

The EHE Foundation (USA)
The EHE Rare Cancer Charity (UK)
The EHE Rare Cancer Foundation (Australia)



Quarterly Newsletter for the EHE Group
April - June 2020

the pledge

Edition 21



Welcome

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Welcome to “The Pledge”, our quarterly newsletter covering the activities of the EHE Group.

This is our **21st edition**, for the second quarter of 2020. This has been a difficult quarter as the world has grappled with the COVID19 pandemic. While some of the activities of the EHE Group have been curtailed, due to lock-down and social distancing, we remain totally focused on all our core objectives. EHE does not stop because of COVID19, and nor have we.

We hope that you enjoy the contents of this edition, and as always we want to say a huge thank you to all our supporters for their contributions.

We also more than ever want to wish you all good health.

Be cautious, stay well and **“Just Live”**.



Highlights

Membership continues to grow

The EHE Patient Support Facebook page membership exceeded 1,800 in the second quarter of the year. We continue to see a growing group of patient members worldwide, a fact that drives us even harder in our pursuit of a cure for EHE.

USA launches its Patient Advocate Leader Program

The EHE Foundation launched its Patient Advocate Leader (PAL) Program, their new volunteer opportunity. PALs are a diverse, passionate and highly motivated group of volunteers (patients diagnosed with EHE and caregivers) who want to learn more about EHE, support our mission and advocate on behalf of others affected by EHE.

UK Charity expanding

The EHE Rare Cancer Charity was delighted to welcome their new volunteer Executive Director to the Charity. At the same time, the Board of Trustees has been supplemented with the arrival of an experienced researcher.

The EHE Foundation's Virtual 5K is up and running

Despite COVID19, many EHE supporters in the USA have been able to participate in the Foundation's annual virtual 5K event while complying with social distancing protocols.

EHE research published

The 2017 and 2018 'Health-Related Quality of Life' study of EHE patients across different countries, led by Dr. Marije Weidema at the The Radboud University Medical Center in the Netherlands, was published. This is the first study based entirely on the EHE Group patient membership.

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

the **pledge** Edition 21



01 Patient Support and Advocacy

The EHE Group strives to provide support to everybody diagnosed with EHE, and 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 passionately pursued by all three of the EHE foundations. But it is only because of the tireless energy and contribution of so many of our members, many of them being EHE patients themselves, that we are able to provide the levels of patient support we do.

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.

Joe Mulligan is in the news again!

EHE patients have not been immune from the treatment issues faced by many cancer patients due to COVID19. Nine-year old Joe Mulligan is one such person. His story was picked up by several media outlets, shining a spot-light on the difficulties faced by cancer patients during this unprecedented time. It also brought yet more coverage and awareness for EHE.

Jennifer's article talked openly and honestly about how their family came to terms with Joe's diagnosis, and dealt with the immediate impact. Jennifer noted how a strengths-perspective model helped her manage both her mental health turmoil and her son's medical needs.

"I am so thankful for all my colleagues at Healthfirst who shared resources or allowed me to just tell my story. I've learned to respond to questions with our family motto 'LIVE, LAUGH, and Have Faith.' It's that attitude that steeled us, and moved us to create a virtual 5K EHE walk that anyone could do without having to leave their homes. We also worked with The EHE Foundation to create a virtual library for the organization."

Joe, Jennifer and the whole Mulligan family are a wonderful example of how determined, brave and inspiring people can be when faced with something as devastating as an EHE diagnosis. We want to thank them for openly and honestly sharing their story, and for helping to grow awareness of EHE.

hoping Joe does well...
Prayers go to Joe and his family

And Joe's story was also a key part of another article posted by Jennifer Mulligan, Joe's mother. She wrote the article for her company for mental health awareness month.

UK WhatsApp group growing

Sometimes one of the biggest challenges for a diverse group is just keeping in touch. Sally Baker, EHE member based in London, posted news of the UK WhatsApp group.

Currently there are 13 members, but they would love to have more. So if you want to join, please contact Sally on 07748631217.

"We have an EHE U.K. social group on WhatsApp, which is great for keeping in touch in a more informal way, providing support and friendship, and enabling people to meet up if they have appointments etc at the same time. If you would like to join this group, please contact me on 07748 631217 with your mobile number, and we can add you to the group."

The EHE Foundation holds its first Virtual Community Conference!

On April 25th The Board and Management of The EHE Foundation (US) held their first Virtual Community Conference, inviting all members to join them in a video-conference so people could meet the foundation's leadership, learn about the foundation, and what is ahead.

