

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



Quarterly Newsletter for the EHE Group
January - March 2020

the pledge

Edition 20



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Welcome

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

This is our 20th edition, for the first quarter of 2020. We hope that you enjoy reading it, and we want to say a massive thank you to all our supporters for their contributions. But today, as the world faces an horrendous pandemic, we also more than ever want to wish you all good health.

It can be difficult to stay strong and positive in the face of so much grim news. But if there is one thing we can say about our EHE family, it is that you are all fighters. And at times like this your combined support, warmth, and love for each other shines brighter than ever. Be cautious, stay well and ***Just Live***.



Highlights

EHE Foundation joins the CZI Rare as One Project

This quarter saw the amazing news that The EHE Foundation had been selected to be part of the Chan Zuckerberg Initiative's Rare as One Project. See our 'Breaking News' section on the next page for more details of this game-changing project.

5th Anniversary celebrations

The EHE foundations in the USA, UK and Australia will all be celebrating their 5th Birthdays this year. First up was The EHE Foundation in February. Happy Birthday guys!! You rock!!

UK Biobank close to launch

Collecting tissue, fluid and blood samples is critical to the support and encouragement of EHE research. The EHE Rare Cancer Charity hopes that the UK National EHE Biobank will go live in the very near future.

Charlie Medwin's Atlantic row raises £40,000

Charlie Medwin and two friends completed their trans-Atlantic row in 38 days. In the process Charlie raised an amazing £40,000 for EHE research. Just an awesome performance.

Charity Ball raises over £11,000

Allana Parker's EHE Charity Ball, organised to simultaneously celebrate a 400 day marathon relay of her closest friends, was held in February and raised over £11,000. A fantastic effort.

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

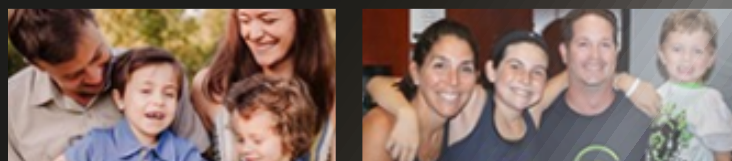
the **pledge** Edition 20





Breaking news

The EHE Foundation joins the Chan Zuckerberg Initiative's Rare As One Network



On 3rd February, The EHE Foundation was delighted and honoured to announce that it will receive a \$450,000 award from the Chan Zuckerberg Initiative (CZI) to drive progress towards treatments and a cure for Epithelioid Hemangioendothelioma (EHE).

“No one is more committed to finding cures for rare diseases than the patients and families of those affected by these disorders. We are also proud to support patient-led organizations as they pursue diagnoses, information, and treatment options in partnership with researchers and clinicians.”

Priscilla Chan, Co-Founder & Co-CEO of CZI

The award recognizes The EHE Foundation as part of CZI's **Rare As One Network**, a two-year program that provides \$13.5 million in funding to a network of rare disease patient-led organizations. As part of CZI's Rare As One Project, these grants are aimed at supporting and lifting up the work that patient communities are doing to accelerate research and drive progress in the fight against rare diseases.

CZI will provide The EHE Foundation with funding, training, community mentorship, and capacity-building services to assist in establishing a network of researchers and clinicians, convening their community, and developing a research agenda.

The EHE foundations have always recognised that patients are a powerful force in driving research for rare disease. Patients provide critical insights about their diseases and information that can fuel significant discoveries.



“We are incredibly grateful to CZI for their support and funding. The opportunity to be a part of the CZI Rare As One Project is game-changing in the rare disease world. The knowledge of patients suffering from a rare disease is key to driving breakthroughs in research and treatment. The lack of resources and infrastructure to support such patient-led research has held progress back—but this program is a significant step forward in eliminating these barriers.”

Jenni Kovach, Board President of The EHE Foundation



And with rare diseases, it is creating the environment and infrastructure to allow the worldwide patient base to come together that is so important to creating the patient numbers needed to make any analysis meaningful. Being part of the CZI's Rare As One Network will help us build on the foundation we have laid and allow us to learn from and work with other patient-led organizations to accelerate progress on rare disease together.

The EHE community world-wide extends our deepest thanks to the Chan Zuckerberg Initiative for this game-changing award. And we want to thank The EHE Foundation team who worked so hard over several months, and whose professionalism, passion and dedication to the EHE cause were certainly key in securing this award.

For more information about CZI and the Rare As One Project, please visit rareasone.org



01 Patient Support and Advocacy

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

Our fifth anniversary year

2015 was the year that our first three EHE not-for-profits were established and got up and running. First off the taxi rank in February of that year was The EHE Foundation in the USA. August saw The EHE Rare Cancer Charity UK go live, and then in November The EHE Rare Cancer Foundation Australia went live down under. None of us really knew what to expect. Wow, how brilliant the support has been, exceeding our wildest expectations.

