

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**  
October - December 2022

the  
**pledge** **Edition 31**



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**Front cover, left to right:**

EHE-RCFA Director Di Hirsh; Dr Silvia Stacchiotti (INT Milan);  
EHE-RCFA Director Jonathan Granek; and Dr Alessandro Gronchi (INT Milan)

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# Welcome

Welcome to our quarterly newsletter, **The Pledge**, covering the key activities of the EHE Group. This is our 31st edition, for the fourth quarter of 2022.

We hope that you enjoy reading it, and are inspired by the stories included within it. As always we want and need to say a huge 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. ***“Just Live”***.



# Highlights

## **Michelle drives awareness and fundraising in Canada**

Michelle Lynn continued to run, literally, an unbelievable EHE awareness and fundraising campaign to the very end of the year, raising C\$25,500 for EHE research, and is already working on 2023.

## **Giving Tuesday matched-funding campaign a huge success**

The EHE Foundation were thrilled to report that their Giving Tuesday matched-funding campaign had successfully raised \$150,000 which will be used to fund the 2023 Research Grants Program.

## **Champions of EHE are recognised**

The EHE Foundation launched Champions of EHE to coincide with their Giving Tuesday matched-funding campaign and to recognise their contribution to the EHE cause. We are delighted to include these same stories in a special section of this edition of **The Pledge**.

## **UK signs third research contract with INT, Milan**

The EHE Rare Cancer Charity has signed its third research contract with INT, Milan. This contract will provide funding to support the set up and administration of a pan-European prospective observational registry of EHE patients, the first of its type in the world.

## **EHE Foundation Presents EHE Biobank at CTOS 2022**

We are excited to be able to report that Denise Robinson and Patty Cogswell of the EHE Foundation presented the EHE Biobank poster at the CTOS 2022 Conference in Vancouver, Canada

## **The EHE Foundation on the MSK Benefactor Wall Class of 2021**

The EHE Foundation has been formally recognised and given the honour of being included on the Memorial Sloan Kettering Benefactor Wall for 2021.

## **We say thank you and farewell to Medha**

There was sadness in the EHE Foundation in November when Medha Deoras Sutliff left her role as Executive Director, but she will be staying in touch.

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

the **pledge** Edition 31



# 01 Patient Support and Advocacy

Supporting our global patient community is a key objective of all the foundations that make up The EHE Group.

Increasing awareness and understanding of EHE amongst the general public and other relevant groups also forms a key focus of our activities, and together with patient support, form the core of the patient support and advocacy objectives that are common to all the EHE foundations. However, we recognise that we can only achieve these objectives 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.

## ***“Cancer doesn’t define me. Hope does”***

Michelle Lynn is based in Canada and after her diagnosis late in 2021 decided that she would take EHE head on, driving awareness and fundraising campaigns with huge energy and determination. The fourth quarter was no different with a series of impressive events as Michelle continued to personify our ***Just Live*** motto.

First up was the Trunk or Treat event where the whole family engaged in a **Frozen** afternoon. The family “took home the win” but far more important for Michelle was just taking part. As she said:



Only two weeks later Michelle, who hates running, participated in the Prince Edward Island Marathon, 10km event which happened to be on the Pregnancy and Infant Loss Awareness Remembrance Day. She included her children across the finish line, together with the blue balloon in memory of Gabriel, their son “**born sleeping in 2014**”. Complete with her asthma, 17 liver tumours, innumerable lung tumours, 1 thigh tumour and 1 knee tumour, Michelle ran 10kms in one hour, pushing a 58 pound buggy. Why does Michelle do this?



**“ I remember attending this event last year, 2 months after diagnosis and truly not knowing if I’d be there the following year. Well, here I am! Stronger than ever! ”**

**“ I do it to remind myself; I can; so I will, until it’s no longer a choice. I do it to feel alive. To **Just Live**, using my pain as power. ”**

And of course she does it for her family:

**“Today, I did it for them; my beautiful kids who pushed me across the finish line. My husband and family whom I fight every day of my life for, so I can keep being Momma. I can’t stop. I won’t stop. I WILL NOT STOP. I can do extraordinary things. Cancer doesn’t define me. Hope does. And to all the other Mommas, thank you for your tremendous support; to those who travelled near and far to watch me do the unthinkable. I did it and I still hate running!”**

In November Michelle posted news that CBC had asked her to do a ‘Day in the life of...’ news interview about her cancer journey. Michelle however saw the opportunity to include the wider EHE community, and asked for help and ideas.

**“What do you want Canada to know about us; about EHE? Share any facts, tidbits of info, anything you think will be great to spread the word about EHE! I’m hopeful it will not only spread awareness about EHE but also some dollars towards the PRO CARE EHE Research Team here in Canada! So please send me your ideas and thoughts. I’m doing this for US!!!”**

Fiona Ross posted news in late December that the article had been published.

**“I’m sharing this news about my fellow Canadian and EHE patient, Michelle Lynn. Thank you so much for your work and advocacy.”**

The article is a powerful description of what it is like to face and then live with an EHE diagnosis. The importance of Ty, her husband, and her three kids, Hatton, Adeline and Juliet, and the love Michelle has for them also shines through. Michelle’s medical case was also commented on by Dr Abha Gupta, her medical oncologist at the Princess Margaret Cancer Centre in Toronto.

We want to join Fiona in thanking Michelle for all that she is achieving in terms of spreading awareness of EHE, not just from this article, but all the other EHE exposure that she has delivered and that which is in the pipeline. Michelle you are an extraordinary advocate for the EHE community. We had difficulty picking our favourite photo, but eventually all agreed it had to be the photo of you running with a buggie both in front of and behind you. Run well and ***Just Live.***

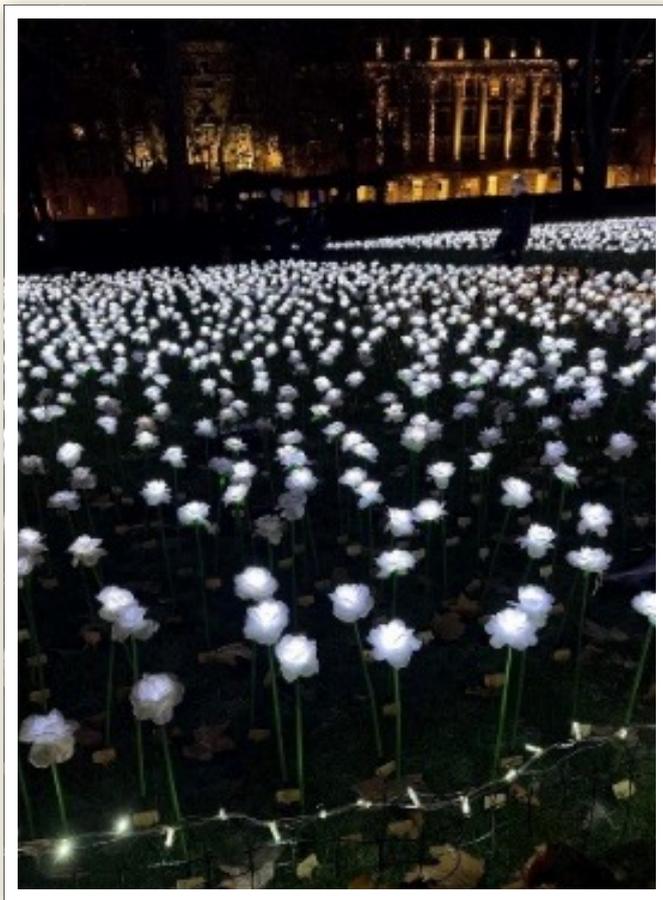


# 01 Patient Support and Advocacy

## A poignant memory

In early December, the Royal Marsden Hospital ran its annual 'Ever After Garden' programme, where thousands of white roses illuminate Grosvenor Square in Central London. Each rose is dedicated in memory of a loved one for a small donation to the Royal Marsden Cancer Charity. This year saw Dee Evans post news that she had placed a rose in the garden in memory of her lovely daughter Hannah, together with this wonderfully moving photograph.

That was a lovely gesture, Dee, and one that we are sure Hannah was watching and will have loved.



## Jane Gutkovich Talks Immunotherapy

EHE Community Connections is a virtual meeting hosted by The EHE Foundation that brings forward relevant EHE topics, such as immunotherapy. It is designed to share information while advocating for and improving the lives of EHE patients.



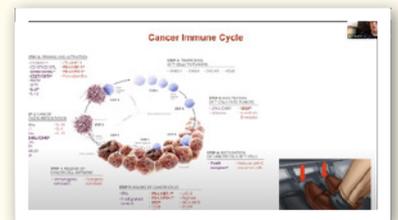
In October, Jane Gutkovich, Board Member Emeritus of The EHE Foundation, led a discussion entitled **“Immunotherapy: how it works and its role in the treatment of EHE.”**

Julie Wahl, Vice President of The EHE Foundation said:

**“EHE patients often inquire about immunotherapy. Jane helped dissect a complex topic and explained how an EHE patient’s immune system can play a role in fighting a rare cancer like EHE. We are grateful for Jane’s passion and dedication. She is a cherished member of our EHE community.”**

The recording of Jane’s presentation along with other Community Connections topics and recordings can be found at: <https://fightehe.org/community-connections/>

We want to congratulate Jane on yet another great talk, and would encourage anybody who wants to know more about the subject to watch Jane’s presentation.



## Meet-and-Greet Down Under

There's no better feeling than meeting other EHE fighters, so Jonathan Granek, Director of The EHE Rare Cancer Foundation Australia (EHE-RCFA), wasted no time in setting up a social gathering for EHE members in Sydney, coinciding with the Australia & New Zealand Sarcoma Association's (ANZSA) Annual Scientific Meeting! All agreed that it was wonderful to have the chance to actually meet in person, to share information and stories, and a few hugs.



EHE Directors Jonathan Granek and Di Hirsh OAM were there together with Jenny Shipley, a long-time supporter and ex-EHE-RCFA Director

who has lived with EHE for over 10 years; Leanne Millard another active supporter of all EHE-RCFA events who lives by our **Just Live** motto; and Brett Horley a newly diagnosed patient who is just starting his EHE journey. Jonathan Granek took the opportunity to update everybody on some of the research and advocacy projects that the EHE-RCFA and indeed the wider EHE community were engaged with.

EHE-RCFA Director, Jane Biddlecombe, who was not able to attend noted:

**“It's so weird, that these are my family, my people and seeing this photo, just makes me smile. What a wonderful get together.”**

We hope that everybody had a great time and enjoyed the get together. The smiles in the photo suggest you did!

