research section of this newsletter to see which projects have been supported.

Research updates from MSK and Sheffield University

We are delighted to be able to post research updates from Memorial Sloan Kettering in New York and from the Bateson Centre at Sheffield University in the UK in this edition of The Pledge.'

EHE international research review programme is started

The EHE Group has initiated a programme of international meetings where EHE researchers are invited to present their research to other researchers. The first such presentation was given by Emily who is completing her four-year PhD at Manchester University.

EHE Italia – Non solo Laura is growing

The newest of the EHE Group of not-for-profits is the 'Associazione EHE ITALIA - Non solo Laura'. This quarter saw their activities and engagement with the EHE global community growing.

Grassroots fundraising delivers great results

We are again grateful for some wonderful grassroots fundraising from the EHE global community.

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

the **pledge** Edition 30



01 Patient Support and Advocacy

The EHE Group strives to provide support to everybody diagnosed with EHE. At the same time we work hard to increase awareness and understanding of EHE amongst the general public and all other relevant groups. These two goals are at the core of the patient support and advocacy objectives that are common to all the EHE foundations. But we can only achieve them with the tireless energy and contribution of so many of our members, many of them being EHE patients themselves. So as always, we want to thank all our supporters who have contributed to this critical part of our activity, examples of which are provided in this section.

Hugh Leonard visits the London Cancer Hub

In late July, Hugh Leonard of the EHE Rare Cancer Charity, was delighted to share some photos from his visit to the London Cancer Hub. Hugh was visiting the new Institute of Cancer Research campus in Sutton, SW London, next door to the Royal Marsden's Sutton facility, to meet with Dr Paul Huang to discuss and review their ongoing EHE research. Hugh commented:

“It was my first visit and I have to say the place is amazing. There are a lot of brilliant minds working on cancer research, and some of them are working on EHE. These guys are super dedicated and really want to know about EHE and how they can help. Banking samples into an EHE-dedicated biobank is critical to the research effort, and we are once again ‘punching above our weight’ on this key component of research into a rare sarcoma. It is clear that if we have the funds, and can deliver the samples, teams like the one at the ICR and researchers like them around the globe will continue to work very hard to help us find a cure for EHE.”



Hugh came away feeling very optimistic about the future. So if you ever wonder why the EHE foundations and the EHE community spend so much energy on fundraising and biobanks, this is why.

- **RAISE THE FUNDS!**
- **DRIVE THE RESEARCH!**
- **FIND THE CURE!**



Michelle Lynn is spreading the word!

Michelle joined our EHE global community in 2021 following her EHE diagnosis. Since then Michelle has been on the EHE roller coaster that most patients face in the early days of their EHE journey. Some find it hard to take on much else through this period, but Michelle has taken up the baton and thrown herself into raising awareness of EHE.



In early July, Michelle posted news that she was featuring in an awareness campaign for the hospital that is providing her medical care:

“Hey EHE friends! more EHE awareness going out there today. I was super honoured to be asked to do this for the Princess Margaret Cancer Foundation for Sarcoma month in Canada. Hugs to you all from PEI, Canada.”

The Princess Margaret Cancer Foundation campaign told Michelle’s story so far, and included several very honest and heartfelt comments from Michelle about her cancer. Arriving home after the two-hour drive, having received her diagnosis, and seeing her children was



the moment it all sank in. **“I cannot allow this to take me,”** Michelle vowed, her fighting spirit shining through. The campaign was also well timed, coinciding with a very substantial donation for EHE research from the

Sarcoma Cancer Foundation of Canada. **“This donation is thrilling and it gives me more hope,”** Michelle said. **“They haven’t figured it out yet. But they will.”**

Michelle’s drive to help raise awareness was again in evidence when she posted news in September that she was going to run in the Terry Fox Run. Terry Fox also had a sarcoma cancer which ultimately took his life after an incredible and courageous fight. He lost his leg to cancer but that didn’t stop him from running across Canada. He wasn’t able to finish the route but became a Canadian legend.

Michelle explained:

“I started running again once I was diagnosed and stabilized. I was doing 10kms until Covid hit me in July. Now I’m working my way back up! This Sunday is the race and I’d love to wear our EHE shirt that was created by a fellow EHE runner in the group!”

We were delighted to hear that Michelle had been able to get the EHE shirt she wanted, and posted news that she had completed the 5km run in 27 minutes.

Michelle was delighted:

“It may not be that far, but I did it and I’m proud. I felt it was a worthy ‘Just Live’ moment.”



01 Patient Support and Advocacy

What is scanxiety and how to manage it

Maeve Baechler shares her scanxiety tips

In August, Maeve Baechler, an EHE patient herself and life coach, shared news of her new blog and related information that she hopes will help people with 'scanxiety', a recognised period of psychological stress and anxiety felt by cancer patients as they approach their next scans.

"In an attempt to help others through scan day(s), I wrote a blog post about my insights and what works for me. There is also a PDF with scanxiety tips at the bottom of the post if you are interested. Hope this helps!"



Thank you Maeve for sharing this with the EHE community. Maeve would love to hear what works for other patients on scan day, as well as any feedback you may have for her relating to her blog and other scanxiety materials. Here is the link to her site: <https://lifecancercoach.com>

And reviews for Maeve's coaching are very positive indeed. Maggie Cameron wrote:

"Just wanted to take a minute to thank Maeve Baechler for the fantastic coaching session this week! She was kind, patient and deftly helped me see what my next steps are to achieve my personal goals. If you haven't taken her up on her coaching offer, please do it. She's really great! I feel so much better already!"



'Community Connections' is growing

Community Connections is a program launched earlier this year to promote ongoing engagement and resource sharing for the benefit of the entire EHE global community. Guest speakers highlight EHE specific topics and issues. Each virtual session is truly unique in content and delivery. Some sessions are recorded, but others will remain private to ensure participants feel free to have an open dialogue. There is no cost to attend, but pre-registration is required. The overall goal is to share valuable information while advocating for and improving the lives of EHE patients. We hope patients and caregivers join these sessions to share their thoughts, get questions answered and express the issues that matter most to them, while ensuring they have the tools to advocate for their personal care.

What Happened at ASCO? EHE Update with Jane Gutkovich (Saturday, July 23rd, 2022)

The July Community Connections featured EHE patient advocate, Jane Gutkovich.



Jane Gutkovich, Board Member Emeritus
The EHE Foundation

Jane is one of the founders of The EHE Foundation, and currently in the role of distinguished Board Member Emeritus. In this role, Jane works strategically

with the Foundation and global partners to continue to support patients and recruit researchers to EHE.

Jane attended the 2022 American Society of Clinical Oncology (ASCO) Meeting held June 3-6th in Chicago, IL. This is the largest cancer meeting in the world, with 40,000 oncology professionals presenting more than 2,000 abstracts and more than 2,500 poster presentations. EHE was included in at least 6 presentations or posters, which was very exciting! Jane's presentation provided a high-level overview of key

areas of research presented at the meeting, including biomarkers and the role of inflammation in cancer.

Jane said of her experience:

“It was so exciting to see EHE being included in several groundbreaking studies. Talking with doctors and scientists and seeing their genuine interest in EHE gave me hope and reassurance that effective treatment is on the horizon.”