In 2020 we will see all three of the EHE entities reach their fifth birthdays. First is the EHE Foundation's birthday, and in late February Julie Wahl posted a birthday message:

“Happy 5th Birthday to The EHE Foundation!
I never imagined how far we would come in 5 years. We now have 5 foundations and several groups of people around the world that are all fighting EHE together. We have research projects in progress, EHE patients in clinical trials, successful fundraising efforts, working relationships with EHE doctors and researchers, and the support of our global EHE community. Looking forward to the next 5 years! ”



We want to congratulate everybody that has been involved and helped with the running and administration of The EHE Foundation over the past five years. And echo the huge thanks for all our wonderful supporters. Here's to the next five years indeed. **Just Live!**

Canada has its EHE Facebook page up and running!

Our members in Canada have been working hard to raise funds for EHE research, which they have been able to initiate under Dr Razak at the Mt Sinai Clinic in Toronto. Dr Razak's research is testing the hypothesis that EHE carries a genomic complexity that will have immune signature and a neoepitope that predicts response to immunotherapy. **"It is so exciting to see this research underway"** said Fiona Louise who has been the driving force behind these initiatives.

To assist in the great progress already made however, Canada wanted to have their own Facebook platform. We were delighted therefore when Fiona posted the news that Karen Starr-Lang had created an EHE Canada page for Canadian EHE patients and their families. **"Please search for it and request to join"** said Fiona. We want to congratulate Karen and thank her for getting one more EHE Facebook page up and running.



What a profile!

Awareness of EHE grows through many different routes, but they all have one common aspect -somebody has to make the time and effort and have the desire to spread that information, as explained by Lisa Hartle De Young:

"Every person counts in the fight against EHE and sarcoma. We are so lucky to have the support of Dr. Jerad Gardner, pathologist and professor at the University of Arkansas. He continues to share his knowledge of EHE tumors and sarcoma across the globe. Awareness and education of the pathology community is essential to getting an accurate diagnosis. Congratulations"

Dr. Jerad Gardner, Associate Professor of Pathology and Dermatology at the University of Arkansas for Medical Sciences, has an impressive social media profile and was recently recognized for using social media to connect medical information between the public, patients, and medical community.



He stated these connections have changed how he has practiced medicine. Dr. Gardner has been a part of our community for years and we are grateful for his contribution in bringing awareness to sarcoma and EHE.

Read the full article here: <https://www.arkansasonline.com/news/2020/feb/09/dr-jerad-michael-gardner-20200209/>



01 Patient Support and Advocacy

Dr Wilky introduces EHE

Dr. Breelyn Wilky introduced EHE to worldwide attendees of the Interventional Radiology Conference in Miami, Florida in January 2020. One of the great challenges of any disease as rare as EHE is raising awareness, so we could not be more grateful to Dr Wilky for providing this exposure. Dr. Wilky gave an overview of EHE and discussed clinical vignettes, treatment options, and our patient-driven organization. Dr. Wilky, currently Associate Professor, Division of Medical Oncology, University of Colorado, Anschutz Medical Campus, is a long-time advocate of EHE patients and currently serves on the Advisory Board of The EHE Foundation.



Dr. Wilky's slides can be viewed here:

<https://breelynwikymd.com/2020/01/22/intro-to-ehe-slides-from-spectrum-2020/>

Nicola pleads for Covid-19 to be taken seriously

The coronavirus pandemic and resultant Covid-19 illness is scary for everybody, but there is a small group in society for who it is extremely frightening. For these high-risk patients, macho and mindless behaviour by members of the public ignoring the government's social restrictions puts their lives at risk, and those of the public.

Nicola Henderson from Yate in south-west England is one such high-risk individual, following her liver transplant in 2019 due to EHE. Nicola and her friend Leanne Woodruff were determined to try and educate as many people as they could in their area about the predicament of people like Nicola. So they took Nicola's story to the local paper who were delighted to try and help. Leanne, with no journalistic training or back-ground wrote an excellent article which we hope will help people understand why social distancing and restricted living conditions are so important.

We want to thank Nicola and Leanne for taking the initiative, and spelling out for people the risks faced by patients with significant medical conditions like EHE. Well done indeed.



Joe and the Mulligan Family Make a Difference

Joseph was diagnosed with EHE in October 2019. His family was devastated by the news. They did not know anything about EHE or what the treatment plan would look like. **“We cried for days,”** his mom, Jennifer Mulligan stated. However, the Mulligan family quickly started making a difference by creating awareness for EHE and helping others.

In early January, Joseph collected toys to support Sloan Kettering’s Children’s Activity Cancer Center and his own school. Upon delivering the toys to Sloan Kettering, Jennifer stated:

“ We loved giving the 300 plus new toy donations to Memorial Sloan Kettering Kids. Each label had a little something about EHE. Dr. Meyers is our awesome Pediatric Sarcoma Oncologist. We love educating others about our rare cancer! ”

Not only did this amazing family make a difference for other children, but they raised EHE awareness at the same time.