## “Farewell” and “Thank You” to Medha

The EHE Foundation and the global EHE community said “goodbye” to the Foundation's Executive Director, Medha Deoras-Sutliff. Jenni Kovach, The EHE Foundation President, announced that Medha would be leaving at the end of November, and reminded everybody just how important Medha had been. Jenni said:

**“Medha came into the foundation at a time when we were experiencing much change and growth. She has been instrumental in building capacity, strengthening our fundraising efforts, expanding support to the EHE community, and improving our day-to-day operations. Having never heard of EHE prior to her role with us, Medha quickly became and will continue to be part of the EHE family. Please join me in thanking Medha for her tremendous work and dedication she has provided to the foundation and to our community.”**



# 01 Patient Support and Advocacy

## Fiona Ross will be speaking

Fiona Ross posted news that awareness of EHE will also be on the agenda in Canada in early 2023.

“Hopefully another success for Canadian EHE awareness, I have been invited to speak to the first year class of medical students at McMaster University on 1st February next year. Mac has a very progressive take on medical school and I am hoping to get some young, clever minds interested in EHE before they are formally trained and out practising. It is a long game, I know, but hopefully still worth it. I will be talking to them about EHE, patient advocacy and rare disease. I think they will be recording as well.”

This is wonderful news Fiona, and we are excited that these students will hear about our disease from such a strong patient advocate. Let us know how it goes and if you are able to share a link to the recording, then please do that too.

## More *Just Live* Tattoos!

Liz Walsh created a small flurry of tattoo-related posts in October with a simple question:

“... Anyone have cancer journey tattoos that you might like to share?”

An immediate response from the EHE community displayed many *Just Live* tattoos.

Many patients and supporters have their own definition of *Just Live* and the reason for their tattoo. Ronda Johnson said:

“**Keep fighting** and **Just Live** are a reminder that all my day-to-day efforts are part of the fight and to live as myself, not defined by my disease!”

We believe Georgiana Trandafir would have loved to see them, too, and would have been so happy to see how popular they have become. In December, Jane Gutkovich explained:

“Today is the birthday of Georgiana Trandafir, an EHE warrior who gave this group our famous **Just Live** motto. Georgiana would be 38 today, but EHE took her life just a few weeks before her 30th birthday. Georgiana joined this group when she was already quite unwell, going through chemo, and radiation, but she immediately joined us in spreading awareness and working on the registry. She worked so hard! We often didn't know how sick she felt!

Shortly before she lost her battle with EHE, Georgiana posted a tattoo image, a heartbeat with the words *Just Live*, which she wanted to get as a sign of her defiance and to beat this monster. She sadly never got it. But *Just Live* became the inseparable motto of our community, with dozens of our members now having this tattoo. I send Georgiana a happy birthday message every year, I miss her. **Just Live!**”

Learn more about the *Just Live* motto here: <https://fightehe.org/just-live/>



## A Heartfelt Meeting

Our EHE Community spans the globe and its very special when our members get together and meet face-to-face. Dee Evans (UK) and Karen Tuttle (US) rejoiced in finally meeting each other, while never forgetting the sadness of what had brought them together. Dee explained:

**“We know EHE is one of the worst things on God’s green earth and can bring a lot of heartache and pain, but here is one of the best things about EHE. This FB page brings us altogether as one family, irrelevant of age, colour, creed or where we live.**

**This wonderful woman, Karen Tuttle, helped me through so much pain, so many dark days and I hope I have done my little bit to help her. We both lost our beautiful babies to this disgusting disease. Karen in Orlando, FL (US) and me in UK. I promised we would meet up one day. And that day was today. My family and I are on holiday in Orlando and took a trip to Clearwater, FL to scatter some of my daughter’s ashes. But today, I met my kindred spirit, this woman of strength and love and absolute resilience. Today was the best day in my EHE lifetime.”**

We all wish that Dee and Karen had never had any reason to meet each other or need to offer each other help and support. However, we are grateful, considering the sadness that they have both endured, that they were able to have this special time together. It’s a great reminder of the importance of the support that comes from within our own EHE community.



## Welcoming New Directors and Medical Advisors

The EHE Rare Cancer Foundation Australia (EHE-RCFA) held its AGM on November 28, 2022.

Directors, registered members and interested patients attended this online event to learn first-hand about the exciting work and accomplishments over the past year, including promising research projects which are being supported.

The AGM saw the re-election of Founding Directors Jane Biddlecombe, Jonathan Granek and Anthony Wise with expressions of interest from two additional volunteers. The EHE-RCFA is pleased to welcome and introduce the following new directors, Maggie Cadona and Dianne Hirsh OAM to the EHE-RCFA Board.

Maggie has been a long-time supporter of the EHE-RCFA, actively volunteering and participating in EHE fundraisers since 2016. She brings over 20-years’ experience in small business management. Whilst assisting the EHE-RCFA with its finance management and compliance, Maggie has expressed that she’s also keen to learn and support in other day to day aspects of the foundation.

Di brings a wealth of experience having worked in the Not for Profit sector for over 20 years. A former lecturer and tutor in Linguistics, Di has previously worked on patient information leaflets for Monash University for Arthritis. More recently Di took on the role of fundraising coordinator in 2022 and led Australia’s EHE Rare Cancer Challenge campaign.

The EHE-RCFA was also pleased to announce at the AGM that Dr Silvia Stacchiotti accepted an invitation to join the EHE-RCFA’s Medical Advisory Panel and has already begun to facilitate introductions with the INT research team.

With the additions of Dr Stacchiotti, Maggie and Di, the EHE-RCFA looks forward to expanding and enhancing its operations to better serve the EHE community.



# 01 Patient Support and Advocacy

## Dr. Vesel and Dr. Maeve Baechler - Round 3

The EHE Community Connections program has included sessions led by Dr. Tamara Vesel and Dr. Maeve Baechler. These sessions have been addressing the issue of **“Who am I now? Integrating the Cancer Identity into the Self”** and have received very positive feedback. November 12th saw Drs. Vesel and Baechler conducting their third session in their series of talks. Maggie Cameron, EHE patient, commented:

**“These sessions are fantastic. They've really helped me to learn how I integrate EHE into my identity. Both doctors come from an amazing place of support and warmth. I look forward to the next session on Feb 11th. I also love that I don't have to attend every session to get so much value from participating!”**

Dr. Vesel, MD, Tufts University School of Medicine, is a palliative care physician and has extensive experience in pain management. She has become an invaluable resource to the EHE community as she helps to create safe spaces for people to meet, talk, and reflect on their identify as EHE patients. Dr. Baechler is an EHE patient herself and provides life coaching for cancer patients. She also generously translates EHE Group materials into German. Both generously give their time and talents to help EHE patients and are an integral part of our EHE community.



## EHE Chat with Leah

The EHE Chat program, a series of informal Saturday get togethers where EHE patients and supporters can come together to literally share a virtual coffee, meet each other, and discuss anything they want to, have proved a great success.

November saw the latest of these sessions where Leah Heinrich talked about her EHE experience, spanning diagnosis, liver, and lung involvement, Sirolimus treatment, a clinical trial, and tumor ablation.

Leah said:

**“Although no EHE case is exactly the same, it helps to know that other EHE patients are going through similar experiences. I shared my story in hopes that it will help other patients in the chat to know they are not alone. If it helps one patient, it is worth it.”**

To maintain confidentiality sessions are not recorded and no details of the chat are disclosed, but we do want to thank and congratulate participants for their openness and willingness to help others.

## Keren Stern at Hockey Fights Cancer

In November, Keren Stern enjoyed Hockey Fights Cancer Knight, which is hosted by the Vegas Golden Knights hockey team. Here is Keren with her **“I Fight For”** sign with the Knights mascot, Chance.



## EHE-RCFA Director, Jonathan Granek Recognised for his Consumer Representation and Advocacy Work

The EHE Rare Cancer Foundation Australia were proud and pleased to report on the recognition of the work of EHE-RCFA Director, Jonathan Granek, who was invited to present to the Peter Mac Community Advisory Committee (CAC) - a subcommittee of the Peter Mac Board.

Jonathan has always been a keen advocate for effective consumer involvement and spoke at the September meeting about his own experiences as a rare cancer patient, work with Australian research institutes and researchers, and the advocacy work he does for the EHE Rare Cancer Foundation Australia.

The committee's purpose is to provide advice and guidance to Peter Mac's Board of Directors in relation to the integration of consumer and community views.

This group helps to drive the integration of consumer, carer and community views into strategic planning and health service development across the hospital, for the benefit of patients and the broader community.

We also want to congratulate Jonathan for his excellent and dedicated work representing and promoting the EHE patient community. It is indeed hard to think of a better advocate for our cause.

## A night at the Knicks

In November, EHE patient Joe Mulligan attended a Knicks game as a guest of honor. Not only did the Mulligan family use the exciting opportunity to create EHE awareness, but Joe shared his resiliency and positive attitude with the NY Knicks basketball



team. Jennifer Mulligan said:

**“Joseph was invited to not only enjoy VIP seats under the net on the floor for the NY Knicks basketball game, but he went ahead as head coach for the night, too. This enhancement gift from Make-A-Wish allowed him to meet the players at Madison Square Garden. He even hung out with the players on another occasion. Joe wore an EHE pin and gave out pins to spread awareness of EHE.”**

Thanks again to Team Mulligan for continuing to share our mission and thanks to Make-A-Wish for providing Joe with this fun experience.

## Sharing a Bit of her Story

Kate Czyzewski, EHE patient, shared a link in December to an article and said, **“I’m grateful to Jersey’s Best magazine for allowing me to share a bit of EHE with their readers.”**



It was also wonderful to read about Kate's job in her own words:

**“With anybody going through any sort of medical diagnosis, you realize how time is precious. There are a lot of blessings that are in my life right now, like being the manager and events coordinator here at Thunder Road Books in Spring Lake. I decided to launch a second career here, and it has been such a magical community that we’ve built here. So, being able to get up and do this every day has been very, very cool.”**

Thank you, Kate, for inspiring all EHE patients to follow their true passion and for this exposure for EHE.



# 02 Champions of EHE

The EHE Foundation launched 'Champions of EHE' in early November:

Our vision at The EHE Foundation is to live in a world where EHE is easily diagnosed and treatable. The support of our community directly impacts every single person diagnosed with EHE. Patients, donors, doctors and researchers help us make that vision a reality.

