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
April – June 2021

the pledge

Edition 25

Just Live

The GRIT baseball team, supporting EHE and Joe Mulligan

Contents

Welcome

Welcome to the 25th edition of **“The Pledge”,** the quarterly newsletter of the EHE Group, covering the second quarter of 2021. We continue to see a slow but steady increase in all areas of our Group’s activity as we slowly come out of the pandemic, or get used to working within it.

Patient support and advocacy activities are expanding once more; research is back up and running, albeit with some restrictions; and fundraising is also growing, which is wonderful as we continue to see greater research opportunity and increasing funding demands. These are good challenges to face when one thinks back to 2015 and our collective questions as to whether our fledgling foundations would make a difference. Thanks to all of you, they have! We hope that you enjoy this edition, and once again we want to say a huge thank you to all our supporters for their contributions. ***“Just Live”.***

Highlights

The EHE Foundation's patient resources expand

The second quarter saw The EHE Foundation launch its 'Provider Directory' while continuing to expand its EHE library. Providing such patient resources remains a key objective.

European activity is expanding

Our European focus now includes research collaboration between INT Milan and ICR London; the initiation of European-wide EHE patient engagement; and the establishment of EHE Italia-Non solo Laura, the first European EHE foundation.

ESMO Consensus Paper finalised and published

In the last edition we reported that the ESMO EHE Consensus Paper was near to completion. We are delighted to confirm that the paper has now been published. The EHE Group are working with ESMO to provide a patient-friendly form of the document so that the contents are accessible to all.

UK EHE Biobank goes live

Following the US biobank launch last quarter, the EHE Rare Cancer Charity were delighted to announce that the UK National EHE Biobank went live in April. Patient enrolment is ongoing.

Competition exceeds Kimberley's expectations

Kimberley Young wins a design competition in the US that leads to great fashion, major fundraising and great exposure for EHE. What a great win!

New research collaboration is up and running

A collaborative research project between INT in Milan and the ICR in London is being funded by the EHE Group, and has started to recruit patients. This project will be evaluating cytokines, hormones and microDNAs, all as potential novel biomarkers for EHE.

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

the pledge

Edition 25

Just live

01 Patient Support and Advocacy

The EHE Group's patient support continues to be largely delivered through its worldwide Facebook page which connects with over 2,100 people in over 75 countries across the globe, as well as more local social media platforms.

Our global page, driven by the tireless energy and contribution of so many of our members, most of whom are EHE patients themselves, continues to inspire and support our worldwide EHE community. It is this community that continues to warmly welcome and compassionately support anyone diagnosed with EHE, wherever they may live. It is also for this community that our EHE foundations work so hard to deliver increased awareness of EHE while striving to create ever-greater support and connectivity for our members. We thank all our supporters who have contributed to this critical part of our activity, examples of which are provided in this section.

LARNIE LIVING continues to grow

A big part of increasing awareness of EHE is patients telling their stories and sharing information. In our modern digital world there are many different forms that this sharing can take: websites, videos, blogs, and podcasts are just a few. Allana Parker, based in the UK, established such a podcast to share not only her story, but the story of others, and discussions with specialists and other EHE patients. The LARNIE LIVING podcast has been listened to by many, and in April, Allana posted her latest interview with fellow EHE patient Mariana Coutinho who lives in Portugal.

> “Hello everyone, just to let you all know the podcast recorded with Mariana Coutinho is now available on www.larnieliving.com just click this link then press for podcasts. It's episode 4 called Mariana and Me. Also available on iTunes, Spotify and many other podcast sites xx”

We would love to report on other such sites set up by EHE patients across the globe. So if you have a website, a blog, a podcast or any other form of media where you share your details or talk about EHE, please send the link to us and we'll include you in our future editions. And thanks to Allana for all she does to spread awareness of EHE.

Larnie Living

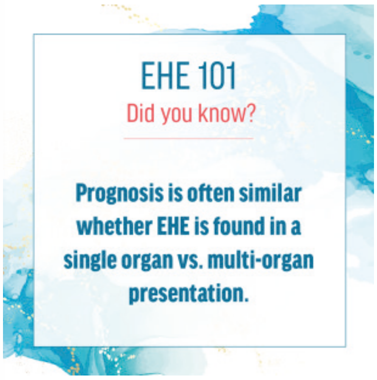
A rare cancer thriver with EHE Sarcoma, just living ....

EHE 101: An Awareness Campaign for April

Shortly after our three initial EHE foundations were established in 2015 (in the US, UK and Australia) the idea of an EHE day or period in the calendar was raised. Our goal was simply to have a time when our EHE community world-wide would come together and focus on EHE, in any way that they wanted.
It was quickly decided that with a global membership with multiple different climates and time zones, it would be better to have an EHE month as opposed to an EHE day. April was eventually selected as EHE Awareness month.

In April 2021, The EHE Foundation launched their 'EHE 101' campaign to help spread awareness of EHE.

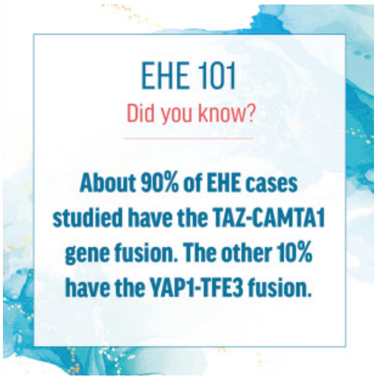
But raising awareness of EHE is not restricted to just April. Feel free to share these posts and images from The EHE Foundation's Facebook page to help family and friends gain a better understanding of this unique cancer.



EHE 101

Did you know?

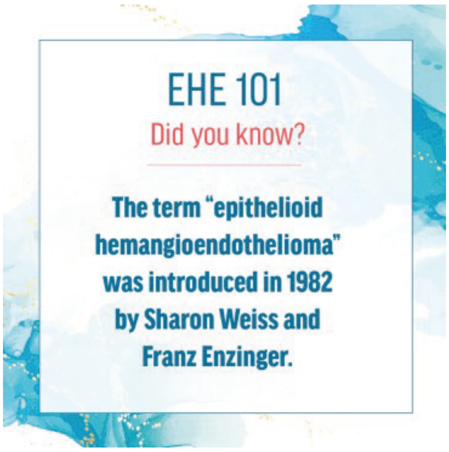
Prognosis is often similar whether EHE is found in a single organ vs. multi-organ presentation.



EHE 101

Did you know?

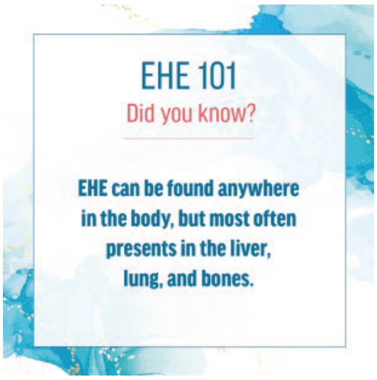
About 90% of EHE cases studied have the TAZ-CAMTA1 gene fusion. The other 10% have the YAP1-TFE3 fusion.



EHE 101

Did you know?

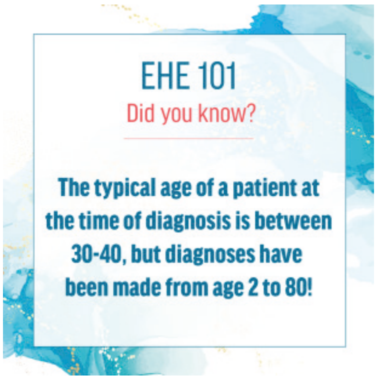
The term "epithelioid hemangioendothelioma" was introduced in 1982 by Sharon Weiss and Franz Enzinger.



EHE 101

Did you know?

EHE can be found anywhere in the body, but most often presents in the liver, lung, and bones.



EHE 101

Did you know?

The typical age of a patient at the time of diagnosis is between 30-40, but diagnoses have been made from age 2 to 80!