The conference was a great success, with nearly 40 participants. Jenni Case Kovach, President of The EHE Foundation shared her thanks for all those who participated.

"A big thank you to all who joined the EHE virtual community call on Saturday! We hope it helped you to learn more about us and our unwavering commitment to find treatments and a cure for EHE."



01 Patient Support and Advocacy

“Thank you Dr Raj”

There are many exceptional doctors who care for our EHE family members around the world, and we are grateful for their commitment. Treating a rare cancer has many challenges and requires a team effort.

In early April, Summer Keller wanted to simply share her thanks for the care given to her husband, Ryan, by Dr Govindarajan Narayanan, known to us as Dr Raj. He is a leading Interventional Radiologist and has led the way in treating EHE of the liver using IRE ablation.

Summer posted



“We had our online chat with the great Dr Raj. Some of us know him as just AWESOME. My husband had IRE performed by him last July. He is simply amazing. Caring, kind, compassionate, understanding. Thank you Dr Raj.”

Executive Director is raising awareness

One of our group's global objectives is to raise awareness of EHE wherever and whenever possible. So when Global Genes asked to run an interview with The EHE Foundation's Executive Director, Medha Deoras-Sutliff, she was delighted to take part. Medha shared:

“I'm very thankful to Global Genes for this opportunity to raise awareness of EHE and highlight the Foundation's incredible efforts. Media exposure always helps as we continue to fight for limited dollars, treatments and cure!!”

The interview provides great online exposure for EHE, and provides insight to how The EHE Foundation is doing everything they can to battle this rare disease. “You can't assume anything, as the patient journey is always changing” noted Medha.

We hope that people take the time to read the interview at: <https://globalgenes.org/2020/04/09/rare-leader-medha-deoras-sutliff-executive-director-the-ehe-foundation/>

Thanks Global Genes and Medha for creating greater awareness of EHE.



A bitter-sweet achievement

Lisa Hartle De Young, Vice President for Patient Liaison, posted an update for the group as another membership milestone was passed.

“Dear EHE Family, today we hit a new bittersweet milestone in our cherished community. We now have 1800 members across the globe. A reminder we are not alone as we **“just live”** and fight this disease together! We are lucky Dawn R. Scott had the vision in 2013 to create this gathering place for all of us, our EHE Patient Support Page. Thank you for sharing your stories and keeping us updated on your progress. Together our voice is stronger and united!”



Patient advocates wanted!

May saw the launch of The EHE Foundation's Patient Advocate Leader (PAL) Program in the USA.

PALs are a diverse, passionate and highly motivated group of volunteers (patients diagnosed with EHE and caregivers) who want to learn more about EHE, support our mission and advocate on behalf of others affected by EHE.

PALs will not only enhance patient engagement and support, but also give EHE patients a voice in many levels of the foundation's work.

The EHE Foundation welcomed applications to the PAL program on a rolling basis through early summer. Stay tuned for the announcement of those joining the PAL program inaugural class of patient advocates.



01 Patient Support and Advocacy

Work goes on, despite COVID19

EHE does not stop progressing, or appearing in new patients, just because COVID19 has appeared. It is relentless, and so the EHE group, including our fledgling Canadian foundation and The Cravat Foundation in the USA, have to be equally relentless in our battle against the disease.

So despite the challenges faced, the EHE group has continued to strive to deliver on all its objectives, working hard for treatment and a cure!



The EHE Foundation Board

A little love goes a long way!

A huge part of our advocacy and patient support battle is getting information about EHE, our foundations, and all that we are doing and hoping to achieve, out to as big an audience as possible. One great way to do this is for all our members to include this information through their own social media. The EHE Foundation (US) stressed this in June with this post:

“When you ‘love’, ‘like’, ‘comment’, or ‘share’ The EHE Foundation’s Facebook posts from our official page, you help multiply the number of people that see our posts. You help us increase EHE awareness, engage supporters, and build relationships. If you are not already part of our network, please consider connecting with us using our social media outlets. Your family and friends are welcome to join us, too! Don’t forget to sign up for our e-mails on our website (www.fightthee.org).”

And that applies to our other EHE group foundations in the UK and Australia, too. Please share our news, stories, and information when you can, and follow us on all available social media outlets



EHE Rare Cancer Charity expanding

One of the great challenges for small charities looking to grow is how to expand its management and personnel without taking on significant additional costs, using money that is needed for research. A hugely valuable source of extraordinary skills can be found within the voluntary community, a large resource pool comprising wonderful people who want to assist different causes by offering some of their valuable time on a voluntary basis. In 2020 the EHE Rare Cancer Charity initiated a search for an experienced senior charity manager, from within this community, who could help develop and direct a number of key elements of the EHERCC’s expanding strategy.