During our Giving Tuesday 2022 campaign, we featured these “Champions of EHE” to show our gratitude for their sacrifice, generosity and dedication. Each one of them has demonstrated ongoing compassion for our mission and for those affected by this rare, one-in-a-million cancer.



## Ajay Pobbati, PhD, RESEARCHER

Ajay Pobbati, PhD, is a passionate researcher at the Cleveland Clinic Lerner Research Institute investigating the Hippo pathway and potential therapeutic targeting strategies. The EHE Foundation are excited to have awarded Ajay a 2022 EHE Research Grant, where he aims to identify an FDA-approved drug for EHE treatment.

Outside the lab, Ajay is an energetic father who enjoys traveling, reading, and tasting various types of cuisine and cocktails. We are grateful for Ajay's talents and contributions to the EHE community - he is a true EHE champion.



## Jeff Holding, DONOR

The support of generous donors like Jeff Holding directly impacts every single person diagnosed with EHE and helps us make that vision a reality.



**“We are steadfast supporters of the EHE cause as having it hit so close to home made us first aware of this horrible disease. Yet, because it is so rare, very little is known about it, thus making it imperative that we support the Foundation’s goal to learn more about this cancer, how to battle against it, and work toward finding the eventual cure. We hope our involvement will inspire others to help.”**

Jeff Holding



# 02 Champions of EHE

## Aimee Liebert, PATIENT

Aimee Liebert is a powerful advocate who was diagnosed in July 2022. She has allowed EHE to make a positive impact on her life.

“Cancer is very silent to others, but very loud for the individual who is diagnosed. Most people look at me like I am a normal, healthy person, and I know question **“Is she really sick?!”** You can’t see my scar or my constant pains, worry, and stress.

EHE has made me more aware and positive towards people and life in general. I try to be more of a DOER now, only because so many people asked me at my initial diagnosis how they can help, which is a very loaded question. It’s hard to ask for help when being diagnosed is so fresh and a major shock. I now just DO for others, maybe it’s as simple as a smile to a stranger, paying for a meal for someone, dropping kindness off, or just doing my best to see things in a positive perspective, which at times I have to remind myself! I want to show my kids and others that challenges in life can make you stronger and a better person. Notice others, pay attention, ask questions and listen, be selfless, and be kind.

This EHE diagnosis is a part of my life now (as there is no cure), and I chose to make it impact my life as something positive. I hope I can help empower others to fight with positivity and strength. Keep perspective in life and remember everyone has challenges in life, but how you choose to face them will make all the difference. No one can really understand and relate to your situation, so instead of being frustrated or feeling let down, know you are strong... smile and you know you’ve got this.”



## John Lamar, PhD, RESEARCHER

John Lamar, PhD, a passionate EHE researcher at [Albany Medical College](#) who investigates the role of the Hippo pathway in cancer progression and metastasis. John's research is focused on identifying potential FDA-approved therapeutic targets for EHE.



The EHE Foundation is so excited to have awarded John with a 2022 EHE Research Grant which was generously matched by private donations to fund his multi-year research. In addition to his research, he devotes time to teaching and training young investigators - developing future generations of EHE researchers. Outside the lab, John is an energetic husband and father of two who enjoys hiking, kayaking, fishing, and being outdoors.

**“While there is still a lot of work to be done, the progress that has been made in the EHE field in the past few years is remarkable. I believe that if we can sustain this momentum, more effective EHE treatments are within our reach.”**

said John. We are so grateful for John's talents and contributions to the EHE community - he is a true EHE Champion.

## Valerie Kouskoff, PhD, RESEARCHER

Valerie Kouskoff, PhD is a passionate researcher at The University of Manchester in the UK. The EHE Foundation is also excited to have awarded Valerie a 2022 EHE Research Grant where she aims to investigate the druggability of the DNA damage response interference by TAZ-CAMTA1. Valerie has been researching EHE since 2016.

Outside the lab, Valerie is enthusiastic about gardening, reading and enjoys long walks in the Peak District with her dog, Teddy. We are grateful for her talents and contributions to the EHE community - she is a true Champion of EHE.



# 02 Champions of EHE

## Makenna DeMatteo, PATIENT

Makenna is 14 years old and was diagnosed with EHE in June 2022. She shared about her EHE diagnosis:

“It has changed my life by showing me that I should be grateful for the things I have in my life. Examples of those would be my family, my friends, just being able to take a breath of fresh air, being able to live my life without worrying I may get sick, or worrying people will make fun of me for something I would never wish upon anyone else.”

As an EHE Patient, Makenna’s inspirational advice to others who are diagnosed with EHE is:

“Live your best life, to the fullest. Life is hard, but it is worth living. I never realized how well I had it and how amazing it was to be healthy until this tumor started forming. I realized some people have to fight for the privilege of experiencing life experiences with those they love. Be strong, and focus on what’s important, don’t let the little negative things ruin your fighting spirit!”



## Amy Houston, PATIENT

“EHE has changed every aspect of my life, and surprisingly, a lot of them, for the good. You think of a cancer diagnosis affecting the physical body, which it does. But for me, the most challenging part has been in my mind. Coming to terms with this new unwanted adjective/label, cancer patient, has been surreal. Prior to my diagnosis, I’d describe myself as an extroverted, positive, high-functioning, type A, overachiever, unselfishly giving, and tying my self-worth to crossing items off my to do list.



After my initial diagnosis, in retrospect, I was in denial. I did not want to tell anyone outside of my immediate family. I’d get the surgery and just move on with my life. I had one, small, rare tumor - this was an anomaly, just another problem to be fixed. After the first surgery, I focused all my attention on my physical health, thinking if I could find the right combination of supplements, yoga, acupuncture, plant-based diet (insert anything), I could prevent a reoccurrence and control this situation.

When the cancer came back and required another surgery, it really affected my mental state and shook my illusion of control and sense of self. It also brought up a lot of challenging feelings and unwanted emotions, I was not prepared for or equipped to deal with. Fortunately, I was referred to an amazing therapist specializing in working with cancer patients. Having a supportive family,

caring friends, and spirituality is great and a blessing, but having a therapist where you can share your unfiltered thoughts and work through very challenging (and normal) emotions is vital. For anyone that is struggling, I highly recommend getting a good therapist.

Of course, there are good days and bad days, but working with my therapist and with help from my support network, I have been able to reevaluate how I approach and prioritize my life. I've been able to ask for help (gasp), be honest about my feelings and ask for what I need, be more present (a work in progress), and change my self-worth value structure. I'm not sure I would be at this point without the diagnosis and my therapist.”

Amy Houston

## Bridget Zito, PATIENT



“The most difficult part of being diagnosed with EHE and living with it is how much it has changed me and my family. I have been so sick, I have lost so much weight, I barely have any energy, and I experience pain every day. My EHE is only in my liver. My family and friends have really rallied around me and I know I am not alone.”

Bridget Zito

## Colin Straub, PATIENT



Colin, 14 years old, was diagnosed in 2021 with this one-in-a-million cancer:

“EHE has changed my life because it has limited some of the sports and activities I can do. Before my diagnosis I had a lot of abdominal pain that impacted the sports I love, but with treatment I am able to keep playing baseball and basketball to my full potential! My doctors encourage me to stay active and play my sports. Exercise and weight training has helped me keep a positive attitude while increasing my strength and improving my performance on and off the baseball field and basketball court. It's important for me to do activities and things I enjoy and while EHE has changed my life it hasn't stopped me, I push myself and work hard - **Just Live!**”

Colin Straub



# 03 EHE Research

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

## Tyler Davis accesses clinical trial

In an ideal world a patient's medical team would be aware of every clinical trial that is ongoing that relates to their disease, and would be providing a running commentary on these opportunities and their application to the patient's specific circumstances. In an ideal world. However, we are aware that medical teams cannot be knowledgeable about all clinical trials and research developments, and this is why self-advocacy is so important.



In the UK, EHE patient Tyler Davis was investigating and researching clinical trials that would be appropriate for EHE. To his surprise, Tyler found what looked like the perfect fit for his progressive EHE and clinical history, and was amazed to find that the core trial team were based at the hospital he attended in the UK.

At his very next consultation with his oncologist, Tyler asked if he would be eligible for the trial. His case was reviewed, appropriate tests were done and the answer

was yes! Tyler was then pleased to be able to update the EHE community with these developments:

**“I have officially begun participation in an international phase 2 immuno-sarc clinical trial with UCLH for a combined treatment of Sunitinib and Nivolumab. The trial is exploring the effectiveness of the treatments against ultra-rare sarcomas. I'm told this is one of the first trials of its kind in the UK, and I am presently the only person with EHE on the trial. Immunotherapy is not currently available in the UK for treatment of Sarcomas, I hope the trial will yield positive results, not just for myself, but for all in our community and beyond, and give hope to those in the future.**

**I'd like to give thanks to UCLH, and the trial sponsors, Grupo Español de Investigación en Sarcomas (GEIS) and The Jon Moulton Charity Trust. I will update the group as the trial progresses and with the results of future scans. Wish me luck. #justlive.”**

While **The Pledge** does not include detailed clinical information about the nature of a patient's EHE or their clinical treatment, we were delighted to read Tyler's first updates from the trial which were positive.



Tyler was able to report that:

**“ The trial doctors are very happy with the results. ”**

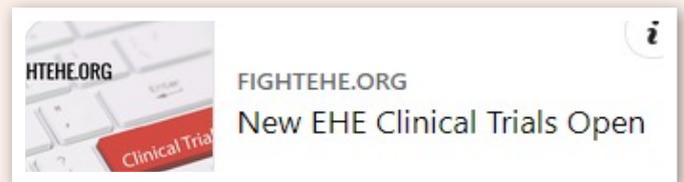
We also loved Tyler’s forward-looking statement, namely:

**“ I’m going to kick EHE’s arse. ”**

Tyler will be continuing to post updates on the EHE Support Group page on Facebook, so anybody who wants to follow Tyler’s journey can do this by searching the Facebook page under the name of Tyler Davis. We want to thank Tyler for sharing all this information, and indeed for joining the trial and being a trail-blazer for our patient community. We of course also want to wish him continued success. Long may his doctors continue to be happy with his results!

Further details of this trial can be found at: <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-of-sunitinib-and-nivolumab-for-sarcoma-immunosarc2>

Jenni Case Kovach, President of The EHE Foundation in the USA also wanted to remind all EHE Patients that The EHE Foundation works hard to maintain its clinical trial resources on its website at: <https://fightehe.org/ehe-clinical-trials/>



We would note that often clinical trials may be country specific, so understanding what is available in your country of residence is important. Also, the different EHE foundations would love to hear of any clinical trials that EHE patients become aware of and that are open to EHE patients so that we can ensure the resource is as up to date and complete as possible.