While the research presented at ASCO can be highly technical, Jane's presentation included key takeaways for patients to bring to their care team. This session was recorded and you can view Jane's presentation [here](#) on The Foundation website.

Integrating the Cancer Identity into the Self

(Saturday, August 6th, 2022)



Dr. Tamara Vesel

Dr. Maeve Baechler

Dr. Tamara Vesel and Dr. Maeve Baechler hosted the second session in their series in August. The session explored questions such

as: Why is it important to contemplate on identity after

the cancer diagnosis? How does the issue of identity relate to symptoms during cancer treatment? What are the ups and downs of resisting versus incorporating cancer diagnosis into one's life?



This summer The EHE Foundation launched a new support initiative, EHEChats. This new series is formed from feedback from patients and caregivers who want to stay connected in a casual, interactive, and personal format. These are

one-hour monthly Zoom meetings hosted by Julie Wahl. The chats are informal, open discussions around a theme. Chats are not recorded. Sometimes it just



helps to see the faces and hear the voices of those who understand some of what patients and caregivers are

going through. All patients and caregivers are welcome to attend! Pre-registration is required, please go to www.fightthehe.org for more information.



At the September 24th Chat session, JoAnna ones shared her EHE journey which spans a clinical trial, liver transplant, radiation, and giving birth to her beautiful baby.

Please keep checking The EHE Foundation website or upcoming Community Connections and EHE Chat dates to keep the support, education, and conversations going!



01 Patient Support and Advocacy

Getting together is always special

We know from experience that being able to meet fellow EHE patients is very special for all those dealing with EHE. So we were not surprised to see Fiona Louise's excited post about meeting fellow Canadian Michelle Lynn.

“It is so special when we get to meet others with our ultra-rare disease. Thank you Michelle Lynn and family for your incredible hospitality and for sharing your beautiful island home. **#Just Live!**”



Getting together was also the theme in Europe in the third quarter when Andrei Ivanescu and Caterina Colaci from 'Associazione EHE ITALIA - Non solo Laura' travelled to London and took the chance to meet up with Hugh Leonard from the EHE Rare Cancer Charity UK. There was a lot of discussion about all the activities of the two groups and how they can support each other. Andrei and Caterina live in Milan, where Silvia Stacchiotti and the INT research teams are based, so everybody agreed that this would be a great venue for the next meeting. Hugh and Andrei took the chance to also capture a short joint video that Andrei and Caterina wanted to share with all the members of EHE Italia.



EHE Patient Advocacy at ESMO 2022!

EHE champions were on the global stage on September 10th, at the ESMO2022 Congress in Paris, France. ESMO, the European Society of Medical Oncology, is a leading professional organization for medical oncology education and information. Dr. Silvia Stacchiotti, a leading EHE clinical expert (Italy), and Hugh Leonard, Chair of Trustees of the EHE Rare Cancer Charity (UK), spoke in a session entitled '**Ultra-rare sarcoma: Navigating an endless sea.**' Dr. Stacchiotti discussed the drugs and research needed to better treat ultra-rare sarcomas, and Hugh eloquently presented the importance of collaboration and partnership among patients, advocates, researchers, doctors, government, and pharma in the effort to find effective treatments for EHE as an ultra-rare cancer.



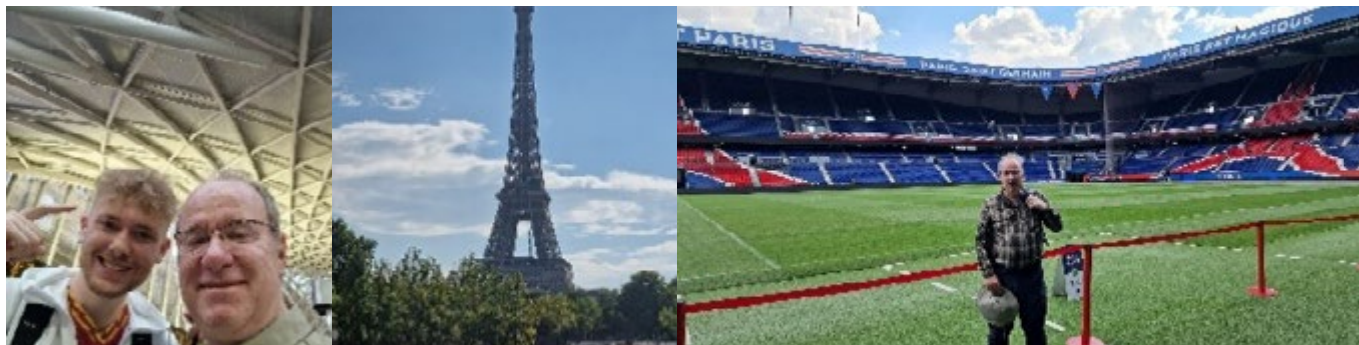
Denise Robinson, Director of Research for the EHE Foundation, and Jane Gutkovich both attended ESMO virtually. Denise commented:

“Hugh has placed EHE patients and advocates on one of the world’s largest oncology stages and clearly points out that collaboration with patients, and EHE research facilitated by patients is essential to finding treatments and cures for EHE.”

Tattoos on display

It is a while since we have seen a montage of our much loved EHE Just Live tattoos, but that changed in August when Tanya Ness posted her simple question “**Can I see some EHE tattoos? Please.**” So here are just some of those posted. We hope you enjoy them. We particularly like the matching sunflower tattoos for ‘sarcoma’!





Andrew Miller's exploring Europe

Andrew Miller is another member of our EHE family who is following the ***Just Live!*** mantra. Following positive scan results in July, Andrew Miller embarked on a two month inter-rail trip around Europe with his son. We hope that Andrew and his son have a really great time.

Maeve Baechler shares Samira's 'Manta Planner'

A cancer diagnosis is a terrible thing for anybody to face, and typically will turn a patients life upside down. One of the key challenges is that it is a situation for which most people are completely unprepared. Maeve Baechler, an EHE patient herself, was therefore interested when she was introduced to another cancer survivor.

“Jane Gutkovich recently connected me to Samira, a young breast cancer survivor who presented at ASCO this year and founder of Manta Cares. She designed the "Manta Planner"- an all-in-one tool for cancer patients, caregivers and survivors. I have enjoyed getting to know Samira virtually and connecting with her over a common vision of improving patient self-advocacy and the caregiver experience.”

Samira's Manta Planner is organized into sections (e.g. Diagnosis, Treatment Plan, Symptom Plan, Research Notes) and includes important prompts. For example under the Diagnosis section, question prompts include: What additional tests should I be doing? Can we get prior authorization for these tests? Which tests are most sensitive for my cancer? There is a symptom journal and a section to take notes at every appointment, which is very useful. Maeve went on:

“Given the complex and dynamic nature of EHE, I think this planner could be invaluable to some of you. Samira has given me an EHE discount code for our Facebook group if anyone is interested. And if you do decide to utilize one, she is interested in how you guys like the planner and if you have any suggestions for improvement. The current planner is on it's 4th iteration, I believe. She got wonderful feedback from oncologists, patients and caregivers.”



Maeve wanted to be clear that she does not receive any commission for this product. “I simply find it an incredible tool, and is research backed!” We want to thank Maeve for bringing this to the attention of

the EHE community. For those interested, by using the code 'EHE22' you will receive a 15% discount.