Following a four month process, the charity is delighted to welcome Mike Rich into the group. Mike is an experienced CEO and Senior Manager with a track record leading strategic operations in the charitable and not-for-profit sector. Mike’s areas of expertise include raising the profile of charitable organisations through effective marketing, public relations, lobbying and fundraising strategies. Mike also brings well-developed business acumen covering HR, finance, project management and client development; providing leadership and direction to teams of up

to 16 people, while aligning commercial practices to the organisation’s ideological objectives. Mike also has extensive experience of building and managing volunteers and will be helping the charity build the core skills it needs.



Mike Rich

The Trustees are clearly very excited about Mike joining the team, as Hugh Leonard explained.

“It is fantastic to have Mike come on board. In all our early engagements with Mike it quickly became apparent to us that he has so much to offer through his extensive experience and knowledge of the charity sector. We are looking forward to working with Mike as we move forward and deliver the strategy and objectives of the EHERCC.”

It’s fantastic
to have
Mike come
on board! ”

01 Patient Support and Advocacy

Cancer Research specialist joins EHERCC

One of the key areas that the EHERRC Trustees are always keen to explore are ways to enhance the research understanding and capabilities of the Board of Trustees. Dr Kate Hooper explained:

“While Liz Milligan and I both have technical backgrounds, we are definitely not cancer research specialists. So bringing in real expertise on to the Board of Trustees was an obvious objective, helping us with the development of our research strategy, engagement with possible researchers, evaluation of grant applications received, and the ongoing monitoring of the projects we are funding.”

The Charity is therefore delighted to be able to announce that Dr Oliver Pearce, Group Leader at the Barts Cancer Institute in London, has agreed to join the Board of Trustees. Oliver’s lab at Bart’s is focused on the tumour microenvironment (TME, where they are particularly interested in understanding the composition and function of the tumour extracellular matrix in immunosuppression.

Hugh Leonard explained:

“Oliver’s lab is not working on EHE, but Oliver brings real, up-to-date, cancer research expertise into the Board of Trustees. We are all so excited to have him join us. There is also a personal connection for Oliver as his cousin was diagnosed with EHE in 2005. We know that Oliver will be able to play an important part as we continue to strive to fund EHE research and seek new treatments and hopefully find a cure for EHE.”



Dr Oliver Pearce

Dr Oliver Pearce joins the Board of Trustees

02 EHE Research

COVID19 has had a major impact on research through the second quarter of 2020, with nearly all labs closed due to lock-down and social distancing. We have taken the chance here therefore not only to report progress through the quarter, but to also provide an overview of some of the EHE research that the EHE group is helping to deliver by providing patient information, tissue samples, and funding.

Progress through the quarter

Important Projects Initiated in the USA

The EHE library is live! Jane Gutkovich posted news that the online library of EHE publications had finally been created and was accessible on The EHE Foundation website.

“Several volunteers from this group offered their help and worked very hard to make it happen. Please join me in thanking Mariana Coutinho, Jennifer Mulligan, Cathy Patterson Wulfse, Brian Harpst, Leah Heinrich and Jonathan Granek!!! You guys are awesome! A true example of “by the people, for the people!”

“This is just a beginning, so we started with the most common EHE locations. But we will be building up a more diverse library and there will be more and more information there!”

The library can be found at <https://fightehe.org/ehe-online-library/>



Circulating DNA project launched: After a lot of preparatory work, The EHE Foundation was delighted to be able to report that a research project looking to identify circulating DNA (ctDNA) biomarkers was initiated during the second quarter.

“The project is based at the Mayo Clinic, with EHE now being included within a wider project seeking to identify ctDNA in different types of cancer” noted Jane Gutkovich. “We are delighted to see the start of this important piece of research. If we can identify ctDNA for EHE, it could have significant consequences in our ability not only to diagnose EHE, but may also be useful as an early-warning system for doctors that the progressive nature of a patient’s EHE is changing.”

The project is being led at the Mayo Clinic by Dr Minetta Liu.

Retrospective study approved: The EHE Foundation was also excited to be able to report that its global retrospective study of EHE had received its first approvals. The study protocols were approved at the Mayo Clinic, during the second quarter. Although the Mayo Clinic will be just one of the institutions participating in the study worldwide, the Mayo has played a key role in preparing the protocols and



02 EHE Research

associated study documentation. We extend our sincere thanks to Dr Scott Okuno (and the team at the Mayo) for all their help in developing these materials. Work will now progress with the enrolment of other institutions into this important international project.