# 03 EHE Research

## The EHE Foundation Presents EHE Biobank at CTOS 2022

Denise Robinson, Director of Research and Patty Cogswell, EHE Biobank Coordinator for The EHE Foundation highlighted the EHE Biobank (US) in a co-authored poster entitled: **EHE Biobank | Patients Powering Rare Cancer Model Development & Translational Research** at the 2022 Annual Meeting of the Connective Tissue Oncology Society (CTOS) in Vancouver, British Columbia, Canada. The meeting, held in November, brought together hundreds of physicians and scientists from around the world with an emphasis on sarcoma clinical care and research (EHE belongs to a group of cancers called sarcomas).

The poster highlighted that today, there are no human EHE cell lines in existence. It also highlighted the publication of the first EHE PDX (patient derived xenograft) model recently developed at the Istituto Nazionale Tumori (INT) in Milan, Italy by Dr. Nadia Zaffaroni and the EHE GEM model (genetically engineered mouse) developed by Dr. Brian Rubin at the Cleveland Clinic, Ohio USA.

To address the unmet need of biospecimens which are required to make EHE models (cell lines and other disease models) and to advance EHE research, The EHE Foundation initiated the EHE Biobank. The EHE Biobank is a patient-led initiative aiming to centralize EHE biospecimens, making specimens readily available for ethical research while actively seeking research partners to develop additional EHE models.

At the time of the poster presentation, 51 patients had engaged with the EHE Biobank Coordinator, 33 participants had provided Informed Consent, 18 EHE biospecimens were successfully collected. Of the specimens collected 15 have been distributed to researchers to advance EHE research. The poster can be seen on the following double page spread.

Denise Robinson noted:

**“ it is important to understand that not everyone who provides their Consent to donate tissue or other body fluids to the EHE Biobank actually has a procedure scheduled that would allow collection of a biospecimen. We often talk with people who are interested in donating when or if they have a surgery or fluid drain in the future - they are just being proactive, and we are grateful. ”**

Denise continued:

**“ if you have questions about how you can contribute to the EHE Biobank, or how the process works, please do not hesitate to get in touch with the Biobank staff by emailing [biobank@fightehe.org](mailto:biobank@fightehe.org) ”**

Jenni Kovach, President of The EHE Foundation, who donated a tissue sample herself following surgery earlier in the year, also posted messages to encourage patients to support the EHE Biobank under the slogan **“It’s easier than you think”**. In addition, Jenni wanted to express the Foundation’s gratitude to existing biobank supporters:

**“ It is with sincerest gratitude that we extend our thanks to each patient who has contributed to the EHE Biobank. Not only have you advanced research in EHE, you have placed EHE patient-driven research on the global stage! ”**



We also want to remind our readers that it is not just The EHE Foundation that has established EHE Biobanking capabilities. Here are details for other EHE biobanks:

### UK Biobanking

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](mailto:EHEbiobank@rmh.nhs.uk) ; or
2. Hugh Leonard at the EHE Rare Cancer Charity (UK) at [hleonard@ehercc.co.uk](mailto:hleonard@ehercc.co.uk)



### Australian biobanking

In Australia, biobanking is being coordinated 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](mailto:info@ehfoundation.com.au)



# 03 EHE Research



## EHE BIOBANK | PATIENTS POWERING RARE CAN

AUTHORS | Denise Robinson, deniserobinson@fightehe.org, 127 E. 4th Street, Corning  
 Patty Cogswell, rarebiorepositoryconsulting@gmail.com, 165 Mensink Rd,

### OBJECTIVES

Epithelioid Hemangioendothelioma (EHE) is an ultra-rare vascular sarcoma with a prevalence of less than 1 per million people.<sup>1</sup> The rarity of this disease, like many rare cancers, presents significant challenges in basic and translational research. In addition to the rare incidence of EHE, researchers studying EHE may not be affiliated with a center treating EHE patients, limiting the opportunity to collect EHE tumor tissue and other biospecimens. EHE biospecimens that are obtained during procedures or surgeries are most often retained at patients' treating centers and are not readily available to researchers. These challenges inhibit EHE model development, as well as basic and translational research due to insufficient availability of EHE biospecimens.

There are relatively few scientists working directly with EHE specimens and today, there are no human EHE cell lines in existence. Recently, the publication of the first EHE PDX (patient derived xenograft) model has been developed and is available<sup>2</sup>; additionally, one EHE GEM model (genetically engineered mouse) was developed in 2021<sup>3</sup>. To address the unmet need of biospecimens required to advance EHE research, The EHE Foundation initiated the EHE Biobank: a collection of biospecimens and clinical data to facilitate research. The EHE Biobank is a patient-led initiative aiming to centralize EHE biospecimens, making specimens readily available for ethical research while actively seeking research partners to develop additional EHE models. The Biobank collects fresh EHE tumor tissue from prospective surgeries as well as archived EHE tumor tissue. Additionally, the Biobank collects serosal effusions, blood, and saliva.

### METHODS

The EHE Foundation engaged expert pathologists and clinicians in the sarcoma medical community, disease-expert patient advocates, EHE researchers, and other rare cancer advocacy organizations to develop a centralized collection of EHE biospecimens. An expert scientist in the field of biobanking, specifically for rare cancers, was enlisted to serve as the EHE Biobank Principal Investigator and Coordinator. A working team was formed to develop the Biobank protocol, Informed Consent templates, and work processes.

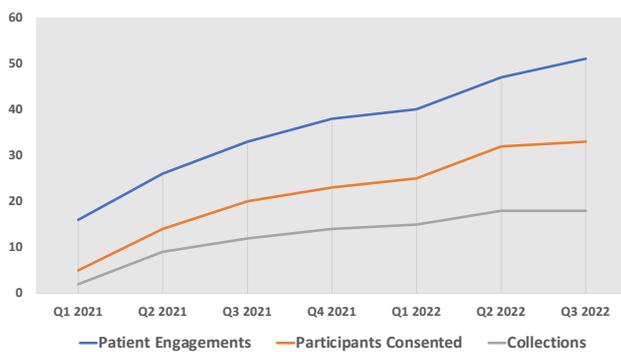
The Foundation took great care in order to identify the institution best suited to serve as the central repository for this ultra-rare cancer. We anticipated fewer than 50 samples per year and assumed close attention would be required during each specimen collection in order to maximize the utilization of each specimen and expedite distribution of specimens to researchers. The Cleveland Clinic BioRepository was selected for its highly skilled team, the capability to provide tailored processes and access to an expert pathologist for a confirmatory assessment of each specimen to verify the EHE tumor-defining gene fusion.

The protocol and supporting documents were reviewed and approved by North Star Review Board, a central Independent Review Board. The protocol was designed to collect biospecimens from participants in the United States only. Specimen collection began in February 2021.

The EHE Foundation is using several mechanisms for patient engagement including its website, [www.fightehe.org](http://www.fightehe.org), newsletters, direct emails, in social channels and in private online patient communities.

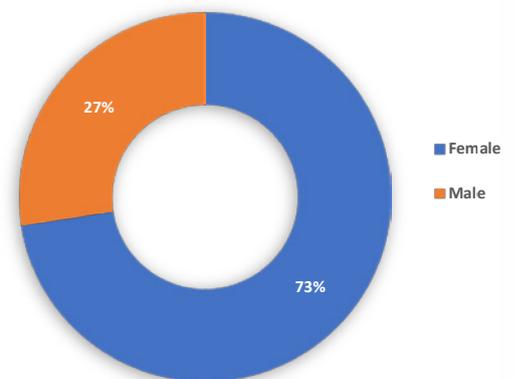
A process for participant engagement was developed to ensure consistency in communications, effective reporting and follow-up from the earliest points of contact with each interested participant. The Biobank Coordinator facilitates the Informed Consent process virtually with each prospective Biobank participant. Informed Consent is administered electronically.

### Patient Engagement & Specimen Collection



Specimen Collection & Distribution	No.
Participants with Data	33
Participants Donated Specimens	17
Tissue Specimens Collected	12
Fluid Specimens Collected	6
Normal-Adjacent Tissue Collected	1
Matched Blood Samples	4
Specimens Distributed to Researchers	15

### Engagement by Gender



## CER MODEL DEVELOPMENT & TRANSLATIONAL RESEARCH

, NY, USA, Director of Research, The EHE Foundation, BA, Research Management  
 Loon Lake, NY, USA, Consultant, Cogswell Consulting, LLC, MS, Biobank Coordinator

### RESULTS

The EHE patient community is highly engaged with The EHE Foundation, readily utilizing The Foundation’s Patient Services team as a resource. Leveraging patient engagement among an active private network of over 2,000 EHE patients and advocates, The EHE Foundation actively promotes the Biobank via social media, patient conferences, events, by email and newsletters, and by communicating with clinicians treating EHE patients.

At this time 51 patients have engaged with the EHE Biobank Coordinator, 33 participants have provided Informed Consent, 18 EHE biospecimens have been collected. Of the specimens collected 15 have been distributed to researchers.

Additionally, engagement among medical and scientific stakeholders in the EHE community has grown significantly during the past 1.5 years. The Foundation has enlisted partner researchers to attempt to develop EHE cell lines using fresh tissue distributed from the EHE Biobank, and while no cell lines have yet been confirmed, we are optimistic for success in the near term. The Foundation is also assessing what additional data we would like to generate on collected biospecimens that could provide information to the scientific community and drug developers.

Key learnings emerged early-on after the project was initiated, revealing the importance of confirming EHE in each sample collected. Because EHE, like other sarcoma sub-types, is commonly misdiagnosed, The EHE Foundation recognized the need to return any findings indicating that a biospecimen was not confirmed as EHE. Thus, the Biobank protocol was amended to permit the return of any such finding to a participant’s care provider engaged during the collection process with a goal to better inform participant medical care.

### CONCLUSIONS

Patient advocates and people living with EHE have the ability to significantly advance rare cancer research and are uniquely positioned to accelerate EHE model development by donating human specimens. Patients’ care teams are integral to this process and are essential in helping advocates educate patients about the importance of contributing to this non-interventional research. In summary, a collaborative approach to engage participants, centralize collected specimens, and actively distribute EHE biospecimens is essential to advancing translational research.

Ongoing active engagement of the EHE community, including advocates, patients, clinicians, and researchers is vital to increase awareness of the importance of specimen donation and its impact on EHE research.