A Little Kindness Goes a Long Way!

Most 12-year-olds are excited to spend their birthday money on the newest gadget or toy. Brendan celebrated his birthday with a pool party, but he didn't

want gifts. He wanted to give his birthday money to The EHE Foundation in honor of his friend, Joe, who was diagnosed with EHE in 2019 at the age of 9. Thank you, Brendan, for gracing us with your kindness and for being such an amazing friend to Joe. We are grateful to so many of you who continue to support our EHE community in so many ways.

EHE Resources @fightehe.org



EHE Library: The EHE Library is an essential resource to view and download articles and is especially helpful to newly

diagnosed patients. It is the largest repository of EHE information in the world for patients to access! The EHE Consensus publication was produced in June 2021 and is the first consolidated publication to provide key facts concerning the management of EHE. It is an excellent reference to share with your doctor, especially if you are seeing someone who is not familiar with EHE. There is also a less technical patient version available [here](https://www.fightehe.org/consensus).



Clinical Trials Listings:

Patients can check this listing to view EHE-specific clinical trials, including two open Phase I clinical

trials. Please contact the Patient Services team at info@fightehe.org with any questions about these studies or if you need assistance contacting a study center. Clinical trials information can be overwhelming, and we encourage you to discuss all clinical trial options with your care team.

US Biobanking

Tissue Donation with the EHE Biobank.

Patients are the key to finding new treatments for EHE! Researchers need tumor tissue, blood, and fluid from EHE patients to understand disease progression and speed development of new drugs and therapies. Without actual EHE tumor cells, much of this research cannot be accomplished. If you have an upcoming surgery, please contact the Biobank team at biobank@fightehe.org. To learn more, visit the website at www.fightehe.org/ehe-biobank/



UK Biobanking

It's not just the USA that is seeking these valuable tissue samples. The EHE Rare Cancer Charity has funded the establishment of the EHE National Biobank which is sited at the Royal Marsden Hospital and is now collecting tissue and fluid samples from EHE patients. If you wish to make contact then please contact:

1. the EHE Tissue Coordinator at the National UK EHE Biobank at the Royal Marsden Hospital at EHEbiobank@rmh.nhs.uk ; or
2. Hugh Leonard at the EHE Rare Cancer Charity (UK) at hleonard@ehercc.co.uk

Australian biobanking

In Australia, biobanking is being coordinate by the EHE Rare Cancer Foundation Australia (EHE-RCFA) and the WEHI Stafford Fox Rare Cancer Research Program. For more information about the Australian biobank please contact the EHE-RCFA at info@ehfoundation.com.au.



“The EHE cancer patients’ motto is **‘Just Live!’** and I’m all in”

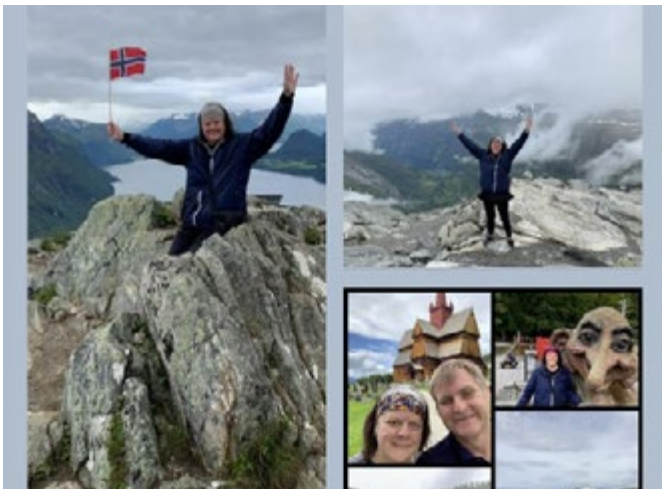
The title of this article is a quote taken from a post from Diana Axness, a member of our EHE family based in the USA. Diana submitted her post on the EHE Patient Support Facebook page to update the EHE community, but as is so often the case, did not want her post to be just a bout EHE. Diana wrote:

“I’m including a picture of me driving my pair of ponies - my happy place. The EHE cancer patients’ motto is **“Just Live!”** and I’m all in.”



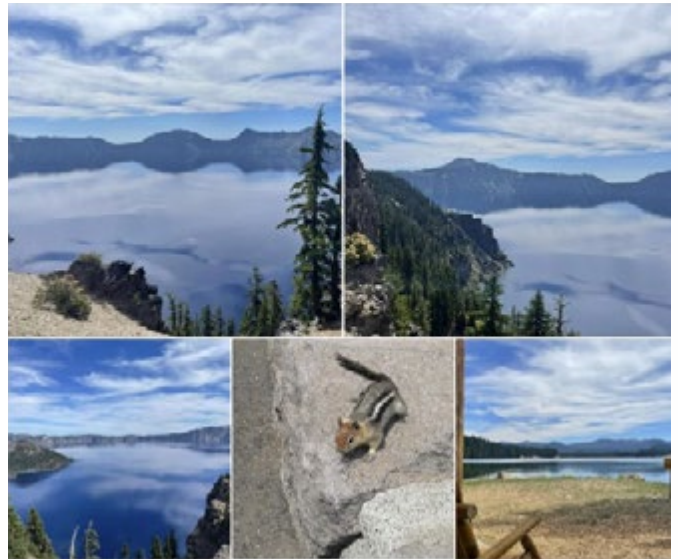
Linda Beaulieu picked the same theme in her post in August, also on the EHE Patient Support Facebook page:

“I really try to live by the motto **‘Just Live!’** After getting good scans results in June, I knew it was a sign that it was time to do our planned trip to Norway. We spent three weeks visiting amazing sites and meeting family. It was wonderful! As I stood at the tops of mountains with my arms in the air I kept thinking ‘heck, I am here! I did it and I am ‘living’! I encourage you all to seize those moments.”



Also in August, Myranda Wolf posted on the EHE Patient Support Facebook page some fantastic photos of her trip in Oregon, just a week after her diagnosis:

“I’ve lived in Oregon since 2010 and have never really explored much. Today my husband and I finally visited Crater Lake (after talking about going for a long time) and have spent the weekend camping with family. It’s only been a week since my diagnosis, but I’m trying to **“Just Live!”** now.”