The 'ISKS' drive is still on

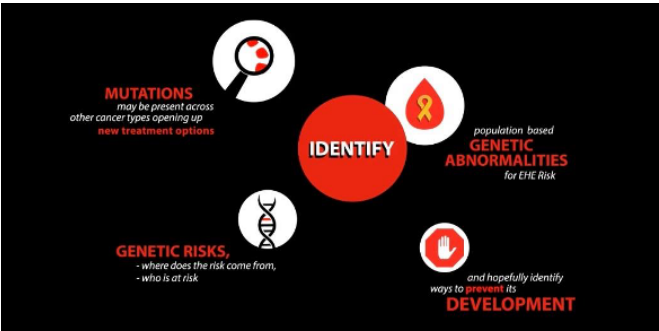
The International Sarcoma Kindred Study (ISKS), centred at the Garvan Institute in Australia, has been active for over a year now. The study is gathering DNA samples from many different sarcoma patients and storing these for future use by researchers who are hoping to answer some of the key questions about these rare cancers.

We are of course very keen to have EHE represented within the DNA data base. In May, Jane Biddlecombe, Director of The EHE Rare Cancer Foundation Australia (EHE-RCFA) posted an update.

“Hi everyone, hope all is well and that each of you are safe where ever you may be in our global community. We are seeking any new patients (globally) who have not yet enrolled in the International Sarcoma Kindred Study. Your participation (survey and blood or hair follicle) will allow us to create a one-of-a-kind EHE resource that will be available to researchers across the globe.”

Once gathered The EHE-RCFA will be partnering with the Garvan Institute to try and identify

- Common distinctive genetic characteristics shared by the EHE patients;
- Correlation of genetic characteristics with EHE behaviour/natural history;
- Compare and contrast EHE with other known sarcomas and diseases; and
- Identify potential therapeutic targets/avenues



“Did you know that as I type this, the 17 EHE patients who enrolled in ISKS last year are currently included in a WHOLE GENOME SEQUENCING project at Garvan right now! This is research we don't have to pay for. Research we hope might give us some clues about EHE germline (not tumour).” Jane continued “We also cannot overestimate the importance of demonstrating to the medical community that we are a motivated, can-do patient cohort; trust me, when we do this, it sends a message to researchers, we are open for business.”

We are hoping that our EHE group members will take up the challenge and engage with this important study. If you want to engage or have any questions, please email the study team at isks@garvan.org.au

If you have any questions you can also contact Medha Deoras-Sutliff mdeorassutliff@fightehe.org in the USA or Hugh Leonard hleonard@ehercc.co.uk in the UK or Jane Biddlecombe in Australia jane.biddlecombe@ehfoundation.com.au and they will try to answer your queries.

EHE Research Published!!

In 2017 and 2018 our EHE Group engaged with a research team led by Dr Marije Weidema at the The Radboud University Medical Center in the Netherlands, who were keen to try and perform a 'Health-Related Quality of Life' study of EHE patients across different countries. They were excited to try and see if they could complete this type of study for such a rare disease. The research team hoped to get 100 participants. Some people said they would not achieve it, but thanks to the great support from so many EHE group members, they surpassed their goal of 100 participants, and achieved 115 in total from 20 different countries!!



The paper has now been completed and published, and was posted at the ESMO 2019 conference. Entitled: “Health-related quality of life and symptom burden of epithelioid hemangioendothelioma patients: a global patient-driven Facebook study in a very rare malignancy”, the paper can be found at

<https://www.tandfonline.com/doi/full/10.1080/0284186X.2020.1766696>

Hugh Leonard commented:

“This is another wonderful achievement as it is a valuable piece of research for EHE that involves only EHE group patient members. It also demonstrates a very important part of our capabilities. We tell researchers and donors that our combined EHE Group can deliver material numbers of EHE participants to a research project when needed. This is important as it helps open up research that might otherwise not be possible. It also amplifies that we are already working collaboratively across the globe, which is also unusual for a rare disease.”

The EHE group directors would just like to say three things:

- 1 Firstly a huge thank you to all who took part. You made this happen. You are awesome.
- 2 Secondly a huge thank you to Prof Lonneke van de Poll, Dr Marije Weiderma, and all the others involved in this important study. Thank you for having the faith to try.
- 3 And thirdly, please don't underestimate how important this sort of group participation is for encouraging future research and engagement with our EHE Group from so many important groups. So please, if there is a call for participation in studies in the future, please please take part. Don't leave it to others. You each can play such an important role.