01 Patient Support and Advocacy

Connecting European Patients

One of the key goals of the EHE Rare Cancer Charity in the UK in 2021 is to build a closer EHE network in Europe, so that the EHE Group can ensure maximum support for, and involvement of, all European patients. Mariana Coutinho, EHE patient member living in Portugal, has been formally appointed as the EHE Rare Cancer Charity's European Coordinator, and will be a key component of this European strategy. Mariana has already begun the process of connecting with our European patient group, as she explained:

> **“The EHE Rare Cancer Charity (UK) wants to connect with all EHE patients from EUROPE in our EHE family and also wants to reach out to even more EHE patients in each country. Being so rare, we can only benefit from this cooperation between us. This will hopefully make it easier to improve research and the care we receive while living in Europe, and will help us ensure that EHE patients get the maximum exposure to any future study or research or clinical trial opportunities.”**

This is also coinciding with a number of other exciting European initiatives, as Hugh Leonard explained:

> **“Strengthening our European patient network is just one part of our European strategy. As part of our patient focus we are looking to join a number of the key European sarcoma and rare disease umbrella patient organisations who will be able to assist. On the research front we are already funding collaborative EHE research between INT in Milan and the ICR in London. We are also in discussion with these groups about not only expanding their project but also reaching out to other European centres to discuss ways to coordinate our EHE data gathering. This of course has also coincided with the important ESMO EHE Consensus Paper that was finalised earlier this year and is now publicly available.”**

Mariana will be playing a critical role in reaching out to other European patients and also coordinating with the patient groups that the UK charity is joining. She explained:

> **“Ultimately our hope is to have an EHE patient group recognised in each European country, with one or two coordinators with whom we can liaise. We hope that this network, as it grows, will allow us to establish an open and positive two way communication pathway where we can assist those patients with information and experience, but also seek their input and participation in, for example, patient data and information gathering processes. And excitingly, we now have an Italian EHE foundation that will also be involved.”**

We look forward to reporting on how this exciting European strategy is progressing in later editions of The Pledge.

EHE Group: coordinating EHE activity across the globe

One of the challenges of our global EHE approach is the continuous need to manage and coordinate all activities. Hugh Leonard, Chair of Trustees in the UK, outlined:

> **“As a worldwide group with limited funding but a global footprint, our continual focus is on ensuring that we are not duplicating any work unnecessarily, and that everybody is properly informed and fully aware of what is taking place. We try to share as much of the work as we can, and where we can, produce products that can be used across the globe.”**

This is not only true of foundation work products, but also applies to the different research initiatives we are funding, as Medha Deoras Sutliff, Executive Director in the USA, outlined:

> **“Our foundations are now promoting, funding and reporting on multiple EHE projects across the globe, including here in the USA, the UK and Europe, and in Australia. It is part of the responsibility of our foundations to therefore ensure that this global research is complimentary wherever possible; that our projects have different objectives and are not duplicating each other, and that the results are shared so that valuable new findings from each research stream are shared in case they may impact how another piece of research is progressed.”**

Reviewing our objectives and continually assessing if we are getting the maximum ‘bang for our buck’ is also critical, as Jonathan Granek, a Founding Director in Australia, described:

> **“Each research project is a unique project in its own right, but how the project is set up and positioned, how it is described in its ethics application, and whether or not it can be easily expanded, or repurposed, is critical to ensuring we get the maximum value for the research funds we spend. We try to ensure that if there are potential areas of follow-on research, or areas of research that may be different but use similar initial data, then that is captured at the outset. So for example, we try and ensure that every data set, registry or study we do is not limited by geographical location.”**

To achieve all this, the three foundations decided to meet regularly to share information, discuss strategy, and agree objectives. That can be complex with different time zones, but everybody understands the importance of this collaboration, formally known as the EHE Group. Jenni Case Kovach, President of the US foundation noted:

> **“We try to ensure that we have a global meeting every two to three months, or more urgently if required. I think we would all like to have more time, but we cover all the main topics and the energy and passion that the group brings to the fight against EHE is always great to see. We may be small and we may be rare, but we sure have a lot of ambition and fight, and also a lot of good humor. I am confident with the group we have that we are, and will continue, to make a difference for the EHE global community.”**

And here is a screenshot of the last EHE Group meeting with Jenni Case Kovach, Hugh Leonard, Jono Granek, Medha Deoras Sutliff, Denise Robinson, and Jane Biddlecombe all in attendance. As Jane Biddlecombe said:

> **“Always great catching up with fellow worldwide EHE foundation Directors and Board members! Everything we do is with patients at the core, we strive to ensure that each country is represented and that our collaborations cross borders. Maybe our next photo will include our Canadian & European contingents? ALONE WE ARE RARE, TOGETHER WE ARE STRONG.”**

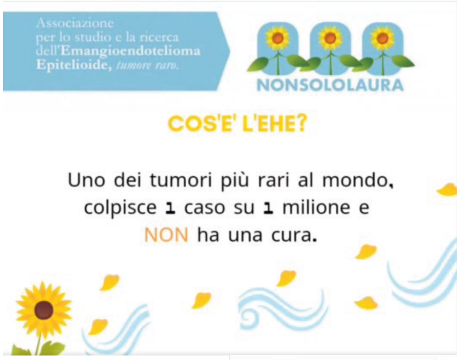
01 Patient Support and Advocacy

EHE Italia continues to grow

In our last edition of The Pledge we reported the fantastic news that the Italian EHE community had completed the establishment of an Italian foundation. The foundation is called **EHE Italia-Non solo Laura.**

EHE Italia is moving forward on a number of fronts, finalising its website and Facebook pages, and preparing different fundraising campaigns. They have also been spreading news about their foundation and EHE through social media, including their lovely slide presentation set to music. We cannot replicate the music in this newsletter, but we are delighted to include the simple and beautifully effective slides:

> “È fantastico avere una nuova fondazione nella nostra rete di organizzazioni EHE. Grazie Italia per aver compiuto questo enorme passo e per essersi unito alla battaglia contro l’EHE. Vi amiamo tutti!!”



Associazione
per lo studio e la ricerca
dell'**Emangioendotelioma**
Epitelioide, *tumore raro.*

NONSOLOLAURA

COS'E' L'EHE?

Uno dei tumori più rari al mondo, colpisce 1 caso su 1 milione e NON ha una cura.

Associazione
per lo studio e la ricerca
dell'**Emangioendotelioma**
Epitelioide, *tumore raro.*

NONSOLOLAURA

I NOSTRI OBIETTIVI:

- Raccogliere fondi;
- Collaborare con USA, UK, Australia e Canada per creare una rete di Centri specializzati a sostegno dei pazienti;
- Finanziare borse di studio per la ricerca.

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Epitelioide, *tumore raro.*

NONSOLOLAURA

IL NOSTRO SOGNO:

Fare in modo che la diagnosi di EHE SMETTA DI FARE PAURA.

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Epitelioide, *tumore raro.*

NONSOLOLAURA

AIUTACI AD AIUTARE

Donando anche solo 1 euro potrai regalare SPERANZA.

c/c bancario a BANCA ETICA filiale di Napoli

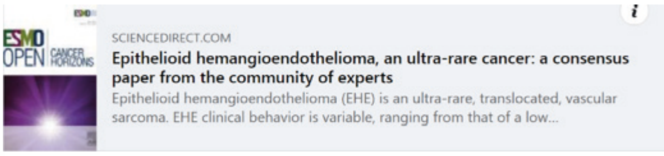
Associazione
per lo studio e la ricerca
dell'**Emangioendotelioma**
Epitelioide, *tumore raro.*

NONSOLOLAURA

GRAZIE!

ESMO EHE Consensus Paper goes live

In recent editions of The Pledge we have reported on the exceptional process, led by Dr Silvia Stacchiotti from INT in Milan, that led to the drafting of the ESMO EHE Consensus paper. We are now delighted to confirm that the Consensus Paper has been finalised, approved and published.



SCIENCEDIRECT.COM

Epithelioid hemangioendothelioma, an ultra-rare cancer: a consensus paper from the community of experts

Epithelioid hemangioendothelioma (EHE) is an ultra-rare, translocated, vascular sarcoma. EHE clinical behavior is variable, ranging from that of a low...

Hugh Leonard who participated in the meeting explained the importance of the paper:

> “This is without doubt the most thorough and complete analysis and collation of clinical experience and expertise relating to EHE yet achieved. The actual consensus meeting included over 90 multidisciplinary experts, mostly from Europe, but also from the USA, Asia and Japan. We could not be more grateful to Dr Stacchiotti, ESMO and all participants for organising and taking part in this vital process.”

It was not just the UK that were involved, however. Medha Deoras Sutliff and Jane Gutkovich also participated in the meeting to represent our EHE global community. Medha also noted the importance of this consensus process:

> “We are super proud to be part of this milestone initiative in EHE clinical care! This consensus paper provides key recommendations on the management of epithelioid hemangioendothelioma (EHE). Thank you to Dr Silvia Stacchiotti for her leadership and guidance of this ground-breaking resource!”