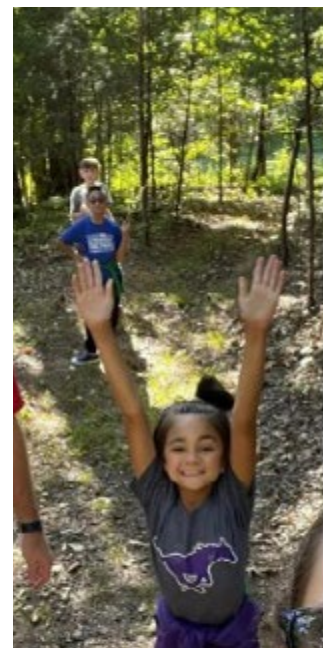
In September, it was Sarah Bright Yanza's turn to post:

“Today my mom turns 70! When I was diagnosed with EHE (9/26/16), I didn't know if I would be alive for milestones like birthdays, graduations, weddings, etc. What a blessing to have had a mother like mine that has given everything for her family (she is really unreal and so special). For her birthday, we surprised her and flew to Chicago to spend time with family, including my 94-year-old grandmother. Four generations were able to be together! Most certainly, a moment we will cherish and never forget. **Just Live!**”

Later in the month Sarah posted again on the 6th Anniversary of her diagnosis. Sarah noted that these had been six tough years; a roller coaster of a ride. Six years of scanxiety, aches and pains, worry, being careful not to do too much, too little, to eat this or not to eat that, of checking the EHE support page and being knocked down again and again to learn more EHE warriors had become angels. But Sarah also could see some upsides:

“It's been six years of slowing down and soaking in life. Six years of being present. Six years of feeling my full body heartily laugh. Six years of really looking at my children and walking alongside their griefs and joys. Six years of saying yes to what serves me and no to what does not. Six years of taking the trips, making the hard decisions, and leaving the house messy to head out for an adventure. Six years of developing amazing heart-centered friendships and pursuing/maintaining a beautiful and loving romantic relationship. I still can't say I'm grateful for EHE. I'm never going to be happy for what it has taken from me or done to each of you. Yet, I do see, even in this how much I've gained. For that, I am grateful. **Just Live!**”

We love these '**Just Live!**' messages, and we thank all those who post them, providing inspiration and encouragement for our global community. So Diana, Linda, Myranda and Sarah, keep enjoying your lives to the full, and **Just Live!**



02 EHE Research

We will ultimately defeat EHE because the questions that we do not have answers to today will be answered by the research we are funding, and the future research that we continue to promote and facilitate. This research will also lead to the generation of new drugs and treatments to manage and defeat this rare cancer. The following pages provide an update on our research-related activities.

A huge announcement

Fiona Ross, a champion of the EHE cause based in Canada, had teased the EHE family in the second quarter with hints of a big announcement. We were all thrilled at the beginning of the third quarter therefore when she posted news of a \$1 million investment in EHE research. Sarcoma Cancer Foundation of Canada, to whom the investment gift was made, celebrated the largest ever investment in Canadian EHE sarcoma cancer research:



RESEARCH INTO RARE FORM OF VASCULAR SARCOMA CANCER RECEIVES \$1 MILLION IN FUNDING

The Sarcoma Cancer Foundation of Canada were excited to announce this one-million-dollar investment into an exciting new research initiative that will evolve the collective baseline of Epithelioid

Hemangioendothelioma (EHE), a rare vascular form of a sarcoma. The Canadian-focused research will be joining an existing collaboration of European experts which collectively brings hope to the global EHE community.

The research, led in Canada by Dr. Albiruni Abdul Razak, Medical Oncologist at the Princess Margaret Hospital (PMH)/Mount Sinai Hospital Toronto will be seeking to better understand EHE demographics in patients, treatment patterns, and potential therapeutic targets. Princess Margaret Hospital (PMH) in Toronto will serve as the Canadian site for this project, which will take place over the next five years.

The study is also seeking to identify and validate novel biomarkers for EHE to assist doctors with providing both a reliable prognosis for patients, as well as being able to assess the response of patients to their treatment programs. Dr. Razak commented:

“There is so much more we need to understand about EHE sarcoma in order to offer patients optimal care, and with this support from SCFC, our research has the potential to build on what we already know about the disease and lead us to new outcomes that can improve the lives of patients. We aim to deliver tangible knowledge that would directly impact patient care.”

Miyo Yamashita, President and CEO of Princess Margaret Hospital Foundation added:

“We at Princess Margaret Hospital are pleased to receive this donation for EHE research from the SCFC. We are excited to be part of this project which will lay a strong foundation for EHE research in Canada, complementing PMH’s ongoing dedication to critical sarcoma cancer research.”

Diana Arajs, Chair of the Sarcoma Cancer Foundation of Canada, was also excited:

“We are thrilled to be able to fund this incredibly exciting project and support this transformational work right here in Canada. It’s an exciting time for our community and for all EHE sarcoma patients as we celebrate this landmark million-dollar investment.”

The research team will include scientific and clinical experts located at the Leslie Dan Faculty of Pharmacy, University of Toronto under Professor Christine Allen. They will be collaborating with the European research team that includes the Institut Tumori in Milan, Italy led by Drs Silvia Stachiotti and Nadia Zaffaroni, and the Royal Marsden Hospital/Institute of Cancer Research in London, United Kingdom, led by Professor R Jones and DR P Huang.

The Pledge wants to congratulate the whole research team on receiving this amazing award. While the donor has remained anonymous, we also want to thank them for this amazing gift that will make such a difference. Finally, we want to say congratulations and a huge THANK YOU to our own Fiona Ross who played a key

role in the process. We look forward to providing news of exciting research progress in future editions of The Pledge.

Sharing our research results

As many of you will know, the EHE Group is currently helping to fund multiple EHE research projects in North America, the UK, Europe and Australia. One of the challenges of these research programmes is ensuring the results and knowledge gained is shared with other researchers to maximise the chance of success, minimise the chance of missing something important, and avoid unnecessary duplication. In other words, to ensure that the EHE community get the ‘maximum bang for their buck’!

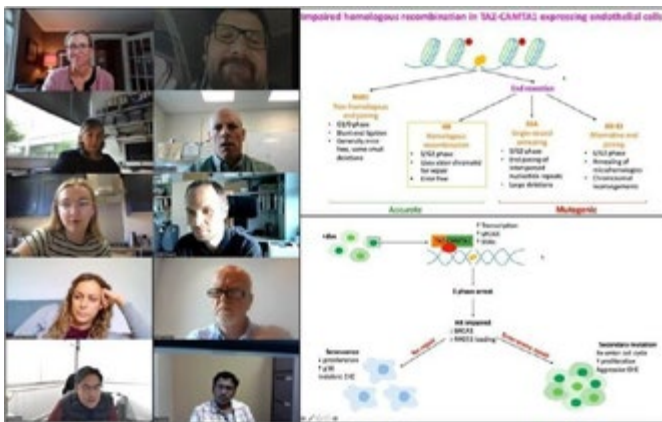
To help achieve this target, and as part of the obligations of the researchers who accept EHE Group funding, researchers will be asked to periodically present their results to a group of fellow EHE researchers so that the group can discuss the results, encourage brainstorming in an energised and creative environment, and think about how to use the research and what follow-on research may be justified.

The first of these meetings was held in July in the UK. Emily Neil, PhD post-graduate working under Dr Valerie Kouskoff at the Division of Developmental Biology and Medicine at The University of Manchester in the UK, presented the results of her last three years of work. Emily’s work has recently focused on how EHE may be impacting the cell cycle, and how DNA damage and secondary mutations may play a key role in the nature of a patient’s EHE. A more detailed description of this work, and the results, can be found in Edition 28 of The Pledge, covering the first quarter of 2022.



02 EHE Research

A core group of fantastic researchers took part. These included John Lamar from Albany Medical College in New York; Munir Tanas from the University of Iowa; Sandro Pasquali from INT in Milan; Paul Huang from the ICR in London; and Ajay Pobbati from Dr Rubin's lab at the Cleveland Clinic. The EHE Rare Cancer Charity was also thrilled to welcome Dr Sorrel Bickley, Director of Research, Policy and Support at Sarcoma UK.



Research personnel from the EHE Group also took part, and were delighted by the discussion and pooling of ideas at the end of the presentation. The EHE Group is now following up with all attendees to capture any further thoughts they may have.