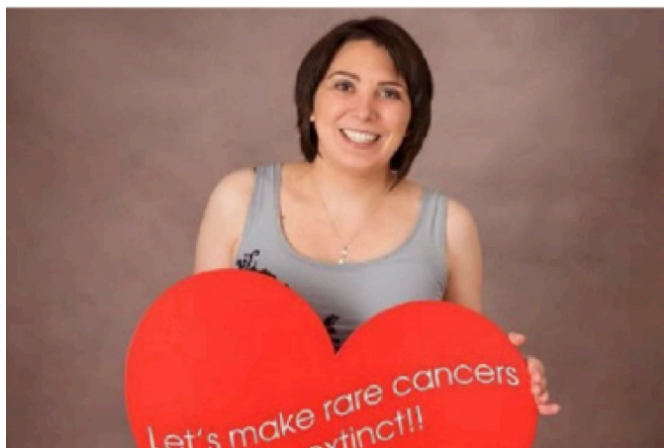


Joseph’s family is currently working on gaining support from family and friends for the 5th Annual EHE Fun Run and Walk while they are quarantined at home. Joseph was a featured story on The EHE Foundation’s Facebook page. The Mulligan family took the opportunity to share how the current pandemic and rare cancer affects their life. Their story was published in a local paper. This amazing family is working to make a difference and we are amazed at their ongoing efforts.

Read the story about their quarantine here:

<https://www.lohud.com/story/news/coronavirus/2020/04/01/how-coronavirus-threatens-ny-boys-battle-cancer-amid-outbreak/2900554001/>

Stonehaven woman’s fundraiser for cancer charities



Adrianna’s in the news again!

In February Adrianna Glennie organised her 40th Birthday gig at the Station Hotel in Stonehaven, Scotland. The event was noticed by local media and the two biggest papers in the Aberdeen and Stonehaven area gave Adrianna another chance to spread awareness about EHE. We hope that Adrianna had a fantastic birthday and want to say a huge thank you for the funds raised, the awareness of EHE created, and her ongoing support for cancer patients.



01 Patient Support and Advocacy

EHE at NIH Rare Disease Day

Medha Deoras Sutliff, Executive Director attended Rare Disease Day at the National Institutes of Health (NIH) on February 28th to represent The EHE Foundation. Medha noted

“We are making connections here and bringing back resources to hopefully lessen the diagnostic odyssey that many of you have had to face.”



Not only was she able to hear about the valuable work being done by the NIH and National Institute of Cancer, but Medha was also able to meet with the Foundation's National Cancer Institute's MyPART program partners with whom they are working to understand EHE. You can learn more about



participating in the NCI MyPART Natural History Study of Rare Solid Tumors here: <https://www.cancer.gov/pediatric-adult-rare-tumor/participate>

In the Foundations 5th anniversary year, it is wonderful to see EHE represented and involved at this Rare Disease Day, not only meeting and discussing ongoing activities, but also taking the chance to discuss future work and new initiatives.

A great coach leads to greater EHE awareness

Melissa McPherson shared news of further coverage for EHE when a reporter picked up Melissa's story. Following a Varsity Spirit employee telling a reporter: **“You want to interview this coach, she embodies her motto.... *just live.*”** the Star-Telegram.com website ran the story about Melissa's great coaching and her EHE. The article read:

“She's a real inspiration. Azle cheer coach leads team to excel despite rare cancer. Melissa McPherson led the Hornets to two state titles and three second-place finishes since she was diagnosed with Epithelioid Hemangioendothelioma (EHE) in 2016.”



Azle coach Melissa McPherson, center on one-knee, is surrounded by her co-ed team at the UIL Spirit State Championships held Jan 16-18, 2020 at the Tarrant County Convention Center in Fort Worth. Azle won a silver medal for McPherson, who is battling a rare form of cancer.

Melissa was shocked that she was the centre of the story, but also delighted to help raise awareness.

“So I got to shine some awareness on our EHE family.” We want to congratulate Melissa for the results of her Cheer leaders and also for the coverage and awareness of EHE.

Read her inspiring story here: <https://www.star-telegram.com/sports/dfwvarsity/article239446078>

Our membership grows

It is always with very mixed feelings that we welcome new members to the worldwide EHE Facebook support page. We are sad that they have had to find us, and start their own EHE journey, but facing this reality, we are happy that they have connected so that they may benefit from the support and advice that is so freely and lovingly offered by EHE patients everywhere. In 2013, we set up the private Facebook group for patient support with 3 members. Today, that FB support group has 1,784 members in over 65 countries worldwide.

We like to think that the impact and volume of our collective group is far greater and far louder than the sum of the individual voices. It is the fundamental fact behind our group's mantra (opposite):

“Alone we are rare, together we are strong.”

Positive vibes from Kathmandu

Our EHE community will both send and receive positive messages about EHE at any opportunity. We were delighted therefore when Leanne Millard posted her news in early March:

“Today I had the great privilege of visiting Boudhanath Stupa in Kathmandu, Nepal. After each full moon, the stupa is redecorated with garlands of marigolds and new prayer flags. I bought a string of prayer flags, wrote on them and they were added to the many others that adorned the stupa. They will be there for a month - flying in the wind singing lots of positive vibes for those with EHE. **Just live!!**”

We want to thank Leanne for remembering our worldwide EHE family on such a wonderful trip and for taking the opportunity to post EHE messages on those extraordinary prayer flags. And thank you also for the great photos. It is amazing to have had the chance to visit such a wonderful country and such special locations. **Just Live!** Indeed.