But this is not the end. The current paper has been produced for the clinical community and as a result is very technical. ESMO however would like a version of the paper that is understandable by the EHE patient community, so that this valuable resource can assist patients also in understanding EHE and considering and participating in meaningful discussions with their own clinicians about treatment and care programmes. Translating this technical paper to a patient-friendly version is a significant piece of work, but in Jane Gutkovich, the EHE Group has the perfect person to take on this task. Jane explained:

> “The consensus paper is quite technical in many aspects. I will do the first draft which we will review internally, followed by Dr Stacchiotti. I will make necessary edits and we will review it again. The idea is to post the final document on all our foundations' websites as a reliable summary of the disease presentation and management, and make it available for any other patient-support groups worldwide, as has been done by other sarcoma groups such as the Chordoma and Desmoid foundations. It is of course a big project which will probably require several drafts and many adjustments, but I hope that by early fall it will be completed.”

We look forward to reporting on the patient version of the paper in our future editions. In the meantime we want to thank Jane for taking on this important job and wish her every success.

01 Patient Support and Advocacy

An awesome team supporting Joe and EHE

Joe Mulligan, who was diagnosed in 2019 at age 9, plays on two baseball teams including a travel team called GRIT. He is a pitcher and just turned 11. Recently, his new team asked if Joe could explain EHE. The team asked to always wear a yellow ribbon on their helmets! These baseball families live and travel all over the northeast US. He's shown here at the Ripken Stadium in Baltimore, Maryland.

Thanks Team Joe for continuing to bring awareness to EHE by wearing ribbons, sharing Joe's story, and for donating so generously to The EHE Foundation. We wish Joe's team every success this season. Smash it out of the park!

Jennifer shared a message that sums up how many of our global EHE members feel:

> **“We are thankful for all our family and friends who support us every day through the good and bad and understand when we can't be part of something. We will continue to support research and a cure! Live life to the fullest! It's ok to cry! But most of all play lots of baseball, laugh, and hold your family tight! EHE will not win in this house! *Just Live*.”**

Kimberly wins and launches new EHE fashion

Kimberly Young shared her exciting news of the competition she entered in May. The contest was hosted by Catalyst for Change (CFC), which is an apparel shop which offers clean, comfortable and functional clothing from Maine and each item sold donates money to the chosen beneficiary. May's contest offered two top designs to win a cash prize. Kimberly, shown here wearing one of the shirts, shared her inspiration and objective of her design:

> **“I submitted a version of our beloved battle cry *Just Live.* My goal with this design was to give *Just Live* a treatment that captures the ruggedness and resilience of my fellow EHE fighters with a Maine spin (hence the pine trees). I'd love an opportunity to help spread awareness of our fight and donate to the cause.”**

Just Live is the unofficial slogan of the EHE community. Kimberly did a great job integrating the Just Live motif with rugged power and resilience, but also the tranquillity of the pine forest in her design. Kimberly's design won and she donated her winnings to The EHE Foundation. CFC also named The EHE Foundation as a beneficiary.

We are grateful to Kimberly and CFC for raising awareness of EHE. Awareness is priceless in its own right, but doing that while raising funds for EHE research is very special.

To learn more about our Just Live motto, go to: **https://fightehe.org/?s=just+live**

To learn more about Just Live products from CFC, and updates on Kimberly's fundraising, please see the Fundraising section in this edition of The Pledge.

Hands on patients support

Many of our members have posted comments about the stress and anxiety of clinical consultations where scan results are being shared, or where new and different treatment options are being discussed. In these situations, it is also commonly recommended within our EHE Group that patients take somebody along who can help with questions, and just remembering afterwards what was said.

On most occasions people will take their partner, or a close relative or friend. But that is not always possible and so we are always delighted to see news of cases where a fellow patient has gone along to assist. Allana Parker posted news of just such a case where Sally was able to participate and support her:

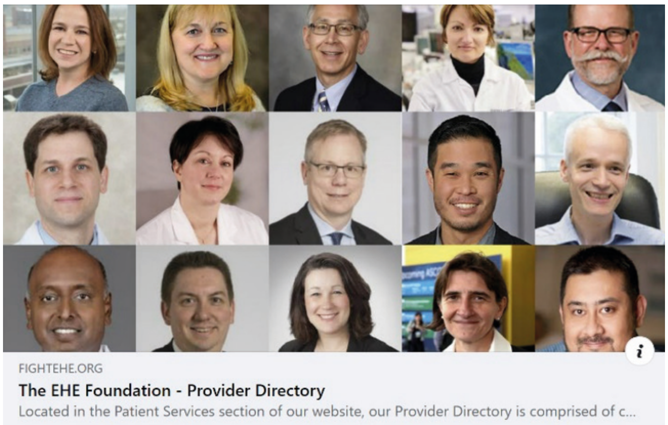
> **“So yesterday I travelled down to London for a consultation with a new surgeon. He was great but Sally Baker was even greater asking the right questions, I was so glad to have her meet me there as hospital transportation wouldn't allow anyone to travel with me and this was my first solo outing in my wheelchair, pretty scary stuff! It makes me so grateful to have this EHE family and especially thankful for Sally, you are a true angel.”**

The people who most understand the mental and physical stress of coping with clinical consultations are of course fellow patients who are going through the same process. So the depth and sincerity of the support that our EHE patients give each other is not a surprise, and is always inspiring. We want to thank once again every patient member in our global community for that support that is so generously and lovingly given. It is priceless.

The EHE Foundation launches its Provider Directory

The EHE Foundation (US) was excited to launch their Provider Directory on June 1st. Julie Wahl, a key member of the Foundation's Patient Services Team, shared her thoughts about the Directory:

> **“We are very excited to share our new online, searchable provider directory! Our Provider Directory is an invaluable tool for global EHE patients and has been a longstanding request for new patients. Finding a sarcoma provider with EHE experience can be daunting and frustrating, but it is a vital part of the diagnostic and treatment process. We hope this tool will ease some of the burden of that process.”**



FIGHTEHE.ORG

The EHE Foundation - Provider Directory

Located in the Patient Services section of our website, our Provider Directory is comprised of c...

The clinicians and institutions listed were identified through their work with The EHE Foundation and EHE patients worldwide. Patients and caregivers may easily sort the list alphabetically by name (just click on the NAME field at the top and you will see the arrows to sort) by state, or by specialty.

The Directory can be accessed at:
https://fightehe.org/provider-directory/
on The EHE Foundation's website.

02 EHE Research

We are pleased to be able to report that the pace of research has continued to increase through the second quarter. We have multiple projects under way, which continue to deliver exciting results, and a pipeline of new projects seeking funding and support. We hope that you will find the research articles in this edition both inspiring and exciting.

Collaborative research underway in Europe

The EHE Group are delighted to be able to confirm that, during the second quarter, a new research project in Europe, which had been contractually concluded last December, is underway. The collaboration is between The Instituto Nazionale dei Tumori (INT) in Milan, Italy, and The Institute of Cancer Research (ICR) in London, UK. A third institute, Memorial Sloan Kettering (MSK) in New York, USA, will be involved in validation of results from INT/ICR. The EHE Group funding however is for the INT/ICR research only, as the MSK work is being funded by a private donation.

FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

ICR The Institute of Cancer Research

The project, **'The evaluation of cytokines and hormones as biomarkers for EHE'** is seeking to explore groups of compounds which may be involved with the development and progress of EHE.

a) Cytokines and hormones are known to play a role in the mediation of processes whereby inflammation may affect, both locally and systemically, tumour progression, metastasis and therapeutic outcomes where a tumour-supportive immune microenvironment may have been established.

b) Estrogen receptor proteins (ERα and Erβ) and membrane-bound G-protein coupled estrogen receptor (GPER) are also known to mediate the effects of estrogen signaling and have also been implicated in the development of cancers such as breast cancer. GPER stimulation activates both YAP and TAZ as key effectors of the Hippo Pathway. This is of particular interest as YAP and TAZ are involved in the EHE defining fusion proteins that drive EHE.

c) MicroRNAs (miRNAs) are small non-coding pieces of RNA that can negatively regulate gene expression at the post-transcriptional level. This deregulation has been proven in several types of human cancer. It has also been shown that miRNAs can be reliably detected in both tissue and blood samples. This has prompted the investigation of miRNAs as novel cancer biomarkers. No information is currently available on miRNA expression and function in EHE.

Dr Silvia Stacchiotti

Dr Paul Huang

The cytokine and hormone biomarker research project is being led by:

Dr Silvia Stacchiotti, with INT in Milan; and

Dr Paul Huang, with ICR in London

This new project has a number of research objectives, split between clinical research and translational research.

Clinical research objectives are:

1. To provide a demographic description of the population affected by advanced EHE
2. To provide a description of clinical presentation, natural history and treatment pattern in patients with advanced EHE
3. To provide a description of tumour-related symptoms and their changes over time
4. To provide a tumor-related pain assessment
5. To prospectively identify clinical prognostic and predictive factors

Translational research objectives are:

1. To assess:
    i) the longitudinal profiles of circulating cytokines, hormones and miRNAs; and
    ii) the ERα, Erβ and GPER expression and the YAP/TAZ activation in tumour tissues, according to the clinical course of the disease.