### REFERENCES

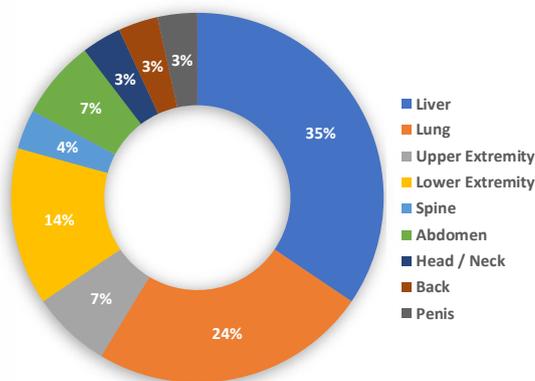
- doi:10.4081/oncol.2014.259
- J Clin Oncol 40, 2022 (suppl 16; abstr 11566)
- <http://www.genesdev.org/cgi/doi/10.1101/gad.348220.120>

### ACKNOWLEDGEMENTS

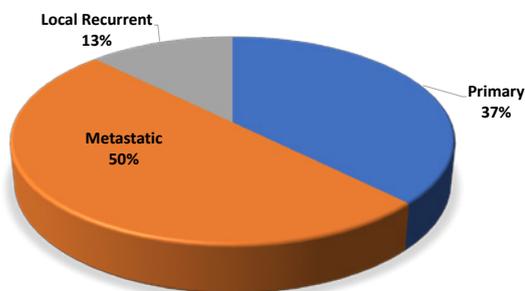
This project is supported by a grant from the Chan-Zuckerberg Initiative Rare As One. The EHE Foundation is grateful for the dedication and expertise of Dr. Brian Rubin, Chair, Pathology & Laboratory Medicine at The Cleveland Clinic and for the partnership of the Cleveland Clinic Biorepository.

The EHE Foundation is grateful to patients who have donated specimens to the EHE Biobank. These patients have given an invaluable contribution toward the advancement of EHE research, and with their gift they give hope for a world where EHE is effectively treated and cured.

**Original Tumor Location**  
 (of Consented Participants)



**Specimen Collection by Disease State**



# 03 EHE Research

## ANZSA Annual Scientific Meeting

The Australia & New Zealand Sarcoma Association (ANZSA) hosted its Annual Scientific Meeting in Sydney (4-5th Nov) which brought top sarcoma clinicians and researchers together with patient advocates. The EHE Rare Cancer Foundation Australia (EHE-RCFA) were of course present, represented by EHE-RCFA Directors Jonathan Granek and Di Hirsh.

This was a fantastic opportunity to network with clinicians and researchers, and hear from International Guest Speakers including Dr Silvia Stacchiotti who showcased EHE as a role model sarcoma effort.

### Special guests:

Jane Biddlecombe, President of the EHE-RCFA, was excited to be able to report on special visitors attending the conference:

**“Every now and then a clinician comes along that changes the game! Moves the EHE community forward in a novel and impactful way, who is inquisitive, motivated and genuinely cares for patients. In our rare cancer community, these special people can offer hope for a cure, or a treatment that works. So when we heard that Dr Stacchiotti and Dr Gronchi had been invited to speak at the Australian Sarcoma Conference, it was a golden opportunity to close the circle and introduce the Australian EHE Foundation.”**

Jonathan Granek made personal and direct introductions to the EHE-RCFA Medical Advisory Team. It was an important milestone and opportunity for the Australian foundation to share their story and how Australia can contribute to the overall EHE cause. Extensive discussions on a number of EHE topics took place with agreement to follow up on a number of items.

### Dr Susie Bae:

Jonathan Granek and Di Hirsh also met with Dr Susie Bae, clinical research fellow for the Australia & New Zealand Sarcoma Association (ANZSA) and an experienced medical oncologist based at the Peter MacCallum Cancer Centre. Dr Bae is also the National Lead overseeing the Australian Sarcoma Database which collects comprehensive sarcoma datasets from sarcoma centres across Australia.

Dr Bae has seen many EHE patients over the years. As a result of Jonathan's decade long clinician / patient relationship, Dr Bae has seen the passion, the work and the outcomes of the EHE-RCFA and is happy to assist the EHE-RCFA in her role as National Lead of the Australian Sarcoma Database.



## EHE Expert Clinicians & Researchers Presented at CTOS 2022

In addition to Denise Robinson and Patty Cogswell presenting at CTOS 2022, Dr. Silvia Stacchiotti, Istituto Nazionale Tumori in Milan, Italy, also presented a poster entitled: **Preliminary assessment of circulating inflammatory cytokines in epithelioid hemangioendothelioma (EHE) patients and in an EHE patient-derived xenograft before and after doxorubicin and sirolimus.** Dr. Stacchiotti is a fierce advocate for EHE patients and a leader in the ultra-rare sarcoma (EHE is not just rare, it is ultra-rare) community of experts and continues to bring EHE research to the forefront of this CTOS working group.

Dr. Scott Okuno, Mayo Clinic, Rochester, MN presented at the SARC Semiannual Meeting as part of CTOS 2022. SARC (Sarcoma Alliance for Research through Collaboration) is a non-profit group of physicians dedicated to sarcoma research, treatment, prevention and cure. Dr. Okuno was recently appointed Chief Medical Officer for SARC, and also serves on the Board of Directors and Scientific Steering Committee.



Patty Cogswell, EHE Biobank Coordinator with Denise Robinson, Director of Research

Denise Robinson and Silvia Stacchiotti, MD

Scott Okuno, MD and Denise Robinson



# 03 EHE Research

## Recognition of our Research Support

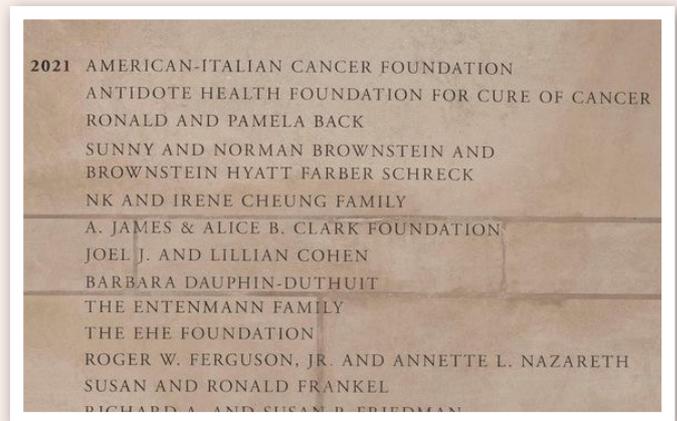
In December Jane Gutkovich shared some wonderful news:

“In recognition of the generous gift to MSK made possible by a private donation, Sloan Kettering Cancer Center has listed The EHE Foundation on the Benefactor Wall Class of 2021! It is a very honorable acknowledgement of our contribution to EHE research, and something this community should be very proud of!!”



Denise Robinson, Director of Research agreed and added:

“We are proud of our partnership with Memorial Sloan Kettering Cancer Center. Patients around the world benefit from the world-class innovative research that takes place at MSKCC in New York City (US). In 2019, MSKCC received a \$1 million 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. The Benefactor Wall is located in the lobby of the Rockefeller Research Laboratories building, 430 East 67th Street, New York, NY, and the inclusion of The EHE Foundation is a beautiful acknowledgement of the contribution to advance the understanding of EHE. This memorial wall represents that together, we are moving mountains in EHE research and clinical care.”



We want to congratulate The EHE Foundation on this special tribute which does indeed reflect and acknowledge the contribution to EHE research and treatment ultimately delivered and driven by the EHE patient community through The EHE Foundation.

## UK signs latest research agreement

The EHE Rare Cancer Charity (UK) was delighted to sign the third of its research contracts with INT in Milan, Italy. With many questions still unanswered regarding EHE, its progression from indolent to progressive, and the lack of systemic treatments, this third contract includes funding for three years to establish and start a pan-European and UK prospective EHE dedicated, clinical registry. The registry will be called PROSPHERES, an abbreviation of: Prospective EHE Registry.

This study will aim to provide a description of the population affected by EHE, giving an insight into the natural history of the disease and its variants, leading to the possible identification of clinical and biochemical prognostic and predictive factors and answering some of the outstanding questions on its management. The primary objectives of the study will include:

- Demographic description of the population affected by EHE

- Description of the natural history and outcome of the disease as a whole and of the three EHE main variants based on disease extension:
  - 1) Primary, localized, single lesion (unifocal disease);
  - 2) Loco-regional (multifocal single-organ involvement)
  - 3) Systemic metastases (multi-organ involvement including loco-regional lymph-node involvement)
- Description of tumour-related symptoms and their changes over time
- Description of tumour-related pain and changes overtime
- Description of current treatment approach for localised disease
- Description of current treatment approach for metastatic disease
- Assessment of disease response to local therapies (radiation therapy, local ablative techniques, ILP, others)
- Assessment of disease response to systemic therapies (cytotoxic chemotherapy, mTOR inhibitors, anti-angiogenic compounds, others)
- Identification of biological and clinical predictors of response to medical therapies
- Identification of biological and clinical prognostic factors
- Description of outcome

The PROSPHERES study will be incorporated in and administered within the STARTER project. STARTER is a Health Programme funded project, coordinated by Dr Annalisa Trama (Department of Research, Evaluative Epidemiology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan) aiming to set-up a clinical registry for EURACAN, the European Reference Network (ERN) dedicated to rare adult solid cancers. It will exploit at a European level, data coming from individual expert health care providers, from national and European registries and it will be interoperable with already existing rare disease registries.

The EURACAN registry will progressively cover all the 10 families of rare adult solid cancers included in EURACAN. However, sarcomas together with rare head and neck cancers have been selected as the two cases to use to get the project started.

Among the sarcoma domain (coordinated by Prof. Paolo G. Casali, Medical Oncology, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan) ultra-rare sarcomas, such as EHE, have been selected as the topic to start with, as the community believe that, given the exceeding rarity of these sarcoma types, international prospective registries could provide an invaluable contribution, both by allowing a better understanding of the natural history of the different diseases and in order to provide external control data, potentially useful in the process of drug development and approval.

This prospective registry will include all consecutive patients with a histological diagnosis of EHE and treated at participating sarcoma reference centers. INT hope that up to 20 sarcoma reference centres across Europe and the UK will be initially included in the study, with a view to registering over 100 patients.