Overview of projects that the EHE Group has contributed to

The EHE Group continues to support EHE research in the USA, Canada, the UK and Australia. In this edition of the pledge we have provided a summary of the UK projects that the group has been supporting. In our next edition we will be summarising the projects that the group has and continues to support in the USA. We hope you find these project summaries informative and inspiring as they have been enabled through the wonderful fundraising support we have received from many of you, and are why we are able to make progress in our battle against EHE.

Developing an EHE zebrafish model

EHRC signed a one-year research contract with the Bateson Centre at the University of Sheffield in mid-2018 to explore the feasibility of creating a valid EHE model using zebrafish. The project, led by Dr Fredericus Van Eeden, is attempting to genetically modify the fish to express the TAZ-CAMTA1 protein in endothelial cells, and thereafter describe the phenotype associated with this model, focusing on the vascular morphology. TAZ-CAMTA1 is used, as this fusion protein is believed to drive EHE.



Dr Van Eeden

After successfully modifying the fish, and seeing germline transmission of the introduced TAZ-CAMTA1 gene fusion, presence of the mutation in endothelial cells has not been seen. The research project was extended and funded for a second year to allow the research team to progress different methods to introduce the gene translocation. Work is ongoing and we continue to hope that success can be achieved, as an EHE zebrafish would be a wonderful addition to Dr Rubin's recently produced EHE mouse model, providing two different animal models for future EHE research and drug screening.

Understand the biology of how EHE affects endothelial cells

This four-year PhD project is using embryonic stem cells to study how the TAZ-CAMTA1 fusion protein affects the development of endothelial cells. Understanding these mechanisms may answer key questions about EHE and high-light potential therapeutic targets. In this project, a TAZ-CAMTA1 gene fusion that is controlled by a molecular 'switch' will be introduced into embryonic stem cells. This will allow the researchers to record what happens when the TAZ-CAMTA1 fusion protein is 'switched on' in the cells, and to better understand how TAZ-CAMTA1 might interfere with the behaviour and identity of endothelial cells in EHE. Led by Dr Kouskoff, her group hopes to develop EHE mouse models and human cell lines that may allow researchers to assess under what conditions EHE tumours spread around the body, assess what happens when the disease progresses from indolent to aggressive phase, and test potential therapies.



Dr Kouskoff

After just one year the project has demonstrated that TAZ-CAMTA1 interferes with early stages of endothelial differentiation. Optimisations for deriving endothelial cell cultures from mouse embryonic stem cells have been identified and used to develop a successful protocol for generating endothelial cells. The research team are ready to use this culture model system to examine different cellular and molecular characteristics of endothelial cells expressing TAZ-CAMTA1, and hopefully provide further insight into EHE progression.

Funding of a Tissue Manager at ICR

EHRC started discussing the setting up of an EHE biobank in the UK in 2016, but initial discussions with different parties failed to make progress. In late 2018, we were delighted therefore when Dr Paul Huang at the Institute of Cancer Research in London, a leading figure in the new Joint Royal Marsden