To this end the analysis will be conducted on the whole study patient population compared to healthy controls, and by stratifying EHE patients who will enter the study in 3 subgroups according to disease behaviour (non-growing disease, slow- growing disease, highly-aggressive disease).

2. The identification and validation of novel biomarkers to inform patient management (prognosticators and predictors of response to medical agents) as well as potential therapeutic targets.

The plan is to include between 50 and 70 patients at INT in Milan, and 18 patients at the ICR in London, in the project over a 36 month period. Profiles of targeted compounds over time in the EHE patient group will be compared to the profiles of the same compounds in healthy individuals.

We look forward to being able to share results of this research with you, but need to recognise that the research objectives are to explore profiles over extended periods of time, and as a result, meaningful results may not be seen for some time.

02 EHE Research

Biobanking – WE NEED YOUR HELP

One of the biggest challenges of dealing with an ultra-rare cancer, such as EHE, is the incredible shortage of biological samples that can be used in research. Jane Gutkovich explained the issue:

> **“There are very few things that are clear and straightforward in cancer. We have all learned that, haven't we? But one of the clear and straightforward things we do know is that having an effective model for any cancer is critical to the success and speed of that research. Without EHE models, whether they are cell lines, or animal models, we will never be able to find a real cure. The ONLY way to make these models is to use fresh EHE tissue immediately after surgery, or tissue that was frozen immediately after the surgery.”**

Accessing bio-samples, whether it is tissue, fluids or blood, from EHE patients is critical for research. This cannot happen unless appropriate infrastructure, processes, procedures and ethical approvals are all in place. This was why The EHE Rare Cancer Foundation (Australia), The EHE Foundation (US), and the EHE Rare Cancer Charity (UK) have all worked hard to ensure that the capture of samples is possible through appropriate approved biobanking systems.

Australia was first to establish a system, as early as 2018, participating in the existing biobanking process established under the WEHI Stafford Fox Rare Cancer Research Program. Then in early 2021, The EHE Foundation launched its landmark research study project: the EHE Biobank in the US. Very soon after that, the EHERCC reported that the National EHE Biobank (UK), funded by the charity and based at the Royal Marsden Hospital, had received its final approvals. The UK biobank has now gone live (see next article).

These EHE biobanking arrangements give the EHE Group a greatly improved ability to ensure EHE tissue or fluids are donated to critical research. This may be blood samples to support EHE biomarker research, such as in Italy and the UK, or to assist in EHE cell line development, which is being conducted through the EHE Foundation's partnership with the Broad Institute's Rare Cancer Dependency Map Initiative in the USA. Cell lines are a particularly important form of model to study cancer behavior and response to various drug therapies. Equally important can be the creation of xenografts where human EHE tissue is inserted into mice, and if the tissue survives it can be used to study the disease.

The value of these biobanks can reach their full potential only if patients agree to donate their tissue samples to them. And that is where we urgently need your help. By simply agreeing to donate tissue and fluid samples, you can make a difference to EHE research, and help bring forward the day when we can find new treatments and maybe a cure for this horrible disease. Of course, each patient must decide if they wish to participate. When you are prepared to do so, please engage, sign up, and become an EHE tissue donor. Don't leave it to others. If you have an upcoming surgical procedure, the more notice you can provide, the easier it will be to make all necessary arrangements.

And the process can be quite straightforward, as Amy Baghdadi found out when she underwent surgery in June:

> “This year my left lung had a few troublemakers start to grow, so I went back to UCSF to have them removed, and the tumors are gone and I am feeling great. To avoid any confusion with UCSF getting my tissue to our new and fabulous EHE BioBank, Cleveland Clinic sent me my own collection kit, which I hand carried into the operation room with me, and the next day the EHE BioBank had my tissues for research. It was so easy and Patty Cogswell, EHE Biobank coordinator, was so helpful! Please, please contact her if you have an upcoming procedure. I am sending lots of love out to all of you in this community, and wishing you all the best. ***Just Live!***”

You can learn much more about tissue donation and biobanking in your area by visiting the biobanking section of the website of your local EHE foundation, as listed below. If you have been diagnosed with EHE and have an upcoming surgery or procedure scheduled, please contact the personnel listed below to learn how you can participate in tissue donation. The personnel listed all work closely with their respective research teams and advisory Boards, to ensure donated tissue samples ultimately get into the hands of key EHE researchers.

In Australia:
Please contact the EHE Rare Cancer Foundation Australia (EHE-RCFA) at **info@ehefoundation.com.au** if you have any queries regarding participating in the WEHI Stafford Fox Rare Cancer Research Program, or to notify the foundation of a recent/upcoming surgical procedure.

In the USA:
Contact Patty Cogswell, EHE Biobank Coordinator, on **1-919-619-1811**, or at **Biobank@fightEHE.org**; or

Visit the EHE Foundation biobanking page at: **https://fightehe.org/ehe-biobank/**

In the UK:
Contact Emma Perkins, EHE Tissue Coordinator at the National UK EHE Biobank at the Royal Marsden Hospital, at **EHEbiobank@rmh.nhs.uk**; or

Hugh Leonard at the EHE Rare Cancer Charity (UK) at **hleonard@ehercc.co.uk**; or

Visit the EHERCC biobanking page at: **https://www.ehercc.org.uk/national-ehe-biobank-uk**

02 EHE Research

UK National EHE Biobank goes live!

In early April, The EHE Rare Cancer Charity was delighted to be able to confirm that the UK National EHE Biobank had gone live and is open to recruit EHE patients who want to contribute their samples to support future EHE research. Kate Hooper, Trustee of the Charity said:

> **“This is so important as accessing bio samples is critical for research but so difficult for ultra-rare cancers. The Biobank will now be collecting both tissue samples and fluid samples from participating EHE patients. But this is a personal choice for every patient. There is no pressure for patients to join, and if a patient decides not to participate, it will make no difference to the treatment and care they receive. It is really their choice.”**

If patients in the UK want to participate, then they can find more details on the EHERCC website at **https://www.ehercc.org.uk/national-ehe-biobank-uk** where they will find further explanations of what is involved, how the biobank works, and why it is important. There is also a Patient Information Sheet and a Patient Consent Form, both of which can be downloaded for those who want to join.

Hugh Leonard wanted to be clear that participation in the biobank was open to everybody in the UK, regardless of location:

> **“This is a national UK-wide biobank so patients can ask for their samples to be included wherever they live in the UK. Patients can achieve this by either asking their hospital and doctors to enrol them and send the samples, or they can enrol directly with the Royal Marsden team and they will then contact the patient’s hospital. Patients will just need to provide their consent. Patients will also be able to give blood samples at their local hospital and these will be sent to the Marsden.”**

The EHERCC is hoping that blood samples can be collected from participating patients every time they have a consultation. The biobank also want to collect samples from diagnostic biopsies, as well as from surgery to remove tumours during treatment. There may in some cases be other fluid samples that would be useful to collect. So even if patients are on ‘wait-and-watch’, there are important contributions that they can make.

If any UK patients are interested and want to know more, or have any questions, then please contact the Tissue Manager (Emma Perkins) at the Royal Marsden Hospital. You can also contact Hugh Leonard by email at hleonard@ehercc.co.uk at the EHE Rare Cancer Charity.

We want to thank the Royal Marsden Hospital who have been instrumental in helping set the biobank up, and who are managing and storing the samples at the Royal Marsden Generic Tissue Bank. We also want to thank the ICR who have also been involved. We could not be more grateful for their brilliant support.

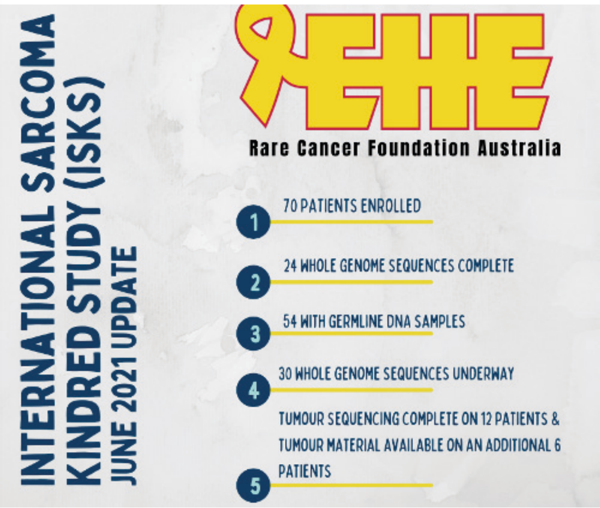
BANK THE SAMPLES – HELP THE RESEARCH – FIND THE CURE

Can you support ISKS?