Hugh Leonard, from the EHE Rare Cancer Charity was excited and said:

**“We are delighted to have signed this contract and now be able to start this important work. This will be the first significant observational study of EHE in the world and we are excited to see the results as they develop over the life of the registry. We hope that some real insights may be gained leading to new treatments for this horrible disease.”**



# 03 EHE Research

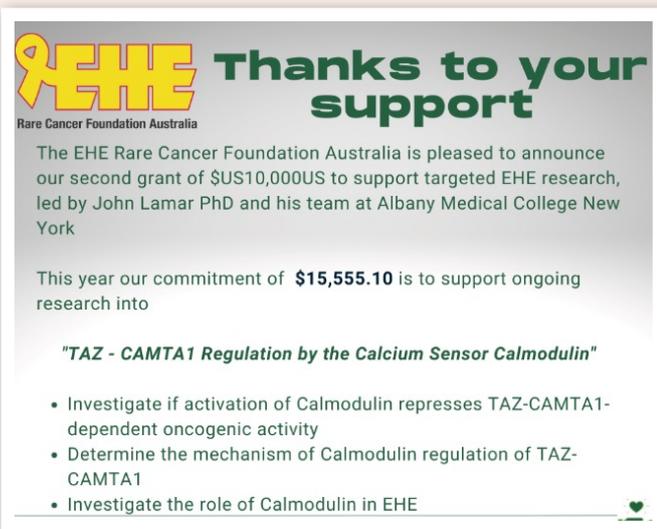
## A Huge THANK YOU!

Jane Biddlecombe, Jonathan Granek and the Board of the EHE Rare Cancer Foundation Australia (EHE-RCFA) wanted to express their thanks for the wonderful donations received from EHE-RCFA supporters in Australia that had enabled the foundation to contribute to the funding of further research by Dr John Lamar at the Albany Medical College in the USA.

Jane Biddlecombe explained:

**“ THANK YOU - YES, I DO MEAN YOU! Thank you to all our wonderful and generous Australian donors. Your contributions and donations in 2021-2022 have allowed the EHE-RCFA to continue contributing financially to ground breaking, front line EHE research.**

**The EHE-RCFA is proud to provide ongoing funding over three years to the value of \$US30,000 to research into EHE by John Lamar which builds upon knowledge gained through previously funded research by the EHE Group (USA, UK and Australia). ”**



**EHE** Thanks to your support  
Rare Cancer Foundation Australia

The EHE Rare Cancer Foundation Australia is pleased to announce our second grant of \$US10,000US to support targeted EHE research, led by John Lamar PhD and his team at Albany Medical College New York

This year our commitment of **\$15,555.10** is to support ongoing research into

**"TAZ - CAMTA1 Regulation by the Calcium Sensor Calmodulin"**

- Investigate if activation of Calmodulin represses TAZ-CAMTA1-dependent oncogenic activity
- Determine the mechanism of Calmodulin regulation of TAZ-CAMTA1
- Investigate the role of Calmodulin in EHE

Well done Australia for this brilliant support which is helping to fund really critical research into EHE.

## EHE-RCFA Meet with INT Researchers

The EHE Rare Cancer Foundation Australia (EHE-RCFA) were thrilled to connect and meet with EHE researchers Dr Nadia Zaffaroni and Dr Pasquali Sandro from National Cancer Institute of Milan (INT) on December 22nd 2022.



The purpose of the meeting was to formally introduce the EHE-RCFA and build upon earlier discussions had with Dr Silvia Stacchiotti regarding opportunities for research collaboration and new research avenues. The EHE-RCFA was pleased to extend its offers to assist the INT team with any projects and to connect with Australian researchers to help expedite research outcomes.

## EHE Represented in Drug Repurposing Programmes

In 2022 the FDA in partnership with researchers at the C-Path Institute established a Drug Repurposing Task Force to develop a model for repurposing more commonly used and less expensive medications for the treatment of sarcoma. This is of interest to EHE patients generally as EHE is a sarcoma, but in particular because part of the project is seeking a label extension of sirolimus for the treatment of EHE.

The label extension of sirolimus is also being supported by The EHE Foundation and the AntiCancer Fund, working closely with a panel of sarcoma experts chaired by Dr Bill Tap from the Memorial Sloan Kettering Cancer Center. We are

delighted that Denise Robinson, Research Director of The EHE Foundation is part of this working group taking this project forward, and at the same time representing EHE patients. EHE patients are also represented by Lisa de Young who was asked to participate in the FDA Drug Repurposing Task Force, also to represent EHE patients.

At the same time, processes seeking similar label extensions of sirolimus have been initiated in Europe with the European Medicines Agency in Brussels; and in the UK, with the new NHS Drug Repurposing Program. Both of these processes are being supported by The EHE Rare Cancer Charity, represented by Hugh Leonard, and the AntiCancer Fund. Medical support is being provided by doctors well known to our community, namely Dr Silvia Stacchiotti from INT in Europe and Prof Robin Jones of the Royal Marsden Hospital in the UK.

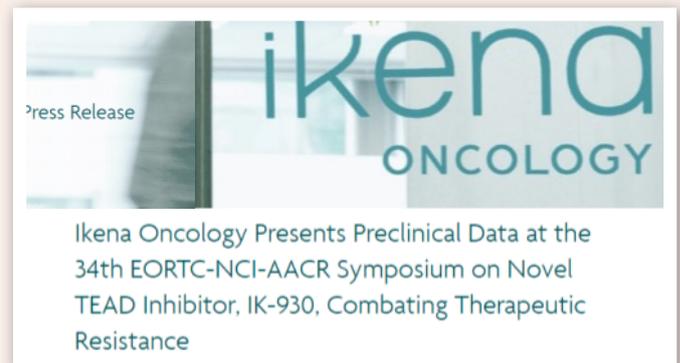
These initiatives are important because, although some patients will be offered sirolimus off label, many will be denied the chance to use sirolimus as it is not formally approved for EHE treatment. In addition, funding entities and insurance companies may also refuse to fund the drug for the same reason.

We wish the EHE Group members every success with securing these label extensions and look forward to sharing more news in future editions of **The Pledge**.

## Ikena Oncology's TEAD Inhibitor Makes News

In October Ikena announced a poster presentation highlighting preclinical data on their novel TEAD inhibitor, IK-930. The poster was presented at the 34th EORTC-NCI-AACR Symposium on Molecular Targets and Cancer Therapeutics in Barcelona, Spain. The poster, entitled **IK-930, a Novel TEAD-inhibitor, Overcomes Hippo/YAP-mediated Adaptive Response to MEK and EGFR-targeted Therapies**, highlighted preclinical data (research that has taken place before testing in humans).

Currently, Ikena is conducting a Phase 1 clinical trial including patients with tumor types with a high frequency of Hippo pathway alterations, including EHE. Supported by their preclinical work, Ikena also plans to explore combinations of IK-930 with other targeted agents for the treatment of other solid tumors.



Denise Robinson, Director of Research (EHE Foundation, USA) said:

“we are excited to see this novel compound proceed to the clinic for testing at leading centers and look forward for more news from Ikena later in 2023. More information on Ikena’s clinical trial of this novel TEAD inhibitor can be found at <http://www.clinicaltrials.gov> with the trial number NCT05228015 or please reach out to [research@fightehe.org](mailto:research@fightehe.org).”

A link to the full press release about the poster presentation can be found at: <https://ir.ikenaoncology.com/news-releases/news-release-details/ikena-oncology-presents-preclinical-data-34th-eortc-nci-aacr?fbclid=IwAROIYpa-1DZ22jEh6xeDE1PiTZNtwkvRRfsEP33PmHgNDD4GankVuFghLz8>

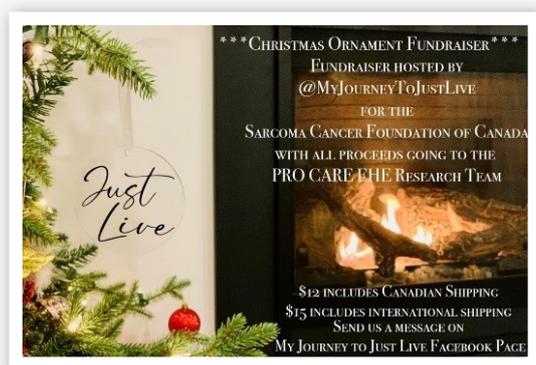


# 04 EHE Fundraising

Today we are proud to have EHE-dedicated research being carried out in 5 different countries over three continents. The EHE Group continues to remain totally focused on raising the funds needed to finance, drive and accelerate this existing critical EHE research programme, as well as the new research that will follow it. We thank all our members, their supporters and members of the public for their fundraising efforts, some of which are described below.

## Christmas decorations get huge response

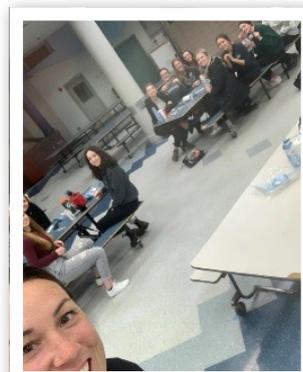
As part of her fundraising campaign through the fourth quarter, Michelle Lynn designed a Christmas ornament with the EHE Group **Just Live** motto. She hoped that she could sell a few for EHE research. Maybe she might sell 100, but not in her wildest dreams did she expect to sell 1,000. But that is exactly what she achieved, raising \$9,750 which with SCFC matched-funding took the total to \$19,500. Michelle could not be more surprised or more grateful.



“ You guys, 1000!!!! I can’t even begin to share how unbelievably grateful my family is for all your love and support on this fundraiser. A fundraiser that’s raising funds for LIFE EXTENDING research and maybe even LIFE SAVING research! Tears fill my eyes. My heart feels like it could burst with happiness. Thank you so much. ”

Michelle could not have achieved this fantastic result without a lot of help, so she wanted to thank all those who had made the campaign so huge!

“ All thanks to Charly, Tessa, Jada, Georgie, Charlie, Missy and quality control, master inspector Sue who all volunteered to support me on making these ornaments. A special “thank you” also to Tammi-Jo, who arranged for the AAA



Girls Bluefield basketball team to gather together in a team building exercise bringing some of these ornaments to life! I was in awe watching them work together, smiling and laughing, as we created our ornaments together. It was pure heart-warming happiness watching these teens do this for ME, a total stranger.