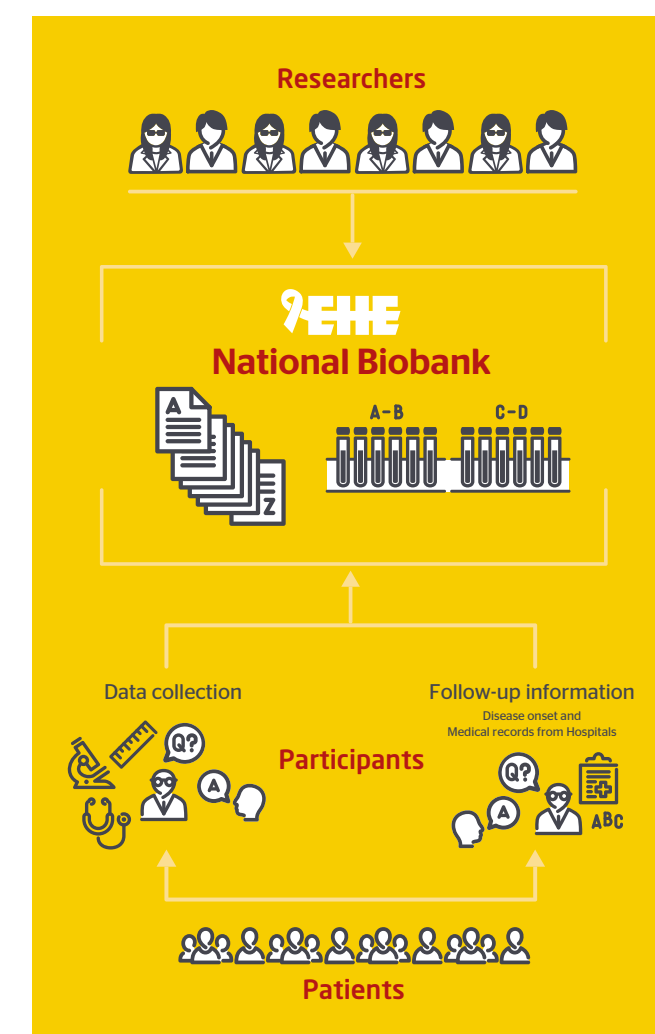
Dr Huang

- ICR Sarcoma Research Centre, engaged in positive discussions about the benefits of an EHE biobank. After further discussions, in mid-2019 the EHRC entered into a pledge agreement with the Royal Marsden Cancer Charity through which the EHRC is funding the role of a Human Tissue Manager working within the sarcoma group at the ICR.

The role was duly filled in August 2019. By the end of the year the Tissue Manager had completed a full review of all historic EHE patient data and sample sets held in the Royal Marsden archive, identifying those that met the first set of three requirements, namely: tissues samples held; clinical records available; and a valid patient consent form for the samples to be used in research activities.

Having completed this task, the Tissue Manager moved to start the preparation of all processes, procedures and documentation required to enable ethics approval to be sought for the set up and ongoing administration of the biobank. The preparatory work is almost completed, and we hope that the application for ethics approval will be submitted very soon.

Once established, the initial target will be to publicise and present the National EHE Biobank to all patients and all sarcoma centres in the UK as we move to ensure we are capturing the maximum sample set possible. It is planned thereafter to seek acceptance of EHE into the PEACE (Posthumous Evaluation of Advanced Cancer Environment) study and expand the function of the biobank by receiving EHE tissue from PEACE. The EHRC also hope in time to reach out to other key European centres to try and encourage and facilitate EHE biobanking over a far wider area.



03 EHE Fundraising

With COVID19 hitting most areas of the world very hard during the second quarter, resulting in severe lock-down and social distancing, a lot of the planned fundraising for EHE during the quarter was either cancelled or postponed worldwide. Not all was cancelled however. The EHE Foundation's 5th Annual Fun Run and Walk will be continuing through the year. Several groups have already completed their runs and walks, as reported below.

We will be working very hard with all our brilliant supporters to get our fundraising activity back up and running through the second half of the year. This will be a significant challenge, but one we cannot ignore as EHE does not stop because of coronavirus. The fight continues, and we will continue to be at the front of that battle.

This year is also the 5th anniversary Year for The EHE Foundation in the USA, The EHE Rare Cancer Charity (UK), and The Rare Cancer Foundation Australia. We felt we should celebrate those five years, starting with the EHE Foundation USA, by including in this edition some memories of the fundraising events completed over those five years in the USA. We hope you enjoy this brief trip down our fundraising memory lane.

Registration is Still Open for the 5th Annual EHE Fun Run and Walk!

While many big and small fundraising events worldwide were cancelled through the second quarter, registration of The EHE Foundation's 5th Annual EHE Fun Run and Walk remained open. Initial shipping of event packs was delayed and the event dates were adjusted to be completed anytime in 2020. This family fun event is for all ages and abilities. It is also virtual, which means it can be done anywhere you are. Many supporters have already completed it while social distancing, and many others are planning to do it in the fall.

To participate you simply register online, have your race packet shipped to you, choose to do a 5K (3.1 miles) or 1K (.62 miles), and complete it anytime in 2020. You can do it alone or with others who

5th Annual EHE Fun Run and Walk

Registration includes:
T-shirt (choice of size)
Bracelet
Temporary Tattoo
Brochure
Race Bib (not shown)
Shipping (US)
Cost: \$30
Register at:
<https://fightthe.org/5th-annual-ehe-fun-run-walk/>

hosted by The EHE Foundation

register. You can join a "team" to walk in honor of, or in memory of, a loved one. You can also leave a note of inspiration. Registering costs \$30 and includes what is shown here: a t-shirt, race bib, EHE bracelet, temporary **"Just Live"** tattoo, and shipping (US only). Registration will remain open at least through to the end of August.

100% of the donations and profits from the event will be dedicated to EHE research. Go to <https://fightthe.org/5th-annual-ehe-fun-run-walk/> for more information or to register.

Here are some of our wonderful EHE supporters who have already completed their virtual event.