Jane Biddlecombe, Director of The EHE Rare Cancer Foundation Australia, posted news in June about the International Sarcoma Kindred Study (ISKS) that is being led by Professor David Thomas at the Garvan Institute in Australia:

> “Firstly thanks to the 70 EHE patients who have already signed up and completed the ISKS test kit. The genetic material (DNA & RNA) will be further analysed later this year with a focus on identifying if there are any additional genetic risk factors for EHE, which may lead to early detection strategies into EHE or sarcoma more broadly.”

For those who haven't yet signed up, or have not returned their test kits, it's not too late to do so. You can start the enrolment process by simply emailing the research team at the Garvan Institute at **isks@garvan.org.au**



Jonathan Granek, a fellow Director of the EHE RCFA, explained why the project is important and how it would hopefully become a resource usable by anybody:

> “The Garvan Institute of Genomic Research, in conjunction with the EHE Rare Cancer Foundation, is encouraging EHE patients across the globe to take part in ISKS. This is a free-to-participate global genetic, biological, epidemiological, clinical resource developed to understand the genetic basis of sarcoma in a population. This project will become a global EHE resource that can be used to identify/study any genetic risk factors for EHE. Understanding genomic risks for EHE may then lead to early detection strategies into EHE or sarcoma more broadly. So while we are delighted to have 70 EHE patients already involved, the more we can get the better and more valuable the study will become.”

In addition to enrolling directly with the Garvan Institute, patients may be able to provide blood samples through participating centres in their own countries. Hugh Leonard explained:

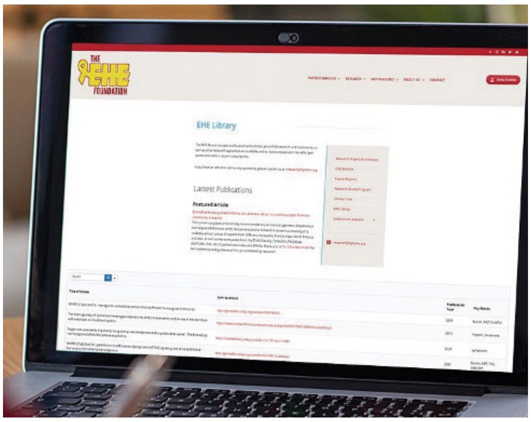
> “We were encouraging people to enrol directly, when we discovered that you can actually enrol and provide samples at some UK participating hospitals. The Royal Marsden is one such hospital. So patients can actually consent and provide a blood sample for the ISKS study when at the Royal Marsden for their standard EHE consultations. It really is that simple. And other hospitals and other countries are involved, so it is well worth checking if that is a possibility.”

02 EHE Research

Our EHE library is growing

One of the key areas the EHE Group has been focused on is building a repository for all scientific papers relating to EHE. Denise Robinson, Director of Research with The EHE Foundation (US) noted:

> **“If there are patients, clinicians or researchers out there looking for EHE information, we hope they will turn to our EHE Library. Our goal is to maintain this as an EHE global resource and a repository of publications and resources where valuable information may be easily located and used to advance both treatment and/or research into EHE.”**



Additional EHE papers were also highlighted this quarter:

“The heterogeneity of Epithelioid Hemangioendothelioma (EHE): A case series and review of the literature with emphasis on treatment options”, a paper by Stijn Witte et al, from the Department of Medical Oncology, Radboud University Medical Centre, Nijmegen, The Netherlands: and

“Epithelioid hemangioendothelioma of bone: A survival analysis of 50 cases from the SEER database (1992–2016)”, a paper by Charlers Gusho et al.

These articles and others are available on The EHE Foundation’s website: **https://fightehe.org/scientific-publications-articles/**

More results from Manchester PhD

In our last edition of The Pledge, we reported that Emily’s RNA sequencing experiment had been completed and that she had begun some initial analysis of the dataset. The aim of the RNA sequencing is to determine differences in the transcriptome of TAZ-CAMTA1 (TC) high, TC low and TC negative endothelial populations when compared to uninduced controls.

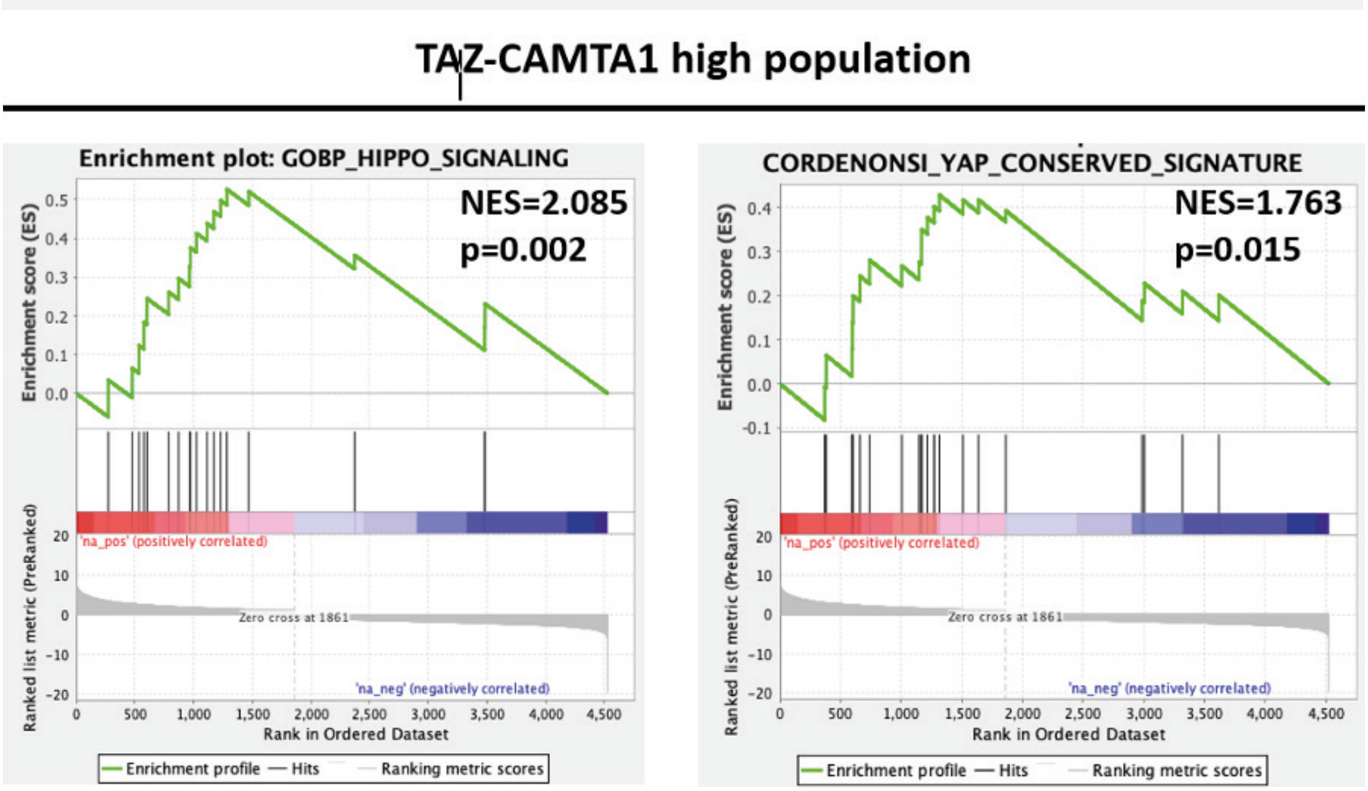
The initial analysis revealed a large number of differentially expressed genes (DEGs) in the TC high endothelial population (4528 DEGs), despite TC only being induced for 24 hours. The number of DEGs in the TC low population was smaller (483), and most of these were in common with the TC high population.

Building on this, Emily has now further characterised the transcriptomic differences between the four populations to investigate alterations to TAZ/YAP target gene expression, chromatin modifiers and the endothelial phenotype.

Gene Set Enrichment Analysis (GSEA) revealed significant enrichment for gene sets relating to the Hippo pathway and recognised TAZ/YAP target genes when comparing TC high and uninduced populations. This effect is similar to that which has been described in the literature in other model systems of TC expression. There was no significant enrichment when comparing with the TC low population.

When compared with uninduced endothelial cells, the TC high population showed a highly significant enrichment of the EHE specific gene set, which has recently been described in a transgenic mouse model of EHE. However, the TC low population again did not show such an effect.