We want to congratulate and thank all those that took part for creating such a positive environment and discussion, and we are delighted to also be able to provide a snapshot of the meeting. We also want to send special thanks to Emily Neil for her great presentation and work.

Jane is talking Immunotherapy

Jane Gutkovich attended an immunotherapy-focused conference at the National Cancer Institute in late September. Excited by what she saw, Jane wanted to share the information with our global EHE community. Jane explained:

“Dear family, I attended a great conference at the National Cancer Institute on the latest progress in immunotherapy where famous leading researchers presented breakthroughs and challenges in this quickly growing field of cancer treatment. We often talk about the role of immunotherapy in EHE. I would love to make another, updated presentation for you (I did one several years ago). I will include the basics of different types of immunotherapy, which ones are most promising for EHE and what evidence we have about immunotherapy in EHE.”

Jane's presentation took place at the end of October and was well attended as always with positive comments afterwards about another great talk. For those who were not able to attend, Jane recorded the event. For those who want to watch this excellent update on immunotherapy research, please follow the link on The EHE Foundation website at www.fightthehe.org.

2022 EHE Research Grant Awards Announcement

The EHE Foundation has completed its 2022 EHE Research Grant cycle and is pleased to share that it has awarded the largest grants funding in its history – totaling \$291,600 of grants to three outstanding applicants. This amazing sum is complemented by additional private funds totaling \$250,000, bringing this year's total research investment from the USA to \$541,600 USD.

These grants significantly advance the mission to find effective treatments for EHE - and would not be possible without the support of the EHE community! Thank you for your continued support!

The 2022 EHE Foundation research grant recipients are:



John Lamar, PhD | Albany Medical Center - Awarded \$200,000 (matching a \$250,000 private, designated donation toward this research) Project: Use of Pre-clinical EHE Models to Identify Druggable Pathways to Treat EHE

Research Goal: To reveal pathways that can be targeted with existing FDA-approved drugs to either eliminate EHE or prevent its growth.

Research Objectives:

- Identify druggable pathways that are required for TAZ-CAMTA1 activity and EHE growth/viability.
- Establish and optimize an EHE transplant model system in mice for testing therapeutic compounds.
- Develop multiplexed *in vivo* assays in mice and use them to test multiple therapeutic targets.



Ajay Pobbati, PhD | Cleveland Clinic - Awarded \$65,000

Project: Repurposing an FDA-approved Drug for EHE Treatment

Research Goal: To identify an FDA-approved drug that can sequester TAZ-CAMTA1

(TC), TEAD, or both in the cytoplasm and inhibit tumorigenesis.

Research Objectives:

- Identify drugs that relocate TC and/or TEAD to the cytoplasm using a subcellular localization screen.
- Perform preclinical characterization of shortlisted drugs.



Valerie Kouskoff, PhD | University of Manchester - \$26,600

Project: Understanding and Exploiting the Genomic Instability Promoted by TAZ-CAMTA1

Research Goal: To understand further how TAZ-CAMTA1 interferes with the DNA damage response and whether this interference represents a therapeutic vulnerability that can be exploited.

Research Objective: Test the druggability of the DNA damage response interference by TAZ-CAMTA1.

Jenni Kovach, President of The EHE Foundation said:

“Without the generous donations and support of the EHE community, we would not be able to award these grants. Together, we are making a significant impact in EHE research, and the Foundation is entirely focused and dedicated to our mission to find effective treatments and one day a cure for EHE. Every single donation makes a difference.”

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

“This year’s grant recipients brought forward the first significant opportunities to fund translational research that aims to identify effective treatments for EHE. These projects leverage years of EHE research and model system development, and if one or all of these researchers can identify drugs that are already approved for use, that potentially can be used to treat EHE - then this year’s research grants investments brings more than treatment; this brings hope.”



02 EHE Research

The EHE Foundation is grateful to their Advisory Board and expert reviewers for their time and careful consideration of this year's grant applications. They are also thankful for the time and talents each of these researchers invest in EHE. And as always, they are eternally grateful for the financial support of the EHE community, which allows them to fund this research. To learn more about previously funded grants, visit the EHE Foundation [Research Projects & Initiatives webpage](#).

The Pledge wants to add its thanks to those advisors and researchers, and of course to all the EHE donors without whom there would be no research. We also want to thank the team at The EHE Foundation for their focus and dedication, whose grant award process has enabled those wonderful donations to be turned into scientifically valid and exciting EHE research. Again, we look forward to providing news of exciting results in future editions of The Pledge.

The EHE Foundation (US) Funds Fellowship Travel Grants

In June, the EHE Foundation provided two Fellowship Travel Grants supporting young investigators' participation in a workshop entitled **"YAP/TAZ and TEAD: At the Crossroads of Cancer."** The workshop is hosted annually by the Telluride Science Research Center (TSRC) and this year was co-led by notable EHE researchers and advocates - John Lamar, PhD, Albany Medical Center and Guy Weinberg, MD, University of Illinois (retired).



The 2022 Fellowship Travel Grant recipients were:

Caleb Seavey, MD, PhD, Cleveland Clinic (US) - Dr. Seavey is a research fellow at the Lerner Research Institute and has been working in Dr. Brian Rubin's Lab since 2019. Dr.

Seavey's presentation at the TSRC was entitled Loss

of CDKN2A in epithelioid hemangioendothelioma enhances tumorigenicity and imparts cellular immortality, thereby facilitating the generation of the first cell lines of this disease.



Karin Schlegelmilch, PhD, The Francis Crick Institute (UK) - Dr. Schlegelmilch is a senior postdoctoral fellow in Dr. Erik Sahai's lab. Her presentation entitled Modelling therapy resistance in cancer highlighted her research

on the role of YAP signaling in the development of resistance to targeted therapy in melanoma which may shed light on mechanisms relevant for other types of cancer, such as EHE.

Dr. John Lamar, co-leader of the workshop, said **"Karin and Caleb made major contributions to the workshop. They both gave outstanding presentations and actively contributed to the discussions. We are so glad they attended and grateful that The EHE Foundation supported these young researchers that helped make our workshop a success."** The workshop was founded by Guy Weinberg in 2017 and brings together knowledgeable experts in the Hippo-YAP/TAZ and EHE fields to share their research during scientific presentations and talk science during group hikes and other social events. In addition to hosting recognized experts in these fields who have long-standing track records of successful research, Dr. Weinberg also believes in the value of having younger scientists attend the workshop; in his words, "...this advances and assures continued interest in important research relevant to EHE." The EHE Foundation has contributed specifically to this approach by funding the attendance of such 'young faculty' as Karin and Caleb through fellowship stipends. These efforts promote participation of talented young scientists and nurture the next generation of EHE researchers.



The EHE Foundation officially initiated this grants program in 2021, recognizing the importance of academic and scientific conferences and the financial barriers that students and young investigators face to attending conferences. The program supports advanced degree students and young investigators who are actively involved in research that supports the mission of The EHE Foundation – to seek treatments and a cure for EHE.