Team Marcey

"My husband, and our dogs Cooper and Nova, walked the 5th Annual EHE 5K for my sister, Marcey Flood. We love you Marcey."

said Ann Marie Leonhard-McConnell.

Marcy passed away on June 27, 2020. We are grateful for the support of Marcey's large extended family and will continue to fight EHE in her honor. Our deepest condolences to Marcey's loved ones.



Team #MNSTRONG

"We had 30 that joined us on a walk together for my sister, Tori Jordan and all those affected by EHE! Others that walked or ran in another town also sent pictures"

said Jill Jordan Miller



Tori is a 41 year old mother of three, grandmother of four and says, **"I am fighting the biggest fight of my life."** Tori is proud to support a cause by an organization that has provided so much love and support.

Portland on the march

"Walking to show support for EHE research in Portland, OR, USA. If there are any others in the Greater Portland region let me know and you can join us next year"

said Karen A. Moore. Her 36-year old daughter is married with two small children, lives in Portland, and has EHE.



03 EHE Fundraising

Team Joe

“Today we had our EHE 5k in NY. We are still not allowed in groups so we did this with social distancing as best as possible! We had over 60 people today and others doing this with their families! So proud of the support and awareness this brings!! Just Live!”

Afterwards Jennifer gave out cupcakes, water, and fruit! “See the beautiful job our bakery did! They also donated them!”

We love the cakes and all the effort of the 60 participants. Awesome job Team Joel!



Events cancelled but funds not wasted

Late March had seen the cancellation of the London Landmarks Half Marathon due to coronavirus lockdown. In May came news that the RideLondon100 cycle event had also been cancelled. Jeff Collins, Trustee of the EHERCC, commented:

“We are obviously sad to see these events not going forward. However, we are guaranteed the same number of places next year in the half marathon, with a reduced entry fee, and the RideLondon event are refunding all their entry fees, so we hope that we will be able to participate at the same level next year.”

Amazon Smile keeps delivering

Lisa Hartle De Young posted news that the total of all funds donated to The EHE Foundation by Amazon Smile was \$5,860.87, and that is just from people online shopping through the Amazon Smile portal. Lisa noted:

“I received this update from Amazon Smile today. Great job EHE Amazon shoppers! For those who are new to our group, you can shop at Amazon Smile and select the EHE Foundation as your designated charity. Amazon Smile is the philanthropic arm of Amazon and they donate a portion of purchases to the EHE Foundation each quarter. It's FREE money and the same exact products and pricing as regular Amazon.”

The same is possible in the UK where the EHE Rare Cancer Charity is also registered with Amazon Smile. So please continue to use this system when buying on line. It really is free money. And a huge thanks to all those who have been doing it and have contributed to the sums already received.

And now for those USA fundraising memories!

2015

Team Laney was launched. In 2015 they organised their first EHE golf tournament, the first of many great events.



2016

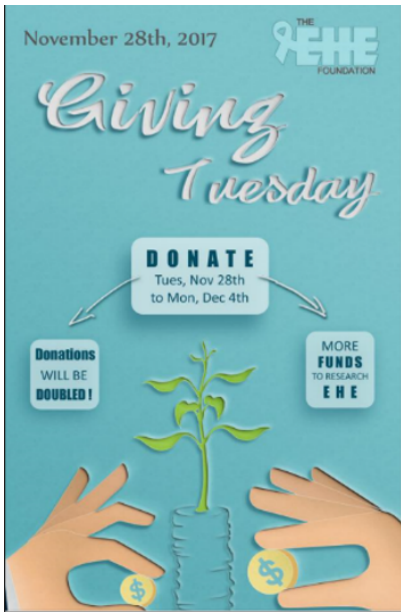
Devin O'Connor holds York EHE Foundation 2nd Golf Outing in memory of Mandy.



03 EHE Fundraising

2017

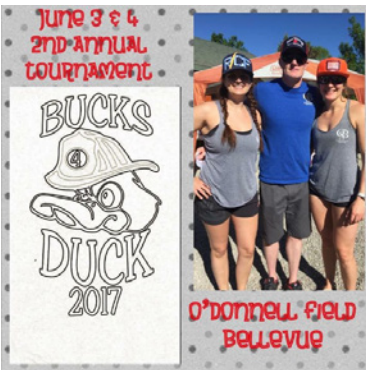
The EHE Foundation completed their second **Virtual 5K Fun Run and Walk event**. Everybody agreed it was the biggest and most successful yet.



The EHE Foundation ran a **matched-funding campaign for Giving Tuesday**. With fantastic support from the Foundation's members and the general public, the event raised over **\$60,000**.