Emily also investigated in the RNA sequencing dataset if there are alterations in the activity of chromatin modifiers upon TC expression which could explain the unexpected large number of DEGs when TC is induced for 24 hours in endothelial cells. To this end, Ingenuity Pathway Analysis (IPA) was used to determine the activation state of upstream regulators of the DEGs identified when TC is induced. Emily’s analysis suggested that some complexes are inhibited while



TC expression in endothelial cells results in transcriptomic alterations to Hippo signalling and chromatin remodelling pathways.
Enrichment plots from GSEA showing significant enrichment for Hippo signalling and YAP conserved signature gene sets, when comparing the transcriptomes of TC high and uninduced endothelial cells.

others are activated in TC expressing endothelial cells. Overall, these data suggest that in the model system, TC does upregulate TAZ target genes, and causes the upregulation of a gene set identified as specific to TC-expressing EHE tumours to a high statistical significance. More experimentation will be required to validate this hypothesis.

Emily also investigated changes in expression of genes implicated in maintaining the endothelial cell phenotype. In the RNA-seq data, Emily observed a decreased expression of multiple transcription factors known to be involved in regulating endothelial cell identity. Overall results suggest that the expression of TC in endothelial cells causes transcriptional changes to genes involved in endothelial cell identity. This is in keeping with our previously reported data showing reduced endothelial marker expression and angiogenic activity of TC expressing cells.

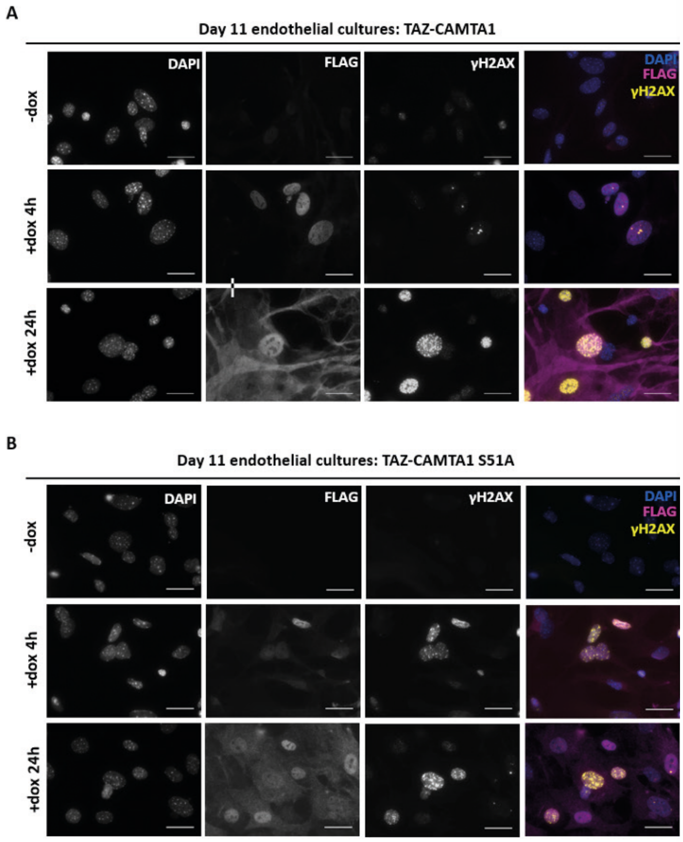
Emily has also completed further investigation into the potential DNA damage present in TC expressing cells. Previous experiments revealed that after 24 hours of TC expression an increase in γH2AX expression occurred, which is suggestive of DNA damage. The next set of experiments aimed to determine whether this also occurs in cells expressing TC S51A, which cannot bind TEAD transcription factors, and how fast the γH2AX expression increases after TC or TC S51A is expressed. In Emily's results γH2AX expression was visible in endothelial cells expressing either TC or TC S51A, and was increased compared to uninduced controls. Expression of H2AX increased further by 24 hours after doxycycline induction in cells expressing TC S51A, similar to previously reported data in endothelial cells expressing TC with an intact TEAD binding domain.

Together, these data suggest that the induction of H2AX expression is not dependent on the interaction of TC with TEAD transcription factors. Furthermore, as an increase in H2AX expression is visible within 4 hours of inducing TC or TC S51A expression, this effect is unlikely to be a result of transcriptomic changes, but is most likely due to TC protein itself activating the DNA damage repair pathway. Further investigation will be required to determine the mechanisms behind this observation.

Increased expression of H2AX is present in endothelial cells after induction of TC or TC S51A expression.

A) Representative images showing day 11 endothelial cells not treated (-dox) or treated (+dox) with doxycycline for 4h or 24h to induce TC expression.

B) Representative images showing day 11 endothelial cells not treated (-dox) or treated (+dox) with doxycycline for 4h or 24h to induce the expression of TC S51A, which cannot bind TEAD transcription factors. In both panels, cells were stained with DAPI (nuclei; blue), FLAG antibody (TAZ-CAMTA1; magenta), and H2AX antibody (phospho-H2AX; yellow). All imaging was performed on a Zeiss fluorescence widefield microscope using a 63x oil immersion objective. Scale bars=25 m.



2022 EHE 360 Conference

In January 2021, The EHE Foundation held the first ever international conference dedicated to Epithelioid Hemangioendothelioma (EHE). Held virtually due to the COVID19 pandemic, the conference took place over two days.

Day 1 was dedicated to EHE research, while Day 2 was dedicated to clinical management of EHE. Everybody who attended agreed that the speakers were exceptional, while the focus and dedication to fighting such a rare cancer was truly inspiring.

We are therefore delighted to now be able to announce that planning for the **2022 EHE 360** Conference has started. And here are the dates!

2022 Planned Virtual Conference Dates

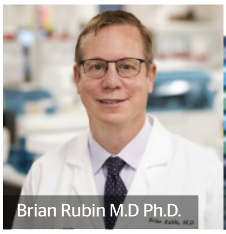
Friday, January 28th - 10:00 am to 3:00 pm ET:
Researchers & Clinicians

Saturday, January 29th - 10:00 am to 2:00 pm ET:
Clinicians & Patients / Advocates

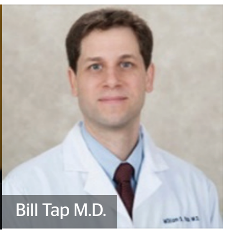
Please save these dates for what will be another amazing occasion. This two-day, ground-breaking virtual event will bring together Researchers, Clinicians, Patients and Advocates to share information, openly collaborate, and advance the fight for effective treatments and a cure for EHE. There will be no charge to attend the conference, but pre-registration will be required. Registration will open this fall.

Building on the important research and clinical management updates presented at the 2021 conference, the **2022 EHE 360** event will expand to include programming recognizing important EHE patient and caregiver needs and concerns.

The EHE Foundation are also honored to announce the **2022 EHE 360** International Conference Co-Chairs:


Brian Rubin M.D Ph.D.


Silvia Stacchiotti M.D.


Bill Tap M.D.

EHE 360 is organized by The EHE Foundation as part of a patient-led research network, in collaboration with the UK EHE Rare Cancer Charity, the EHE Rare Cancer Foundation Australia, key global patient advocacy groups, and our medical and industry partners. Thank you to our generous donors, volunteers and the support of the CZI Rare As One Project.

03 EHE Fundraising

Fundraising activities are back up and running with our members and their supporters once again engaging with energy and enthusiasm. We find the determination of our EHE fundraising warriors inspiring, driven by the simple desire to defeat a relentless cancer. We hope you enjoy the articles below and find them inspiring, and if they do, we encourage you to think about how you might be able to mobilise friends, family and colleagues to help raise the funds we need to ensure we can not only maintain, but also expand our EHE research programmes. Fundraising does not need to involve massive campaigns or extreme sports. It is often the collation of many small sums that adds up to the funding we need.

Rowing for research

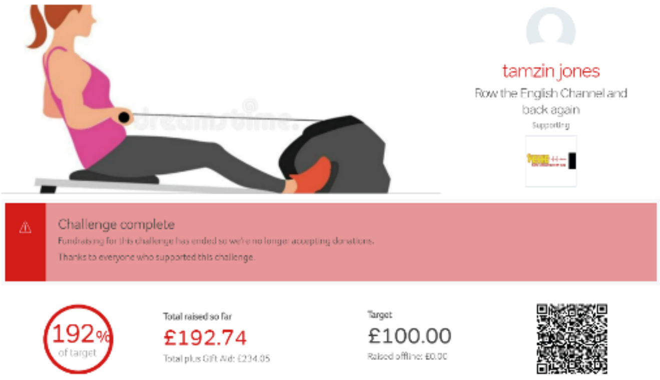
COVID restrictions have had a huge impact on fundraising in all areas, but some people just won't be stopped. Tamzin Jones has been a fantastic supporter of the UK charity, with her auction of promises, dancer-thon and 5k runs, all in support of her dear friend, Kerry Hayman. At the start of April Tamzin launched into her next event on her old rowing machine in her lounge.