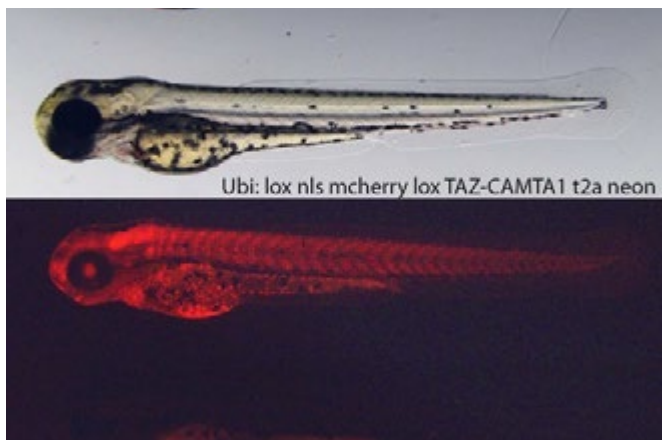
EHE Zebrafish model progressing

As we reported in the 28th edition (Q1 2022) of the Pledge, a four-year project, started in 2018, has been ongoing with the aim of developing a zebrafish model of EHE. Several key challenges have been faced, a key one being the inability to get the TAZ-CAMTA1 gene translocation construct to present in the endothelial cells of zebrafish. So the EHERCC team were excited to report exciting news from Dr Van Eeden in January:



02 EHE Research

“I am very excited because we now have identified 2 independent transmitters of our “switchable” transgenic where TAZ CAMTA can be driven by a new promoter, ubi. Eleanor just sent me this photo 10 mins ago where you can see the “detection marker” in red in the picture below.”



This marker is attached to the construct and so everywhere you see red, the construct is present. It appears everywhere in the fish, including the endothelial cells. Dr Van Eeden went on:

“This means that if all is well, we are just one step away of expressing TAZ-CAMTA1 in zebrafish! We are now first securing the line...a bit of jargon but we need to make sure we use the first few fish coming from the injected parents to establish a stock...but in a month or so from now we can do an injection experiment where we flick the switch and activate TAZ-CAMTA1, and since we have colour markers, we can see if the switch is working.”

The EHERCC were delighted therefore to receive further positive news in October from the research team. Dr Van Eeden explained:

“We have now created several switchable TAZ-CAMTA fish lines. We then needed to create a different line that will allow switching in the endothelial cells. For this, the “Cre” protein needs to be expressed there, but this was also proving to be challenging. However, we obtained a construct from a colleague that contained a GFP (florescent green indicator) tagged version of this protein which would allow us to see directly if that Cre protein is expressed in the right place.”

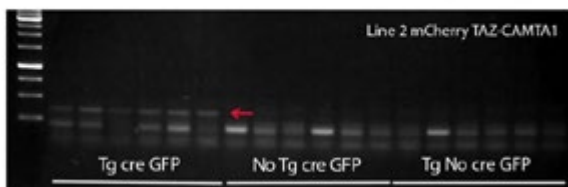
“I am glad to say that we just got our first transmitting fish of this! It is a “GO” fish (the first generation) which means transmission is not seen in all progeny. I am attaching a very first picture of the CreGFP switch transgenic that shows it is expresses the Cre gene in the blood vessels.”



Shortly after his email, a further update was received from Eleanor Markham, the MPhil student undertaking the research:

“As Dr Van Eeden reported, we have obtained a ‘founder’ for *fli1:cre* GFP, with very good blood vessel expression of the “switch protein”. We have now taken the next step and crossed our two lines together. So, the switchable TAZ-CAMTA (*ubi:lox nls-mCherry lox TAZ-CAMTA1* fish (red)) with the blood vessel switch line (*fli1:cre* GFP fish (green)). We have now done PCR tests on embryos that contain both constructs and we can see that the switch is happening when we look at the genome of these fish. This doesn’t yet show that the TAZ-CAMTA is being expressed... but the switch system is doing what it is supposed to do. We will now start looking with antibodies and qPCRs to see if the TAZ-CAMTA RNA, and protein are actually produced... scary but exciting.”

Recombination-specific PCR 



Hugh Leonard of the EHE Rare Cancer Charity is also excited:

“This is where we now find out whether the TAZ-CAMTA1 construct will actually express the TAZ-CAMTA1 fusion protein in the fish endothelial cells, and if it does, whether this fusion protein will affect the fish cells in the same way that it affects humans. Eleanor described it as “scary but exciting!!”. I could not have put it better. We have all our fingers and toes crossed.”

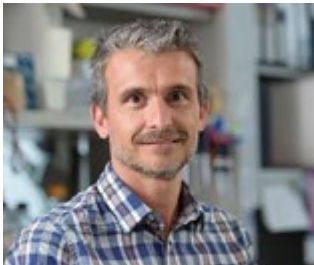
Eleanor will be doing further tests with the fish in the coming weeks to see if it is doing what it is supposed to do. At the same time they will also try to identify further ‘GOs’ to increase the number of experiments they can do in the coming month. We wish the whole team success as they enter this exciting phase of the project.

An Update from Memorial Sloan-Kettering Cancer Center - Investigating the Early Molecular Mechanisms of WWTR1::CAMTA1 and YAP1::TFE3 Gene Fusions in Driving the Pathogenesis of EHE

The EHE community, which includes cancer patients and their families from around the world, benefits from the world-class innovative research that takes place at Memorial Sloan-Kettering Cancer Center (MSKCC) in New York City (US). In 2019, MSKCC received a \$1 million private donation to establish an International Center of Expertise in EHE and since that time, significant knowledge of the disease has been gained and research questions continue to be explored.



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Dr Fabio Vanoli

To expand upon research initiated as part of the EHE Center of Expertise, The EHE Foundation together with the EHE Rare Cancer Foundation Australia (EHE-RCFA) provided a research grant in 2021 to Cristina Antonescu, MD and Fabio

Vanoli, PhD to further investigate the early molecular mechanisms of WWTR1::CAMTA1 and YAP1::TFE3 gene fusions in driving the pathogenesis (the origination and development) of EHE. The research under this specific grant has concluded and Dr. Vanoli recently provided a summary of their research to date:

“Epithelioid hemangioendothelioma (EHE) is a malignant tumor originating from the inner layer of cells covering blood vessels. It affects all ages, but has a distinctive prevalence in young adults. EHE has a ubiquitous presentation, with common sites including liver, lung, and soft tissue. Most tumors have an indolent growth and do not cause symptoms; however, a subset is aggressive, especially in the multifocal setting or pleural involvement. Besides surgical procedures for localized, unifocal lesions, there are no effective therapies, either cytotoxic or targeted, available for EHE patients.”

“Like many other sarcomas affecting young adults, EHE is characterized at the molecular level by a consistent structural aberration, namely a chromosomal translocation. A translocation occurs when two genes, located on different chromosomes, are fused together creating a new gene able to induce cancer formation. In EHE the two genes that are commonly fused together are WWTR1 and CAMTA1. How the two genes, once fused together, cause the initiation and development of the tumor remains unknown, in part because of the lack of faithful EHE models (e.g., cancer-derived cell line) that allow us to further our understanding of EHE pathogenesis.”