The cards that went inside your package explaining the fundraiser and the reason behind the **Just Live** motto were sponsored by Ben P at Dalmac and because of their support, more money went towards our cause! A huge, huge thank you to them! ”

## Giving Tuesday 2023 a Great Success

“ Thank you for helping us reach our \$150,000 goal on Giving Tuesday to fund the 2023 Research Grants Program! A special thanks also to the 374 donors, 16 people affected by EHE who held successful fundraisers, and the countless individuals that shared their personal EHE story and our mission. We are grateful for your contributions and for standing alongside us in this fight against EHE, a one-in-a-million cancer. ”



For several years, Giving Tuesday has been The EHE Foundation's largest fundraiser. It's a global movement to celebrate and encourage giving on the Tuesday after Thanksgiving. This year The EHE Foundation's Board of Directors personally matched donations up to a total of \$65,000.

Jenni Kovach, President of The EHE Foundation, said:

“ This day of generosity unleashed the power of our EHE Community to come together in the name of research. This \$150,000 will fund the 2023 Research Grants Program, which is essential to the advancement of research for EHE. We do not take for granted that our work would not be possible without supporters like you. Thank you so much. ”

In 2022 alone, the Foundation's research investment totalled a record breaking \$541,600, which included funding the 2022 Research Grants Program. These EHE-specific research grants are ongoing at world-class institutions and include three translational science grants that aim to identify potential treatments for EHE.

Thank you to everyone who showed their support for The EHE Foundation on Giving Tuesday.

“ We look forward to sharing our accomplishments as we fund promising research in 2023. ”

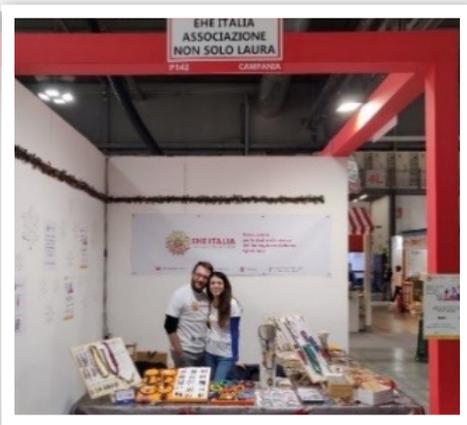


# 04 EHE Fundraising

## Italy are fundraising

Associazione EHE Italia - Non Solo Laura, the newest EHE Group member were delighted to be able to report that they would be holding their first fundraising event in December. EHE Italia President, Andrei Ivanescu, explained:

**“ We are ready for our first fundraising event in Italy at Artigiano in Fiera (Milan)! We have made (and collected from donations) several bijoux and other products. Everything is handmade. The event will last 9 days and we hope to receive a lot of donations and visibility. Cross your fingers for us! ”**



The Association wanted to thank Andrei and Caterina who were manning the stand, and can be seen in the photo here. They also wanted to thank Lucia and Noemi who made and collected most of the products that were for sale!

Congratulations EHE Italia - Non Solo Laura for launching your first fundraising event. We are sure that it will be very successful, and just the first of many.

## Vibrant Headbands to raise research funds

Over the last seven years we have seen a lot of different ways that people have found to raise funds for EHE research, but Sue Dean, Paul Dean's mother came up with a new product, working with friends in the Women's Institute. They decided to knit vibrant headbands for the winter which they are selling to raise funds for EHE research. Sue explained:

**“ With Christmas coming up and the icy cold winds forecast I thought why not put the headbands online so people can buy them. So I've set it up so that they are £10 each. With 80% of that going directly to EHE Rare Cancer Charity UK and the other 20% covering the fees, postage and packaging. It is UK only I'm afraid at the moment. Here is the link, take a look! There are many colours just drop a message with the colour you'd like when you order! ”**

What a fantastic idea, and by the end of the year Sue and her team of helpers had sold an amazing 170 headbands. That's £1,360 for EHE research, and they are still available. Totally brilliant Sue. Huge thanks for such an inspired idea. We love them.



## Kim Young Crushed Main Marathon Goal

Kim Young was diagnosed with EHE in March 2021, and Oct 2nd, 2022 was the second time she ran 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.



Kim teamed up with the Maine Marathon to allow the EHE community, including her family and friends, to either participate in the event or to donate to benefit The EHE Foundation. Participants had the opportunity to select from several events: 5K, 10K, half marathon, full marathon, or marathon relay. Kim ran the full marathon and crushed her goal race time.

As she raced, she wore a shirt with many EHE patients' names on the back. Kim said:

**“ This event is very personal to me. I ran the Maine Marathon not only to raise money for EHE research and create awareness for this rare cancer, but to represent every single patient across the globe. EHE is unpredictable and can turn aggressive very quickly and I ran to represent every patient facing an uncertain future. ”**

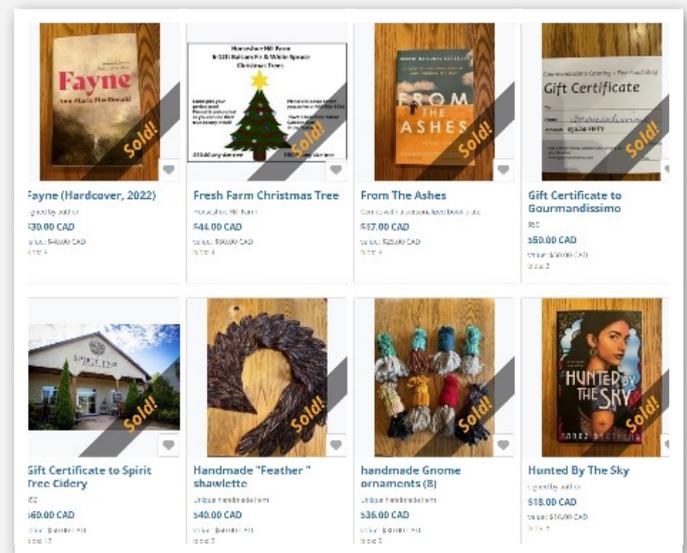
Kim raised \$1,125. We truly appreciate Kim's continued support and encouragement to families affected by EHE.

## Lot No 4!

December also saw the launch of Fiona Ross's next fundraiser, an auction of items donated by business and individuals who wanted to help fund EHE research. Fiona explained:

**“ Hello all, this is the latest fundraiser out of Canada. I wanted to show you because it is free up to 20 items AND it is available in multiple currencies (Euros, NZ dollars, AUS dollars, British Pounds, Canadian dollars and US dollars). It is easy to use and set up as well. The proceeds of this auction will go towards Canadian research into EHE. ”**

The auction was a huge success raising over \$900 for EHE research. When combined with donations and her bottle drive, Fiona had contributed over \$4,100 to the SCDC EHE fund, with the same amount added through the SCFC matched funding programme. Congratulations Canada on another great result.



# 04 EHE Fundraising

## Michelle sees out 2022!

We have reported elsewhere in this edition of **The Pledge** news of the energy that Michelle Lynn has brought to different EHE awareness and fundraising campaigns in Canada. At the very end of the year, Michelle wanted to post an update on what funds she and her supporters had raised, and to say a huge thank you.



**“We raised \$1,800 from a simple bottle drive; \$1,200 from a Facebook birthday fundraiser, and \$9,750 from 1,000 Christmas ornaments sold. Every can, every bottle, every *Just Live* ornament purchased, to every donation made; they all mattered. Every single dollar, counted. And what makes it more special? The Sarcoma Cancer Foundation of Canada is **MATCHING** every dollar raised giving a grand total of \$25,500! You guys did that, so I just want to say THANK YOU so much to everybody who contributed.”**

We want to join Michelle in thanking every single person who donated either their time and support and/or their dollars to her wonderful campaigns. But most of all we want to thank Michelle for her awesome performance. And of course Michelle is already looking at 2023. As she said at the end of her post:

**“Every. Dollar. Counts. Now, let’s see what 2023 can produce! Fundraising never stops.”**

## Student raises funds for EHE research

The fourth quarter started with more news from Canada about an unexpected fundraising success. Fiona Ross explained:

**“I had some unexpected good news today on the fundraising front. A friend had a student looking for community service hours, so I suggested they could help by focusing on EHE fundraising. I did not think much more about it so was really delighted when the student brought in \$1105.00 today that will go towards EHE research.”**

Fiona then posted news that the student involved was in fact legally blind and completed most of her fundraising via phone and email and while walking with family to neighbours’ houses. She is clearly a wonderful person. Please, Fiona, thank your friend and the student from all of us for a great contribution. It just goes to show how important it is to sometimes just let people know how they can help. It’s amazing how often people will then pick up the baton and run with it.

## Stickers and Decals

Summer Keller offered stickers and decals to new EHE community members. The cost of the decals is by donation only. She is helping to raise awareness of EHE for her husband, Ryan, and others who are fighting EHE. Spreading awareness comes in many shapes and sizes and we appreciate your support, Keller family. Contact Summer at [rskeller7@hotmail.com](mailto:rskeller7@hotmail.com) for more information.



## Matched funding from SCFC

At the start of November, in response to Giving Tuesday and The EHE Foundation's Matched-Funding in the USA, Fiona Ross posted news of the Sarcoma Cancer Foundation Canada (SCFC) matched funding campaign that would run to the end of the year.

**“ Hello Canadians, I wanted to make you aware that while we don't have an EHE foundation here in Canada we work closely with the SCFC, of which I am a Board member. We are funding a \$1 MILLION dollar research project here in Canada thanks to a wonderful donation AND the SCFC is matching (doubling!) EHE donations until the end of this year. So essentially we have a Giving Monday, Tuesday, Wednesday, etc until the end of this year! ”**

We join Fiona and the SCFC in thanking Phillip Duke, Michelle Lynn, Fiona and everybody else who contributed, for their donations (no matter what size those donations were) and their fundraising events, all of which were also doubled by matched funding from the SCFC.

Great job Canada. Keep up the wonderful work.



# 04 EHE Fundraising

## Kelly is at it again

Like many of our members who are affected by EHE, Kelly has thrown herself into raising funds for the EHE Rare Cancer Charity in the UK as Kelly's teenage daughter is an EHE patient.

Kelly has organised large work events and evening quiz nights (there is one coming up on 23rd February) but she also never misses a chance and decided to run a small stall in a local fair. This was Kelly's bottle raffle stall at the Penge October Fest Festival, where Kelly raised £261 for EHE research. That's £261 we did not have the day before.



Thank you Kelly, your drive and energy is wonderful. We are so grateful. And we love the fact that Max was there too supporting you from his bed!

## A Friend of the Community

We are always grateful when supporters take the time to create a fundraiser in support of our mission. Lynn, shown here with Jenni, makes wreaths and donates the proceeds to support EHE research.