> “I will be rowing (virtually on an ancient rowing machine) to France, across the English Channel, and back through April. I normally organise a big event every two years, but alas that's been a bit impossible this year. If any of you have any friends that would like somewhere to donate their pennies, please feel free to use my just giving link.”

On the 27th April Tamzin posted news that she had completed her amazing row:

> “YAY!!!! I'M HOME! 9,290 strokes - 42 miles! Thank you to everyone who has supported and donated this month. Not too late tho... APRIL is EHE Awareness Month, so you have until the end of the week to show your support and help those living with this awful cancer find answers, treatments and cures.”

In completing her rowing challenge as planned, Tamzin raised nearly £200 for EHE research, almost double her original target. We want to thank Tamzin for her ongoing awesome support.



tamzin jones

Row the English Channel and back again

Supporting

⚠ Challenge complete

Fundraising for this challenge has ended so we're no longer accepting donations.

Thanks to everyone who supported this challenge.

192% of target

Total raised so far

£192.74

Total plus Gift Aid: £234.05

Target

£100.00

Raised offline: £0.00

A touching 'shout-out'

The second quarter of 2021 included the holy month of Ramadan, a very special period for all practicing Muslims in the world. Fiona Ross, the driving force behind our Canadian EHE group, was extremely touched when a young Canadian Muslim Author posted news about Fiona, EHE, and how donations could be made in support of our EHE group.
Fiona explained:

> “People who practice the Muslim faith are currently in Ramadan. One of the main tenets of Ramadan is to do charitable work and give to charities. A Canadian YA Muslim author just gave EHE research a shout out on Twitter. I am so touched and grateful.”

Retweeted
by Lynn Thomas 🇨🇦 and Melissa Bogaert

S. K. Ali - book updates & news @SajidahWrites · 5h

4. Speaking of friends, @fionaross15 works hard to raise awareness about a rare, untreatable sarcoma: Epitheliod Hemangiothelioma (EHE).

But she seldom talks about its toll on her, being diagnosed with EHE in 2017.

Pls say donation is for EHE research: bit.ly/3gYjc06

Monthly donations are so valuable

The EHE Foundation's Circle of Friends campaign aims to attract supporters who will donate to the Foundation on a regular recurring basis. This form of regular giving is very valuable for any foundation as it provides a regular and predictable income. This quarter, The EHE Foundation posted news that it had almost met its latest target of securing five more monthly donors. We would like to thank those who have made this commitment, and hope that others may follow their lead. We could not be more grateful for the support you would be providing.

To learn more about The EHE Foundation's amazing Circle of Friends members, go to **https://fightehe.org/circle-of-friends/**

03 EHE Fundraising

Nicola is on the march in April!

Fed up with COVID and having endured a significant period of shielding, Nicola Henderson decided that it was time to get out and get motivated now that she was vaccinated!

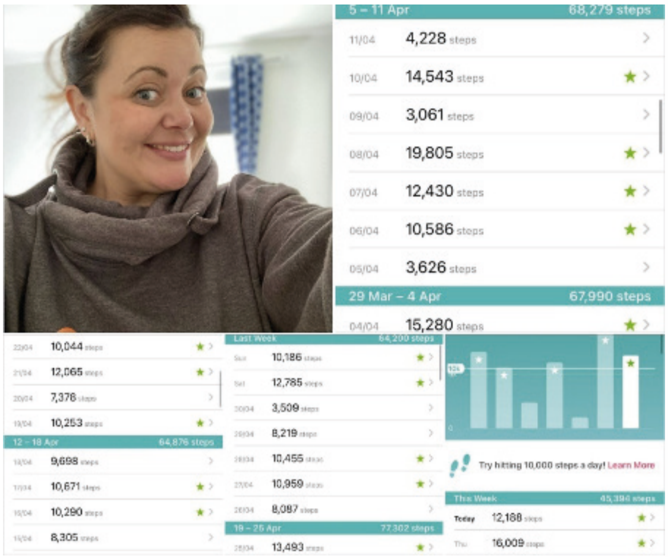
> “So I have decided to do a personal challenge and hopefully raise a few ££ for EHE research. 1st April till 7th May is 37 days. 7th of May 2021 is my 37th birthday. I want to walk 370,000 steps on those 37 days. It's only 10,000 a day. Not a huge amount for most people but for me to get up and out and do this every day would be a big deal.”

As a liver transplant patient, Nicola has had to endure greater levels of social distancing, including in her own home. Recovering from a major transplant is a physically and psychologically daunting process at any time, but adding COVID restrictions on top of all of this makes the process so much harder. But one thing is certain, Nicola is a fighter, and with vaccinations done and the situation improving, she decided it was time to get out!

> “I've had enough, I have spent way too long in my house which has been very tough. I feel up to doing this now, I want to get out and about more, I want to get my fitness back and I need the outside world!! I feel a shell of my former self if I'm honest. I need to do something for me and this just feels a good starting point. ❤️ I know my amazing donor would be cheering me on and I want to do this for them also. 14th April marks 2 years post-transplant. I really am so lucky. Let's do this! 💪”

Nicola and her supporters have always been tremendous fundraisers for the charity, and we were not surprised to see Nicola set up a donation page tied to her 37 day walking challenge. We love the spirit and determination that Nicola has once again shown, and her desire to also help others by raising funds for EHE research. So we were also especially delighted to see her finishing post.

> “It's my BIRTHDAY!!!! I've done it!! 372,981 my target was 370,000!! I was determined to see what my body was capable of, it's not been easy some days but I've done it!!!! My new hoody says it all, HOPE ❤️❤️ I have raised over £1000!! I can't believe it!!! I can't tell you how much that means to us, it gives me and all the EHE patients HOPE for a future without this cancer in our lives! But today I'm feeling lucky to be 37 and I feel so loved!!!!!! Thank you so much everyone!! I love you all ❤️”



5 – 11 Apr 68,279 steps
11/04 4,228 steps
10/04 14,543 steps ★
09/04 3,061 steps
08/04 19,805 steps ★
07/04 12,430 steps ★
06/04 10,586 steps ★
05/04 3,626 steps
29 Mar – 4 Apr 67,990 steps
04/04 15,280 steps ★

22/04 10,044 steps ★
21/04 12,065 steps ★
20/04 7,376 steps
19/04 10,253 steps ★
12 – 18 Apr 64,876 steps
18/04 9,698 steps
17/04 10,671 steps ★
16/04 10,290 steps ★
15/04 8,305 steps

Last Week 64,200 steps
Sun 10,186 steps ★
Sat 12,785 steps ★
30/04 3,509 steps
29/04 8,219 steps
28/04 10,455 steps ★
27/04 10,959 steps ★
26/04 8,087 steps
19 – 25 Apr 77,302 steps
25/04 13,493 steps ★

Try hitting 10,000 steps a day! Learn More

This Week 45,396 steps
Today 12,188 steps ★
Thu 16,009 steps ★

Another plug for Amazon Smile!

Lynne Lewis posted news in June of the latest update from Amazon Smile and wanted to remind everybody of this relatively easy way to raise funds for EHE research if you shop on line.

> “Through Amazon Smile amazon shoppers have donated £183.90 just by shopping with Amazon. Amazon to date has already donated £390.38 in total to EHE Rare Cancer Charity UK, but I am sure we can generate more! So any Amazon shoppers make sure you switch on Amazon Smile!!! #LetsDoThis.”

It really is very easy. Our EHE foundations are registered with Amazon in their respective countries. All you need to do is utilise the Amazon Smile App which allows you to shop as normal, it **DOES NOT** affect the prices you pay, but then donates a small percentage of your purchase price to our cause. But make sure you connect to the right Amazon Smile site for the country you live in! It really is easy money, so if you are able, please use Amazon Smile when buying on line. And if you need help please contact your local EHE foundation who can help guide you through the process.

Fashion raises much needed funding

In the Patient Support and Advocacy section of this newsletter, we shared Kimberly Young's participation in a unique design competition where she was selected as one of two winners. Catalyst For Change (CFC) Wear, an apparel business in Maine, will now be selling products with Kimberly's design while raising awareness of EHE.