02 EHE Research

Our research section this quarter is slightly lighter on content than in our previous editions. This is not in any way indicative of a lack of progress or interest in EHE research. On the contrary we are continuing to push on so many fronts and continuing to expand our EHE research effort. However, as you are all aware, the world is in the grip of a pandemic, fighting the coronavirus. Many of us are now 'locked down', required to stay in our homes, and this also applies to the labs and researchers who are working on EHE.

At the same time the medical community is quite rightfully completely focused on fighting the coronavirus. In these exceptional circumstances it is clearly appropriate to minimise our demands for updates and reporting on our different research projects. We hope that we will be able to provide further updates in the next edition of The Pledge.

We need your tissue

It is likely that in these difficult times, many medical and surgical procedures are being postponed. However, we still want to stress the importance of capturing all EHE tissue and fluid samples whenever we can. Lisa Hartle De Young continued to share this message for our North American members:

“ Genomic analysis of EHE tumors is very important, and may help us ultimately identify new drug targets and treatments for EHE! The EHE Foundation is collaborating with an extremely valuable research program called pattern.org. They facilitate the coordination, collection, and shipping of fresh surgical tissue and fluid (from lungs- pleural effusion) or abdomen (ascites) via RCRF (Rare Cancer Research Foundation) to the Broad Institute where the tissue will be used in the Broad Institute's ground-breaking research program called the Rare Cancer Dependency Map, where they are hoping to create cell line models for rare cancers. THERE IS NO CHARGE TO THE PATIENT. We hope you will consider registering at www.pattern.org and making a difference in solving the mysteries of EHE! Our patients are the solution to ending this horrific disease.”

Our Canadian EHE Members can also participate but currently pattern.org is only able to accept fluid donations from Canada. No fresh tissue can cross the border. But please enrol in Canada as fluid samples are still valuable. And for all those who want to know more about the Rare Cancer Dependency Map project, here is a link to the excellent Broad Institute explanation.

<https://www.youtube.com/watch?>



Mekinist (trametinib) trial update

In May 2017 Dr Scott Schuetze from the University of Michigan, as Principal Investigator, launched a clinical trial, in conjunction with SARC, to examine the efficacy of trametinib (a MEK/MAP kinase pathway inhibitor.) This trial was based on preclinical data developed in Dr Brian Rubin's laboratory and which was presented at the CTOS annual meeting in 2017.

Lisa Hartle De Young shared an update with the group in early February about the trial and its progress, after participating in a call that day with Dr Schuetze:

“Currently 31 participants are enrolled and they are still accepting participants. The most common reported side-effects are facial/skin issues and hair loss. Stability and objective tumor response has been reported as well as lower CRP-SED rates (these are inflammation markers). Reduced pain is also reported. Dr Schuetze also asked me to thank all participants for being so diligent in completing the quality of life forms and providing valuable details.”

One of the key aspects of any trial is understanding exactly what effects the trial drug has had on the tumour. To do this however, post-trial tissue samples are critical. Lisa explained:

“A request was made if you have not already done so, to please consider opting-in to the optional biopsy. This tissue will be examined by Dr Rubin to analyze the impact of Mekinist on EHE tissue. They want to examine a specific mechanism, so obtaining these samples is important. If you have any questions please pm (private message) me, or have your doctor contact the SARC Office at sarc@sarctrails.org.”

We want to thank all those involved in running this EHE-specific trial, and of course all of those patients who have participated and been so diligent in their adherence to and completion of the trial processes and procedures.

A new drug trial is open to EHE

In mid-February Jane Gutkovich shared a link to a new drug trial in Denver which is open to EHE, Jane posted:

“This trial includes a combination of chemo and immunotherapy. All drugs used in this trial have shown some efficacy for EHE, so there is a hope that their combination will be effective in even the most aggressive EHE cases.”

The trial is being conducted by EHE expert, Dr Breelyn Wilky.

Further information can be found at <https://clinicaltrials.gov/ct2/show/NCT04028063>

CLINICALTRIALS.GOV

Doxorubicin Plus Dual Checkpoint Blockade for Soft Tissue Sarcomas - Full Text View - ClinicalTrials.gov

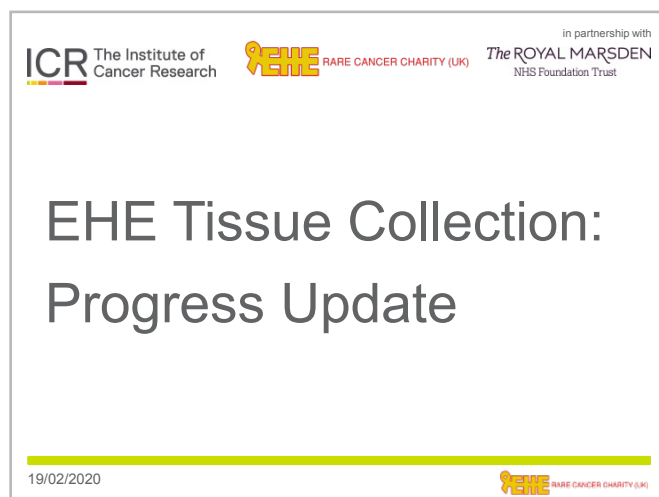
Doxorubicin Plus Dual Checkpoint Blockade for Soft Tissue Sarcomas - Full Text View.