“The aim of our work at MSKCC is to generate these models and study the mechanism underlying cellular transformation and tumor development. Our approach uses the latest CRISPR-Cas9 modern techniques of genome editing in a human naïve wild type cell line (lacking any other genetic aberrations) to generate a new cell line containing the translocation that fuses together the WWTR1 and CAMTA1 genes. Our methodology, which we successfully developed for the first time in 2017 to model another sarcoma relevant translocation, presents several advantages compared to the more classic strategies. The most relevant is the possibility to induce the expression of the translocation product in a timely regulated manner allowing the study of the early steps of tumorigenesis.”

“Another important aspect we are addressing is the choice of the appropriate cell type in which the translocation is generated. It is now well known that the same translocation can generate different tumor types depending on the tissue/cell that has been targeted. We are currently investigating the effect of the translocation in endothelial progenitors, the presumed cell of origin of EHE, and we will expand our analysis to more differentiated blood vessel cells. It is pivotal to use the appropriate cell type not only to characterize the mechanism leading to tumorigenesis, but also to evaluate the response to potential therapeutic approaches.”

“The final goal of our work is to utilize these cell lines as pre-clinical models for drug screening and identification of not yet available targeted therapies to benefit patients with EHE.”

Cristina Antonescu, MD is a co-Investigator of this research and is the Attending Pathologist, Director Bone and Soft Tissue Pathology, Co-Director of Sarcoma Center, Department of Pathology, Memorial Sloan-Kettering Cancer Center (MSKCC) New York, NY.

Fabio Vanoli, PhD is a co-Investigator of this research and is an Assistant Lab Member in the Department of Pathology, Memorial Sloan-Kettering Cancer Center (MSKCC) New York, NY.

The EHE Foundation and EHE-RCFA are grateful to Drs. Vanoli and Antonescu and they look forward to continued advancements in EHE research from their lab.

A Reminder - Why Biobanking Is So Important

Did you catch where Dr. Vanoli mentioned the importance of EHE tissue donation in his research update? He stated, *“How the two genes, once fused together, cause the initiation and development of the tumor remains unknown, in part because of the lack of faithful EHE models (e.g., cancer-derived cell line) that allow us to further our understanding of EHE pathogenesis.”* The lack of models he mentioned, or rather the desperate need for models, was a significant driver in developing the EHE Biobank in the US. Similar biobanks are also available in the UK and Australia, as listed again in this edition of The Pledge.



03 EHE Fundraising

Today we are proud to have EHE-dedicated research being carried out in 4 different countries over three continents. The EHE Group remains totally focused on raising the critical funds needed to finance, drive and accelerate this existing EHE research programme, as well as the new and additional research that we hope will follow it. The EHE group want to thank all their members, their supporters and members of the public for their fundraising efforts, some of which are described below.

Grassroots Fundraising Makes a Difference

On June 6, 2022, at Briarcliff High School in Briarcliff Manor, New York, the Pediatric Cancer Club made a donation to The EHE Foundation. The club made a special presentation to the Mulligan family whose son Joe (12) has been battling Epithelioid Hemangioendothelioma (EHE) for three years. Joe's brother, James, and his friends are all members of the Pediatric Cancer Club. The club does fundraising for pediatric cancer and chooses a recipient for donation at the end of each school year. This year, the club held bake sales, holiday candy cane sales, and a Valentine chocolate heart fundraiser. In support of Joe Mulligan and his family, the club decided to donate to The EHE Foundation this year. They have also pledged continued support to The EHE Foundation.

The presentation not only included the Mulligan family, but Julie and Delaney Wahl were able to be present through FaceTime. Julie is one of the founders of The EHE Foundation and her daughter, Delaney, has been fighting EHE for 8 years. Delaney and Julie were able to express their gratitude and explain how important the donation was to them and to the whole EHE community. It meant a lot to the students to be able to meet and talk to Delaney and Joe, to actually talk to two people who will be directly affected by their hard work and donation.



The club advisor and the administration from Briarcliff Middle and High Schools supported their students' efforts and organized this event. The EHE Foundation would like to send their gratitude to the Briarcliff School District and especially, the Briarcliff High School Pediatric Cancer Club.

Associazione EHE ITALIA - Non solo Laura's first event

Early July saw the Italian EHE foundation, 'Associazione EHE ITALIA - Non solo Laura', taking part in their first event, the Tuscia Open Water 5 km swim. Jane Gutkovich posted news of the event on the EHE Support Group Facebook page:

“ Let's wish good luck and applaud the efforts of the Italian EHE Association! Raising money for EHE research!! We all are cheering for you guys.”

Then on 10th July, EHE Italia shared the news that the event had taken place:

“ Hi everyone! We want to share with you our first event participation as Associazione EHE ITALIA - Non solo Laura. Hope to keep growing and so help the research!”

Andrei Ivanescu shared some great photos of the day:

“ A few photos of the day and the recognition received from the mayor of Caprarola and from @tusciaopenwater. Thank you and congratulations also to Pamela Mancini.”

Caterina Colaci also commented:

“ Fantastic day with fantastic people! It was a pleasure to finally meet you. Thank you for the welcome.”



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Late July also saw Associazione EHE ITALIA - Non solo Laura supporting International Sarcoma Awareness Month:

We love to see the newest of our worldwide EHE foundations engaging with the global EHE

community, and we want to wish them every success in all their activities.

“ July is International Sarcoma Awareness Month, a rare cancer that affects very few people, in our case 1 in 1 million, representing 1% of all adult malignant oncological diseases. Let’s support the research to find a cure! Let’s support the Associazione EHE ITALIA - Non solo Laura, a small donation is enough!”

"I will walk 100 miles"...

Kelly Davis's brother was diagnosed with EHE in early 2022. His diagnosis came “completely out of left field” as they say, and like almost all of our members, was a shock. But also like nearly all of our other members, his family and friends are there to support him. Kelly

decided she wanted to raise funds for EHE research and so we were delighted to see her post in August about her forthcoming campaign, an amazing 100 mile trek along the South Downs Way.

Then, on 13th September, Kelly posted news that they had completed their huge walk:

“ So we made it! We completed the whole 100 Miles!!!! Back at home, slightly broken and completely drained, getting some well-deserved rest in! It’s been a very challenging yet amazing journey for us! It’s probably the hardest thing I’ve ever done in my life! The weather was against us, we had sun, wind, rain, hail and thunder storms! Literally didn’t know what weather we were going to have thrown at us each day! It was so changeable! The terrain was a huge challenge! The hills and elevation were unreal most days! You’ll be able to see that on the Strava totals, the photos just don’t do it justice you cannot see the sheer height of some of the hills and how far we had come. I tracked every day on Strava sometimes a bit late so missed a few miles here and there. We were deliriously tired some days and so stiff from the day before. Each day seemed to roll into the next. A few days there was literally nothing to see, just following stony track after stony track, then climbing higher and higher! Relentless!! No refreshment stops, just had to carry water and food with us along with our waterproof layers and everything else we needed which weighed us down even more! The last day at the Seven Sisters was by far the best day, what with the spectacular views etc. It was also the hardest with the elevation gain of 2,297ft. ”



Kelly Davis
Southdown Way 100 mile Trek for EHE Rare Cancer Charity
We are hoping to raise as much money as possible for EHE Rare Cancer Charity because it will help fund the research programme.
Event: Southdown Way 100 mile Trek, from 2 September 2022 to 9 September 2022
Participants: Karen Peel and Lorraine Wode



123%

£3,715

raised of £3,000 target
by 167 supporters



“ The best part of all this is that we have so far raised £3,390 for “The Rare Cancer Charity” to be able to help fund “The Research Programme” which we’re just over the moon about! I would like to thank each and every one of you that have donated so far! It’s honestly so appreciated!!”