In late **August** Angela Osborn posted some pictures from their annual event that is held in memory of her brother **Brian Frank**. In 2017 they raised a staggering **\$7,000** for EHE research. We were so grateful to Angela and all those involved for this magnificent effort.



Stephanie Herald posted news of the softball tournament, held in memory of **Justin Herald**, on

3rd and 4th June. Stephanie noted "Memorial softball tournament for my man Justin Herald. Part of the **money raised will go to the EHE foundation to help with finding a cure!** So thankful we have such a giving community that will not only keep his memory alive, but give for the cause for so many still fighting the battle!! Thank you everyone for being such a major support in our journey. Couldn't have done it without you all!"

2018

The EHE Foundation's **Giving Tuesday campaign** was a huge success, under the banner "**Alone we are Rare, together we are strong**". It was further supported by the Foundations very powerful "Faces behind EHE" Campaign.



2019

The EHE Foundation complete another wonderful **Giving Tuesday campaign**, and their **5K Virtual run/walk**.



04 And in other news...

Man's Best Friends

We all know that pets can be hugely calming and therapeutic. Many in our EHE family have dogs, and we are always delighted when they share photos of 'Man's best friend'.



Therapeutic photography

The dog theme continued in the quarter with Robinson Ortiz posting another of his inspiring photographs, a simple message and a poem by S. C. Lourie:

“A shout out to everyone who is trying right now.”

Trying to do the right thing.
Trying to keep going.
Trying to hold on.
Trying to discover their flow.
Trying to stay afloat.
Trying to meet each new day.
Trying to love themselves.
Trying new things and new ways.
Trying to find their healing.
I see you. I'm there too.
We're in this together.

a poem from S.C.Lourie



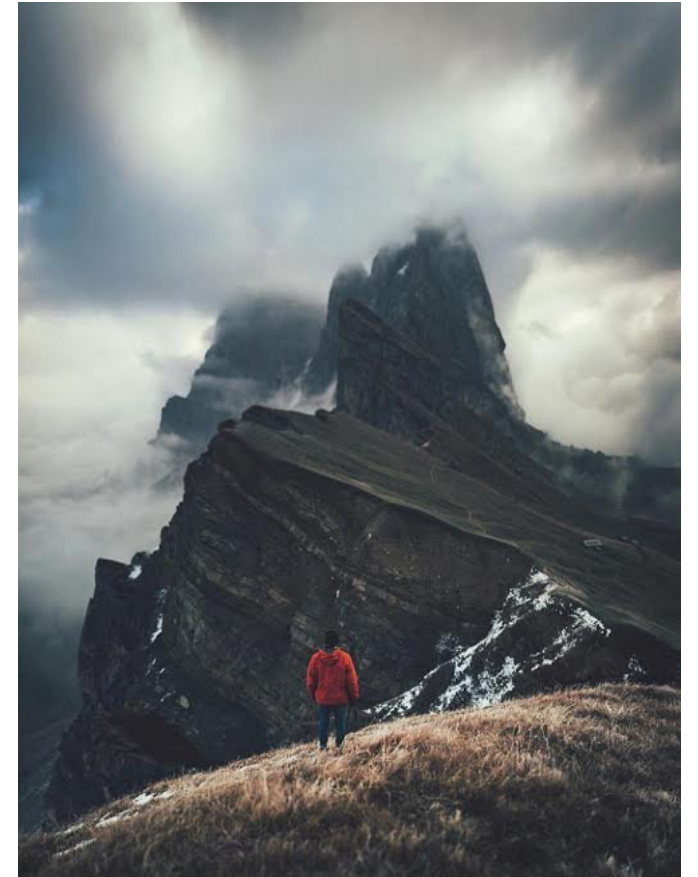
His second photo of the quarter was equally appropriate, and very powerful, with a poem from Lana Rafaela that addresses the extraordinary bravery that our EHE members who are battling EHE demonstrate day after day.

I think it's brave
that you get up in the morning
even if your soul is weary
and your bones ache for a rest.

I think it's brave
that you push away the waves
rolling in every day
and you decide to fight
yet again.

I know there are days
when you feel like giving up,
but I think it's brave
that you never do.

a poem from Lana Rafaela



“I really like it! First tattoo ever and a great reminder.”

Tattoos are back

We always love it when one of our members posts news of their new JustLive tattoo. Jennifer Nichole Wells-Gudenrath is the latest to share her new work of art with the group.

We like it too, Jennifer, and we like the fact that it will raise interest and awareness of EHE. **Thank you!**





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