02 EHE Research

UK EHE National Biobank moving to ethics approval

In August 2019 The EHE Rare Cancer Charity (EHERCC) in the UK initiated a project with the Institute of Cancer Research (ICR) in London, sister organisation to the Royal Marsden Hospital (RMH), to establish a UK national EHE biobank. The project has involved the recruitment and funding of a full time Tissue Manager, Emma, who has been working to pull together all the processes, procedures and documentation required before ethics approval can be obtained and the biobank launched.



At the end of March, Hugh Leonard of the EHERCC, took part in a videoconference with the ICR team to obtain an update on progress. Hugh said:

“ Things have progressed so well. Emma has done a great job preparing all procedures and documents which are now in place. The RMH have also been very helpful, agreeing that the actual biobank sampling and storage procedures will be undertaken by the RMH Generic Tissue Bank (GTB), who already run and administer biobanks for several other cancers.”

The team are now ready to move forward with the ethics approval which will be the last stage of the set up procedures before the biobank goes live. After this the EHERCC and the ICR will be working together to publicise the biobank and encourage participation of all EHE patients and hospitals in the UK. Hugh commented:

“ This is exciting. Tissue and fluid collection is so important to assist with EHE research. Up until now it has been a rather haphazard process with individual patients and the charity working with hospitals on a case by case basis to try and save samples for future research. With this fully-approved EHE national biobank open to the whole UK, and with an accepted sampling programme for each patient, we hope that tissue and fluid sampling and capture will become coordinated, planned and very effective.”

The EHERCC is now working with the biobank team to assist with the completion of the biobank set up and the subsequent publicity of its launch. And that won't be the end. Hugh explained:

“ Our initial focus is on the UK national process and getting this up and running. But once we have achieved that, we will be reaching out to our European partners to try and develop a European-wide EHE biobank process. We are also considering ways to possibly expand the biobank to include other rare cancers. This will be great for the overall treatment of rare cancers, but will also allow us to share costs with other groups. But our initial focus is to get the biobank working efficiently for EHE patients.”

MyPART, a new research program open to EHE Patients

In late January, Jane Gutkovich posted news of a research study being undertaken within the Rare Disease program at National Cancer Institute in the USA. The study, called MyPART (which stands for My Pediatric and Adult Rare Tumour Network), is open to rare cancer patients everywhere as there is no geographical restrictions, and participation is free. In fact, in some cases, the NCI will also cover travel costs. Here are some of the key points, as posted by Jane.

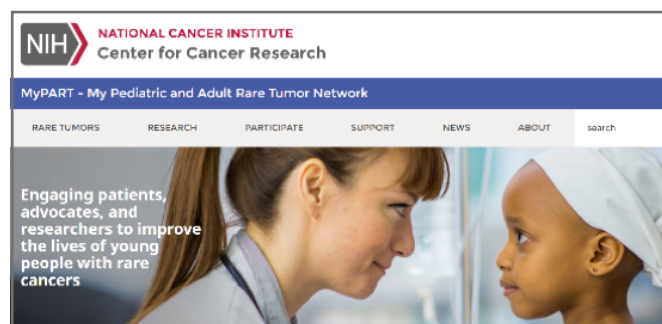
- This program is open to EHE patients!
- Initially, participants will provide some clinical information (medical history, imaging studies and reports, surgical pathology reports) and bio specimens (archived tissue samples and saliva)
- Some participants will be invited to the NIH Clinical Center for additional evaluations and consultation with a team of expert doctors. After evaluation, participants will be provided with recommendations about possible treatment options both at the NCI and/or in other institutions
- The participants will be contacted by NCI on a regular base to update their information
- Tissue will undergo genetic analysis and results will be shared with patients
- Data will be made available to all researchers as it is collected.

Jane continued:

“The benefits are obvious. You will obtain completely free consultations from top specialists and free genetic analysis of your tumor. In addition, you are greatly contributing to EHE research as the data will be available to all researchers.”

There had been concerns about the time it would take for patients to receive their genetic analysis, but Jane was able to post good news about this shortly thereafter:

“The turnaround for genetic testing is now 2-3 weeks!! (In some cases it might take longer if the tissue sample is too small). They are significantly expediting the process!”



Jane encouraged everyone to spend some time reading about the program on their website at <https://www.cancer.gov/pediatric-adult-rare-tumor>. The program coordinator (see the email on the website) will answer your questions about specifics of your particular case. Jane is also happy to answer any questions that our members may have, either through the Facebook page or directly by email at jgutkovich@gmail.com. Jane concluded:

“The bottom line is that participants will get a free genetic analysis done in a relatively short period of time, while contributing tremendously to EHE research and, if needed, will get advice and help from the National Cancer Institute. So please visit their website and post your questions or email me. I will be going over various aspects of this program, so stay tuned for further updates.”



03 EHE Fundraising

Today we are proud to have EHE-dedicated research being carried out in 4 different countries over three continents. The EHE Group remains totally focused on raising the critical funds needed to finance, drive and accelerate this exciting EHE research programme, as well as the new and additional research that we hope 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.