There is also a significant financial benefit for The EHE Foundation. Thanks to Kimberly for donating her prize money. Another huge thanks to her husband, Greg, for matching $700. Of course, we are grateful for Kyle Poissonnier at CFC for hosting this contest, donating for each sale, and making The EHE Foundation a beneficiary. To date, $1,400 has been raised for The EHE Foundation through this event and Kimberly shared her appreciation:

> “Thank you so much to everyone that voted for my apparel design to help me win this contest. CFC will keep the ***Just Live*** shirts in their collection and continue to offer many great colors and styles! $5 of every shirt sale will continue to be donated to the EHE Foundation. Thank you to all of you that helped make this happen.”

Here are some of the fabulous designs offered. Go to **https://www.cfcwear.com/justlive** to order.

03 EHE Fundraising

Allana's birthday fundraise

Allana Parker shared her birthday fundraiser in June and was once again overwhelmed by the support she received. This was particularly uplifting as Allana was battling through some challenges due to her EHE.

> **“Having such a positive response to this year's birthday fundraiser, still a week to go and already over £300. What would we do without our friends and family supporting us?! #feelingblessed.”**

Allana's birthday fundraiser for EHE Rare Cancer Charity (UK)
Fundraiser for EHE Rare Cancer Charity (UK) by Allana Parker

£343 of £150 raised
Ended

The 2021 EHE Fun Run & Walk is on!

The annual Fun Run and Walk in the US typically takes place in April, in honor of EHE Awareness month. This year the Foundation moved it to the fall. It is hard to believe that this year's event will be The EHE Foundation's 6th annual event. And now, hot off the press, the Foundation can provide the details:

> **“Registration for the 6th Annual EHE Fun Run and Walk will open August 1st and close August 31st. Race items will arrive in mid-September. Learn more at: https://fightehe.org/6th-annual-ehe-fun-run-walk/”**

Did you know most participants are not athletes? Many are either affected by EHE or supporting a friend, family, co-worker, neighbor, acquaintance, etc, affected by EHE. Participants simply choose to do a 5K (3.1 miles) or 1K (.62 miles) by walking or running (or any form of exercise). You can even split it up into smaller distances. Supporters also may simply wear the shirt, bracelet, or tattoo to raise awareness and proudly display their support without completing the run or walk.

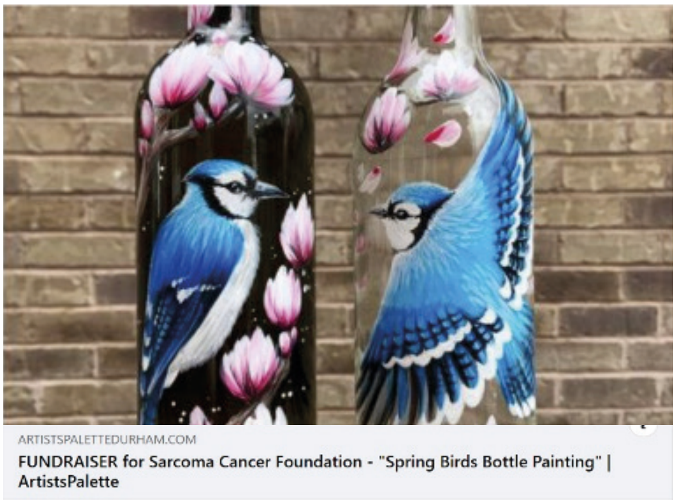
In June, the Foundation held a contest on their social media outlets for the color of the 2021 shirt. Supporters selected the blue shirt as the 2021 EHE Fun Run and Walk shirt color. The Foundation is ready to make personalized flyers for individuals and is adding team names to the website. They are also continuing to ask for interested sponsors. If you'd like more information, please email **info@fightEHE.org** or call **1-877-460-4240**. Let's make it the biggest year yet!

WE FIGHT EHE
STRONGER
TOGETHER
FightEHE.org

Raising funds often needs bottle!

Raising funds during a global pandemic is difficult, partly because getting people together is not easy. The virtual environment however can overcome this, and in May, Fiona Ross used the internet to connect members of our community in an unusual event organised by Artist's Palette Durham.

> **“This is a virtual fundraiser I have arranged for Sarcoma/EHE. We will be painting bottles with expert step by step guidance. It's C$15 to take part and C$6 of this will be donated to sarcoma/EHE in Canada. The cool thing is there is video recorded and you will have access to it at any time. And as long as you have a credit card you can sign up. And C$15 plus tax will be even cheaper for our friends in the UK and US, so please join us!.”**



ARTISTSPALETTEDURHAM.COM

FUNDRAISER for Sarcoma Cancer Foundation - "Spring Birds Bottle Painting" | ArtistsPalette

We love this idea and hope to have photos in our next edition of some of the bottles painted.

Artist's Palette Durham

Saving the loose change all adds up

Fundraising is not always about mega events and huge sporting challenges. Sometimes it's about saving little and often. Hugh and his family decided to do this, following Jessie Hayman's Jessie Jars challenge, by putting their loose change most days in their own EHE jar at home. The last collection started in 2019, and by June this year had expanding into a second jar, despite there being little to contribute during lock down.

The result? After counting and bagging, just over £240 was raised for EHE research.

Decals still available

In previous editions, we included news of Summer Keller's sale of decals and stickers. These are still available for anybody who would like one, as Summer explains:

> **“Raise awareness and help raise money for research with these decals and stickers. Great for cars, water bottles, school binders, helmets, whatever you want to stick it on. $5-$10 Free shipping within US on small orders. Willing to ship outside US.”**

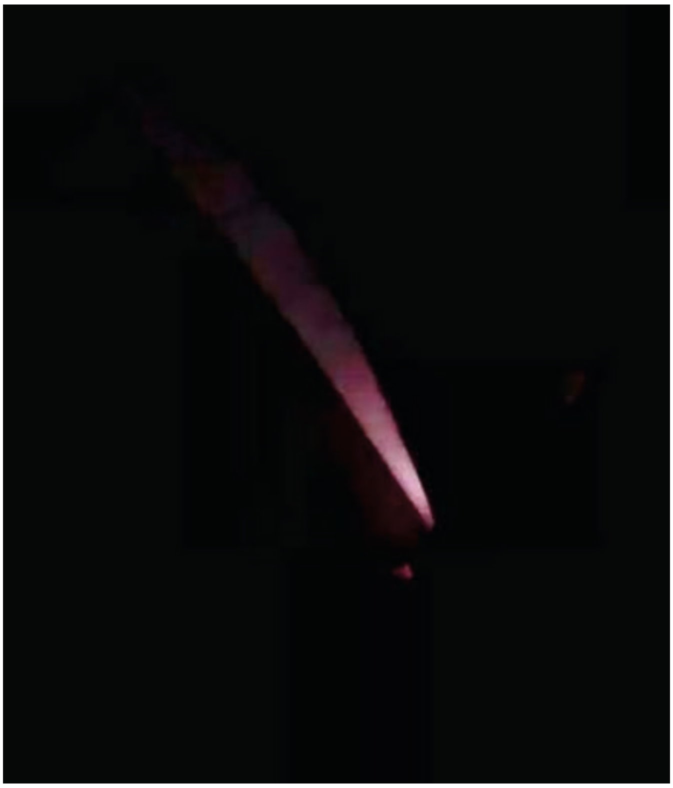
Please contact Summer if you are interested at **Rskeller7@hotmail.com**, and help raise awareness and raise funding for EHE research.

04 And in other news...

Is a shooting star good luck?

It seems that in many cultures it is, for different reasons. We hope it is for Carl Dickson, who posted this amazing photograph of a shooting star, taken in the Colorado.

> “We are out for a camping trip in the high desert of Colorado. Love the night air, the silence except for the sounds of a few night creatures including a few bats. Tonight was a little special as I captured a shooting star, first time in my life I was able to get one on film. Just Live, you never know when those special moments will come or what they will be.”



And it was not just the night sky that was stupendous!

A passion for skiing

We love to see photographs and posts, from our EHE family, of activities that they or their families are participating in. In Carl Dickson's case, it was his son's passion for skiing. For those who wonder what is entailed in learning to do breath-taking aerobatics on skis, then part of the process involves practicing over water!:

> “Though we live in pain every day, we must take the time to fight through to make great memory moments for those we love especially our children as we don't know when that last day will come. Sharing a joyful day, my boy working on one of his passions in life, skiing. ***Just Live!***”

We love the photo Carl, and hope there will be many more such days for you to all enjoy.

Pet's corner

It is always a delight when members of our EHE family send in photos of their pets. Regular readers will know that we have had many photos of dogs and cats. So we were especially pleased when Whitney Paige Witt posted a medical insurance question, but ended her post with a fantastic photo of Bunny!

> “PS: cute picture of my donkey Bunny to bring up some smiles.”

Cute is indeed the word, Whitney!
And smile we did. 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

EHE Italia – Non solo Laura
website not yet available

EHE Canada
website not yet available