**“ My mother-in-law is a true friend to our community. She tirelessly makes wreaths and gives all money raised to research. She also has the *Just Live* tattoo! ”**

said Jenni, EHE patient.



## London Landmarks is on the horizon

Hugh Leonard, Chair of Trustees of the EHE Rare Cancer Charity in the UK posted news of the next running of the London Landmarks Half Marathon in 2023. It's one of the UK charity's two main fundraising events each year, and 2023 will be the biggest yet, with 50 runners hitting the streets of London to raise money for EHE research. Hugh is excited:

Sally Baker, a Trustee of the charity, was also amazed by the number of runners.

“When we participated in the 2018 inaugural event we had 20 runners and that seemed huge. Next year we will have 50. The support is amazing!! We want to say **“Thank you!”** to every single one of them.”

“It's our biggest group of runners yet. We have 20 runners from a fitness group in south London who are all running in support of a teenager in their area who has EHE; there is a team of 16 coming from Wolverhampton who are all running in support of Paul Dean, an EHE patient; while the remaining 14 are all supporting different people.”



# 05 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.

## Getting together

### A Shared Passion

Jenni Kovach, EHE patient, met up with Jane Gutkovich, EHE advocate, in New York City. Jenni and Jane live states away in the US. Jenni commented:

“Whether it’s another EHE patient or someone that shares my passion for finding a cure, meeting face to face with another EHE community member is always so special and meaningful. Meeting with Jane is one of my absolute favorite things about visiting NYC.”



### Enjoying wonderful company (but forgetting the photos!)

The fourth quarter also saw Maeve Baechler post news that she had taken the train across Switzerland to meet with Alessandra Kobel, another EHE-er!

“It was so good to catch up and rant/discuss/relate over all the weird and challenging things we EHE-ers experience. In fact, we talked so much I forgot to take a picture.”

Later in the month, Maeve took another train in the other direction to meet with another EHE-er, Bettina Klöti, in Zurich, again noting how wonderful it is to connect with other members of the group. They clearly had a great time, as Bettina explained:

“I am so glad to have Maeve as a buddy and **“tumor-sister”**. This disease brings so many challenges. Today we talked about PET-scans, deep insights, shrinking and growing tumors, fears, sirolimus and personal transformation over a yummy veggie lunch, like others talk about fashion trends, difficult bosses and weekend getaways. It was inspiring, deep, funny, and enriching. Without this site, we would not have met.”

Wonderfully, they had such a great time they again forgot to take a photo. Maeve did share a short video

from which we were able to grab this simple shot of Zurich, so that will have to do, but we hope to be able to share photos of Maeve, Alessandra and Bettina in the future.



## Action Man

Carl Dickson often posts footage of his awesome kids.

“I know a number of you have seen my boys on here before, just want to share an update on my older little guy, this is why I fight so hard to make it through each day, each month each year... We fight not only for ourselves but them, hope you enjoy.”

## Party Time

We also love to see people embracing the *Just Live* motto of our global community. The Wahl family always inspires us, so we were not surprised to see footage of Delaney and Olivia Wahl, with their cousins, showing us their 'moves' at a Carrie Underwood concert!

Delaney, second from the right, was diagnosed with EHE 8 1/2 years ago and truly embraces our *Just Live* motto!

Great music, great dancing, great spirit! *Just live* indeed.



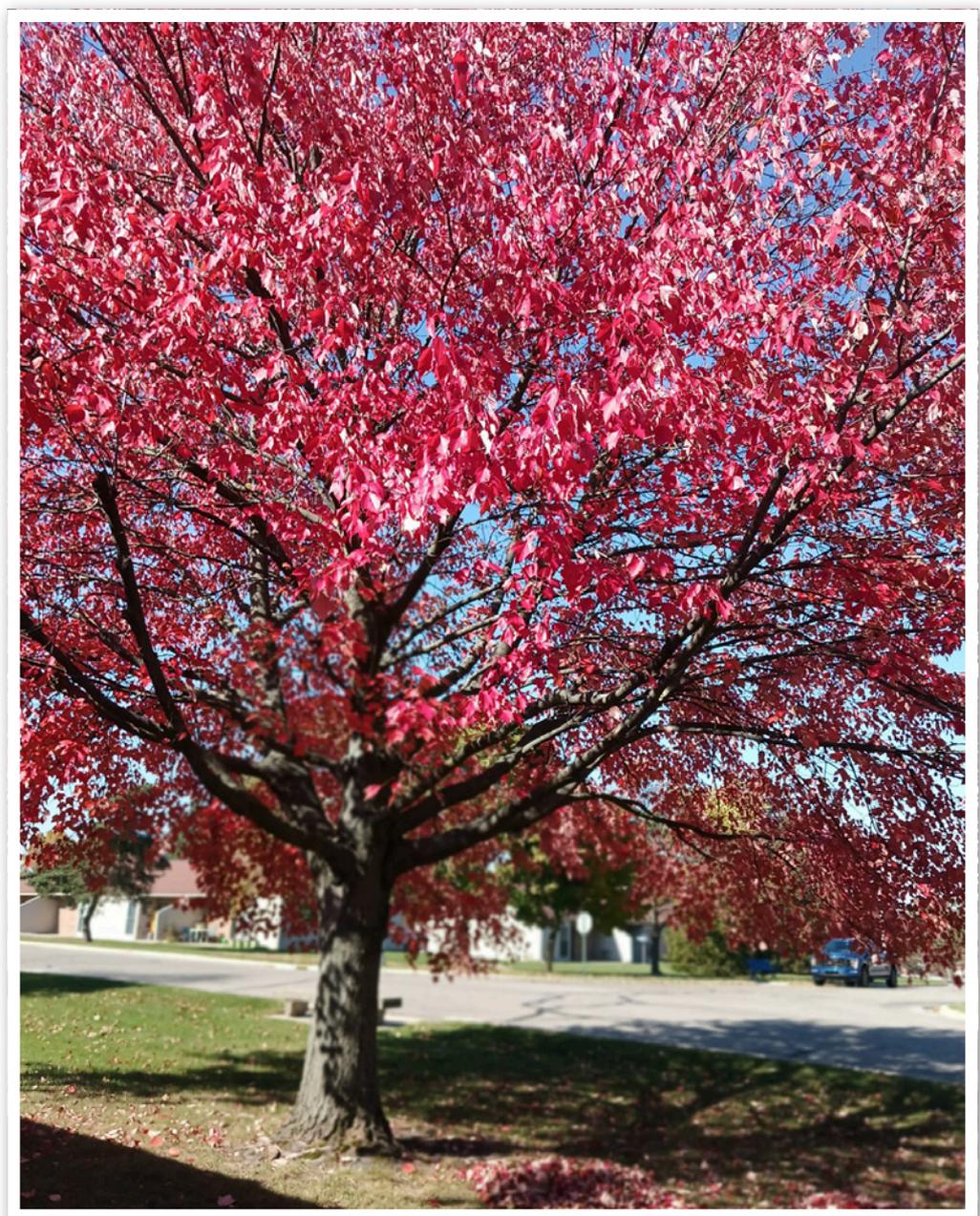
# 05 And in other news...

## Photo Therapy

Every quarter the EHE Support Group Facebook page sees posts from people who just want to share a beautiful photo captured by camera. Q4 was no different and we are once again delighted to share just some of the photos with you all, together with some messages of hope and affection.

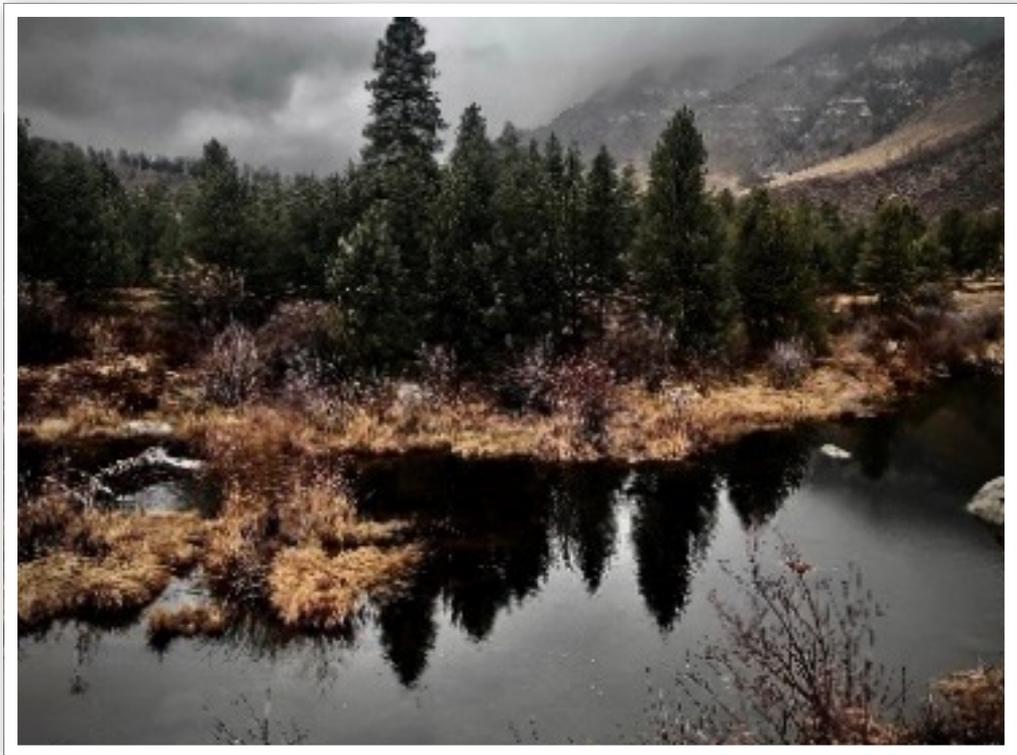
Stephanie Kennedy posted this wonderful tree of pink.

“Good morning, warriors. Today will be a blessed day.”



Carl Dickson shared some more photos of the beauty of nature.

“Yesterday heading to an appointment, the beauty that is out there for us to see was once again making me say “WOW!””





**The EHE Foundation (USA)**

[www.fightehe.org](http://www.fightehe.org)

**The EHE Rare Cancer Charity (UK)**

[www.ehercc.org.uk](http://www.ehercc.org.uk)

**The EHE Rare Cancer Foundation (Australia)**

[www.ehefoundation.com.au](http://www.ehefoundation.com.au)

**EHE Italia - Non solo Laura**

website not yet available

**EHE Canada**

website not yet available