Partying the night away

On 15th February Adrianna Glennie decided to celebrate her 40th birthday with a party and gig at the Station Hotel in Stonehaven, Scotland. Adrianna wanted to raise money for two charities that are close to her heart.

These are the EHE Rare Cancer Charity and Clan Cancer Support. It was a truly brilliant event with great music into the early hours of the morning.

Adrianna's 40th

RARE CANCER EHE CHARITY (UK)

facebook.com/fabbyfotos

**THE CHANDELIER'S
FULL FAT
CEILIDH
COLIN CLYNE
MORE ACTS TO BE
ANNOUNCED**

**FUNDRAISING GAMES
RAFFLE
AUCTION**

**SAT 15 FEB 2020
3PM—MIDNIGHT
STATION HOTEL,
STONEHAVEN**

Music Festival Fundraiser
& Ad's 40th Birthday

**PROCEEDS TO
RARE CANCER
EHE
CHARITY (UK)**

**&
CLAN**

PRIVATE EVENT (TO ALLOW UNDER 18s)

TICKETS FROM:
PAYPAL SEARCH: PAYPAL.ME/EHE20
OR BY BANK TRANSFER
EMAIL: EHE2020@OUTLOOK.COM
TEXT: 07432640090
ADULT TICKETS FROM £23
FURTHER DETAILS ON FACEBOOK

The bottom section of the collage consists of six small photographs. From left to right: 1. Two men, one in a cowboy hat and one in a blue shirt, holding a pink guitar. 2. A group of about ten people, including children and adults, posing for a photo. 3. A man in a cowboy hat and a woman in a blue shirt holding a pink guitar. 4. A man in a cowboy hat and a woman in a blue shirt holding a pink guitar. 5. A group of about ten people, including children and adults, posing for a photo. 6. A man in a cowboy hat and a woman in a blue shirt holding a pink guitar.

The Atlantic conquered

On 12th December, Charlie Medwin and two of his closest friends, Lewis Matthews and Tom Whittle, set off to row the Atlantic under their team name, All-Oar-Nothing, in support of their respective charities, supported by their close friend Chris Slack who had had to pull out at the last minute due to injury. What was their 38 day adventure like? That is best told in Charlie's own words.

“One sensation which resided in all of us every hour of every day was the relentless nature of the ocean.

The first two weeks the weather system meant we were thrown into a baptism of fire from day one. Not only did our bodies have to adjust to new sleeping patterns, excessive exercise and seasickness but now we also had to contend with huge waves throwing us around like rag-dolls, knocking us off our seats and breaking oars.

The second fortnight we were in a high pressure system with no wind and blazing sunshine which meant we would often collapse off the oars after rowing shifts of close to 3 hours during the day in the sweltering heat. The only respite in this period came from an extraordinary experience when a whale, larger than our boat, surfed alongside us and swam with us through the waves for over half an hour.

The final ten days felt like a never-ending journey where we experienced probably the toughest conditions during the crossing and heard a number of boats around us had capsized. The days ticked by and on day 38, with 30 miles left to go, we could see Antigua.”

Antigua.

The All-Oar-Nothing team are now in the process of selling their boat, and will then be able to tally up the funds raised. Charlie's brother Harry is an EHE patient and Charlie therefore decided to raise funds for the EHE Rare Cancer Charity. Charlie hopes that he will be able to donate a final sum close to £25,000. Coupled with major donations previously made directly to the EHE Rare Cancer Charity in support of Charlie, his final total for funds raised will be very close to £40,000!

We want to all once more thank Charlie, Lewis, Chris and Tom, for their fantastic effort and support. We are in 'oar' of what these guys did in support of the EHE Rare Cancer Charity and their other respective causes. We also are very proud of them.



03 EHE Fundraising

An amazing relay completed

It was on 1st January 2019 that Allana Parker posted news that her four wonderful friends, Natalie Ellis, Samantha Power, Ellen Cramoysan, and Sophie Kitchen, were embarking on a 400 day relay to raise funds for EHE research. These were four very determined ladies who were joining the fight against EHE under the name EHERelayRaisers. Each of the four completed amazing challenges over their 100 day section of the relay.

Their relay ended on 4th February 2020, just 4 days before their EHE Masquerade Charity Ball. Supported by a huge group of wonderful friends, family, colleagues and members of the public, the EHERelayRaisers had raised an amazing £4,424.49 which was presented to the EHE Rare Cancer Charity Chair, Hugh Leonard, at the Masquerade Ball.

Allana, presenting the cheque with her four friends, thanked them for their wonderful support and noted that further donations had been promised. Indeed, when the very final financial tally was posted by Allana on 19th February, the EHERelayRaisers total was confirmed at an amazing £4,964.49.



Left to right: Hugh Leonard, Allana Parker, Natalie Ellis, Ellen Cramoysan, Samantha Power, Jade Kitchen

Hugh Leonard noted:

“ this is an absolutely stunning result and is entirely due to the tireless energy and support of these four wonderful friends of Allana. It is only because of people like Natalie, Sam, Ellen and Sophie that we have been able to achieve anything in our fight against EHE. We are so grateful to them all.”