“ The link is still open and will be for a while yet so if you haven’t donated and would like too there is still time <https://www.justgiving.com/fundraising/KellyDavis2022>”

“ I would like to thank Karen Peel for being the best walking partner in the whole wide world! We walked, climbed, laughed, sang, jogged, danced our way through a very long 100 miles and they are memories that I will never forget and always cherish!!!”

“ I’d also like to thank our ‘wingwoman’ Lorraine Windle for being by our side, mapping our routes, helping where she could and picking us up and dropping us off from where we last finished! You’re a star! We appreciate you so much!”

“ Now times to rest.... the thought of putting my feet in a pair of shoes within the next few days actually makes me feel sick!”



We want to congratulate Kelly and Karen for completing this amazing challenge and raising so much for critical EHE research. And we are delighted to be able to report that people continued to donate after Kelly’s post above, so that their total today stands at an amazing £3,715. This is so important, as the reality is that without people like Kelly and Karen, and the funds they raise, there would be practically no research and no new treatments for this horrible disease. So what they have achieved is really awesome. It just remains for us to say “Kelly, Karen, thank you so much”.

Go Kim, GO!

Kim Young is running the Maine Marathon on Oct 2nd! Kim was diagnosed with EHE in March 2021, and this is the second time she is running the Maine Marathon in support of The EHE Foundation. She is a champion for creating awareness for EHE, and we are grateful for her support.

Anyone who wants to donate to Kim’s team or wanted to join her team could participate in these events:

- 5K
- 10K
- Half Marathon
- Full Marathon
- Marathon Relay



03 EHE Fundraising



All donations to Kim's team benefited The EHE Foundation.

Running in memory of a dear colleague

Jess Ralph contacted the EHE Rare Cancer Charity in late September asking if they had any EHE running tops as she was running to raise funds for EHE research. The EHERCC are always delighted to provide running tops if they have them, both to support the runner, but also to spread further awareness of EHE. So they were delighted that they did indeed have the right sized top for Jess for her run on 16th October. Jess explained why she was running for EHE:

“ I am running for my friend, Al Munday, who passed away last year from EHE. He was my boss originally and then married one of my colleagues, Kate, and we all became firm friends. Kate gathered donations when Al passed away and then more recently this year when it was his birthday. I wasn't able to do anything then so decided I'd run for the charity when I was signing up to the Great South.”

We were delighted when Jess posted news of her run.

“ So great news, I made it around in one piece on Sunday (1hr 30) and the current amount raised is £1,004!”

That really is tremendous Jess. Thank you so much. And we are sure that Al would be super proud of your fantastic efforts. We certainly are.



Don't forget the free money we can get from on-line shopping

We want to just once again remind all EHE supporters that there is a valuable source of free funding available when you are shopping on line. This is accessed by shopping through sites like Amazon Smile, or Easyfundraising, and there are others. These sites will donate a small percentage of the money you spend to a charity of your choice. The different EHE foundations are registered in their respective areas and can just be selected with a simple click.

Of course the more people who do this, the greater the funds we can secure for EHE research, so please share with family and friends. In addition to your personal

spending, there may be other sources of spending that can be very valuable. A recent supporter asked their company to purchase all their stationary and office consumables through Amazon Smile, where possible. That gave immediate access to a far greater level of spending.

If you are unsure of how to do this, but want to help, please contact your local EHE foundation or charity and they will be able to assist you. Just make sure that you select the right foundation for your area.

It really is free money, and it really does add up, so if you can do this the EHE foundations would be so grateful.

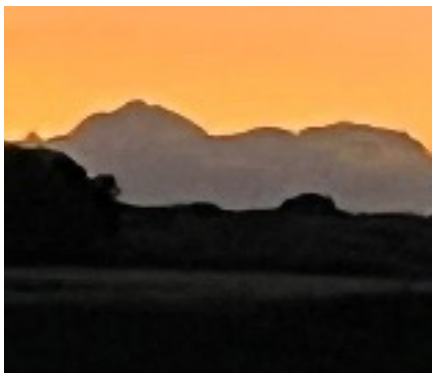


04 And in other news...

Every quarter, people will post stories or short messages that are not necessarily related to EHE. We always include a small selection of these as we think it reflects the spirit of so many of our EHE community, namely that they will not let EHE control or dictate how they lead their lives. They will **“Just Live”!** Here are the contributions for this quarter.

Photo-therapy

Every quarter people post wonderful photographs of a huge range of different subjects. These are always uplifting and we know from the many responses that the photographs are valued and do help remind people that there is more to life than EHE! This quarter has seen many such photos which we are pleased to be able to share with people here!



Carl Dixon posted these amazing photographs with some simple messages.

“Night time on the western”



“Rainbows are often considered a symbol of hope, the beauty after a storm. May there be a rainbow of hope for everyone, for whatever their need is.”



“My little swim at 9,600ft in the fresh air of Colorado! it’s my getaway from cancer and I love it.”



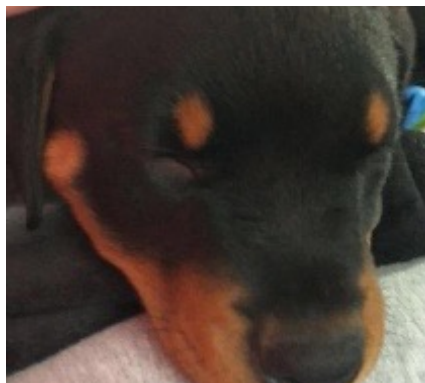
Marriage is in the air

Dee Johnston shared the wonderful news that her dad who is battling EHE cancer had married her mum, his partner of 45 years. Dee wanted to congratulate them both. This is a lovely story and we want to add our heart-felt congratulations too.

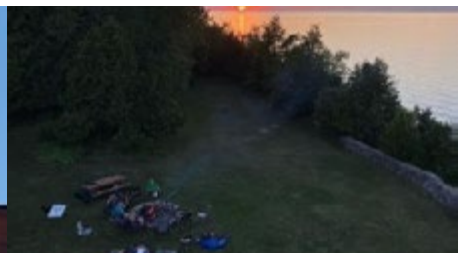
Whitney Paige Witt wanted to just share a **“cute picture for your pleasure”**. We agree, it’s very cute indeed;



Makenna DeMatteo wanted to share a photo of her new little emotional support pup to maybe brighten our day. His name is Rosco!



And Sarah Bright Yaneza sent greetings to her fellow EHE warriors! **“A little adventure with my kiddos this weekend. *Just Live!*”**



In our previous edition of The Pledge we reported on the wonderful news of Delaney Wahl’s engagement to Ethan. This quarter saw the family, including Ethan, on a short vacation to Door County, Wisconsin. Julie Rivers Wahl explained:

“Laney is starting her last year of nursing school and

planning her wedding. She has been on Sirolimus since 2016. This week, we stayed in a lighthouse and explored Door County.”

It is clear that huge amounts of fun were had by all. We love the light house! We also want to wish Delaney and Ethan success in their wedding planning!





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 - Non solo Laura

website not yet available

EHE Canada

website not yet available