Charity Auction in Canada

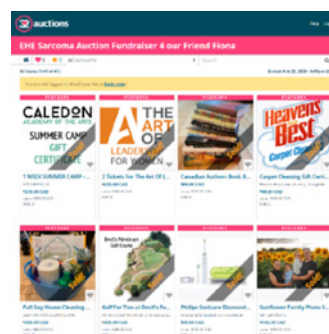
In the second half of February Fiona Louise posted information about the most recent fundraising endeavour to raise funds for EHE research. This was an auction of lots and promises donated by local individuals and businesses. Fiona Louise posted:

“ It is exciting because the idea and energy came from different people.”

The auction raised \$3568. In addition to the auction, a drop the puck and chocolate sales event raised \$878 and a local recycling program donated another \$500.

Fiona went on:

“ I am very happy to report that so far in 2020 my community will have raised over \$5000 for Sarcoma EHE research.”



These are just the latest amazing results of the support and contribution from Fiona's local community, and we cannot thank all those involved enough for their wonderful support.

5th Annual Fun Run and Walk

The EHE Foundation (US) launched its 5th Annual Fun Run and Walk during the first quarter, with registration opening on February 15th.

Out of concern for the health and safety of patients, family, friends, volunteers, and other supporters, The EHE Foundation recently moved the deadline to register to May 1st. However, they are now tentatively removing the deadline date and leaving the registration end date open. The timeline recommended to complete the event (originally April 18th to May 3rd) was extended to **any date during 2020**. Unfortunately, the contracted businesses for printing of materials and t-shirts fall under the “non-essential” business category and have been forced to close until at least the end of April. **Due to this and the safety of our many packing volunteers, race packets (shirts, bracelets, temporary tattoos, etc) will not be mailed until at least mid-May.**

The Foundation apologize for the inconvenience and are happy to offer a refund to anyone that requests it. The EHE Foundation will send an update as soon as we can confirm when items will be shipped.



The EHE Foundation posted:

“This family fun event is for all ages and abilities. It is virtual, which means it can be done anywhere you are. We simply ask you finish the 1K (just over 1/2 mile) or 5K (3.1 miles), either by walking or running. You can do it with others who register, or on your own.”

LeeAnn Conner stated:

“We are also excited to be able to offer team names this year where participants will be able to select a team so that they can participate in honor or memory of a specific person.”

Event sponsorship is also available for any individual or company that would like to have their logo or name on the back of the shirts. Many patients are planning events for the fall.

Julie Rivers Wahl added:

“The funds raised from this event go directly to EHE research, so please sign up, invite your family and friends, and share it on your page. We ask everyone to try to complete their run or walk any way they can by walking, running, roller-skating, biking, or however you wish to complete it. You can even break it up into smaller distances.”

For more information please go to <https://fightehe.org/5th-annual-ehe-fun-run-walk/>

or

email LeeAnn Conner at: leeannconner@fightehe.org.

We encourage everybody who can to join this great event and help us raise funds to beat EHE.

As Julie Rivers Wahl stated,

“Together,
we can find
a cure!!”

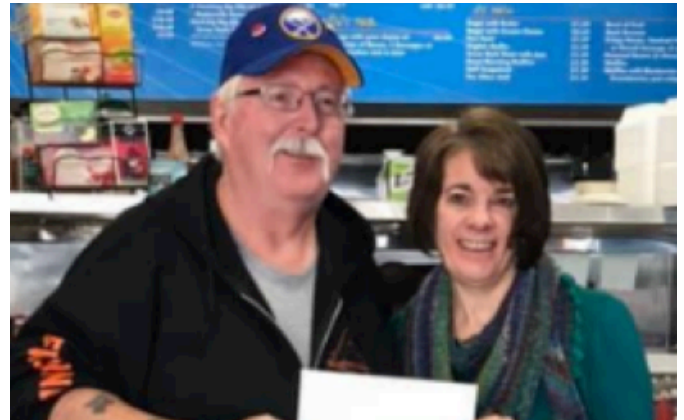


03 EHE Fundraising

Recycling for research

Fiona Louise posted news in February of a local resident who recycles electronics and liquor bottles and donates funds to different causes. Fiona was delighted to be able to report that he had chosen Sarcoma (EHE) as his most recent charity, and provided Fiona with a cheque for \$500 at their breakfast meeting.

We love the idea that a process as important and positive as recycling has also led to such a valuable donation to help fund EHE research.



Birthday fund-raisers continue

Our EHE members continue to unselfishly use their birthdays as opportunities to fundraise for EHE research. These events may not each raise thousands of dollars or pounds, but with over 1,700 members worldwide, the sums would be extraordinary if everybody joined in.

2020 has already seen a number of these birthday campaigns launched in America. We want to say a huge thank you to everybody who has used their birthdays in this way, and an even bigger thank you to all those who donated to them and made them so successful. Here are just a few of the campaign headers from this quarter.



London Landmarks postponed

While the EHE Foundation organises its 5K Fun Run and Walk each year, the UK equivalent is the London Landmarks Half Marathon, where the EHE Rare Cancer Charity has a certain number of places. The 2020 event was scheduled for the 29 March, and with 41 brave souls training hard for the big day, it looked like the 2020 version of this event would be another success. Sadly the London Landmarks Half Marathon was just one of many sporting casualties around the globe, with the announcement of its postponement happening just two weeks before the event itself. **"Gutted"** was the most common word amongst the many posts about the delay. Hugh Leonard explained:

" We knew there was a chance it would not take place, but as people were training hard there was always a hope that we might just get to run it. However, events have moved fast, and we completely understand why the decision was made. These are tough times and we, more than most, know how precious good health is. So we totally support the decision. We hope that the run will be re-organised later in the year. In the meantime we just want to say thank you to all the runners who were planning to run for us, training in the relentless rain that seemed to be a feature of this winter. Keep training, stay healthy and *Just live*"

What a night!

Allana Parker wanted to do something special to celebrate the end of the amazing fundraising relay undertaken by her four wonderful friends, Natalie, Samantha, Ellen, and Sophie, which was completed on 4th February. As a group, these five women of boundless energy decided that holding a charity ball shortly thereafter was a great idea. And so, on 8th February, at Butlins in Skegness, the EHE Masquerade Ball took place. And what a night it was.

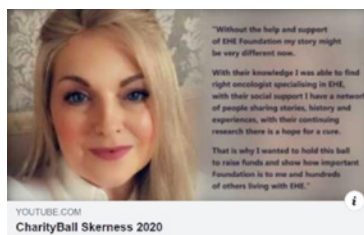


Allana posted the next morning:

“ An absolutely wonderful night at the Masquerade Ball for EHE. Amazing speech by Hugh kept everyone enthralled and the positive comments afterwards from people who knew nothing about EHE made it all the more special. One lady told me she usually falls asleep during speeches but she was mesmerised and wanted to know even more about EHE and the foundation. We are all shattered today but we hope to have a full total of funds raised on the night within the next couple of days. Most definitely a night to remember!”

The event was spectacular with a wonderful setting, fantastic energy and amazing fun had by all who were there. The tables were lovely with beautiful table centres made by the organisers themselves. There was also an amazing video backdrop that had been created by Anna Wydro, featuring EHE patients from all over the globe, which ran continuously through the evening.

Hugh Leonard, Chair of the EHE Rare Cancer Charity, was present and took the opportunity to tell the guests about the charity, its work and its ambitions.



Hugh said:

“ it was such a pleasure to be able to tell all the guests about EHE, the charity and what we are trying to do, thanks to their wonderful support. It was also so exciting to be able to finally meet Allana, Natalie, Samantha, Ellen, and Sophie in person as I had been communicating with them for over a year.”



On the 19th February Allana posted the wonderful news that the funds raised on the night of the Ball totalled an amazing £6,483.05! Allana commented:



“ An absolutely amazing amount that I never expected and with that added to the final total from the girls 400 day relay raiser and collection tins we have an unbelievable £11,447.54! Thank you so much to everybody who supported us and all the companies who donated so much also.”

Allana finished with a simple message:

“ It can be lonely with a rare cancer but with people like you behind us there's strength in numbers!”

The total raised by this group is indeed an amazing amount, and we want to thank Allana, Natalie, Samantha, Ellen, and Sophie, and all the people and companies that supported them throughout for this fantastic achievement.



04 And in other news...

More 'Just Live' tattoos spotted

We love to see photos of **Just Live** emblem tattoos. They have become just one of the common themes that help build bonds across the diverse but close EHE community. This quarter saw the latest version posted by Shelley Caine:



Nicola Henderson in the UK also spotted the logo on an amusing social media post:

“ This made me giggle! Spotted by my husband on a random Facebook post.. someone's made a meme with our tattoo that we all love... I wonder if that's anyone in our groups arm!!! Obviously that's a pretty scary heart rhythm!”

Not with that rhythm.



Photo therapy

Just a few of the fantastic photos posted by our members, and which we know are so appreciated. That may be even more the case as so many people worldwide, in the fight against the coronavirus, face weeks of lock-down in their homes. We hope you enjoy them.

Robinson Ortiz Jr. shared this amazing photo and accompanying words:

“ At the end of the day, bravery isn't a battlefield. Bravery is the quietest thing you will ever know. Bravery is getting up in the morning when your bones are heavy and your heart aches. Bravery is being gentle with yourself, even when you are not a shining example of the person you strive to be. Bravery is forgiving yourself. It is the way you bloom in the direction of goodness. But most of all, bravery is knowing that you will continue to dance even in the midst of life's storms.”

Bianca Sparacino



Carl and Elizabeth Dickson shared some more wonderful photos of their homestead in Colorado. This has been an emotional period for the Dickson's as they have now moved to a new home, but as always, Carl found positive words for the group:

“ We only have 5 days left on our property and what a better way for it to start, an elk strolling through.

Of course it is probably just something I wish to believe but after he jumped the fence he turned his head as if to say “goodbye my friends”.

Life is full of changes, sometimes willingly and other times pushed upon us.

Change is inevitable, grow with it, do not fight against it.

A few more pictures from our home.
Just Live.”

We of course wish the Dickson's success and happiness in their new home.





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