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

Quarterly Newsletter
for the EHE Group
April – June 2019

the pledge

Edition 17

Contents

Welcome

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

This is our 17th edition, for the second quarter of 2019, and as always we want to start by saying a massive thank you to all our supporters for their contributions.

Regardless of what type or magnitude of support and contribution you provide, they are all critical to our success and ability to manage and ultimately defeat EHE.

Thank you to all of you. We hope that you enjoy the newsletter.

Just live

Highlights

Wonderful Gift from Petersen Foundation

The Margie and Robert E. Petersen Foundation has made a transformational $1 million gift to Dr Brian Rubin to support his EHE research. They have also pledged further funding, matching whatever our EHE group can raise over the next 3 years, up to another $1 million. We are truly amazed by their generosity and cannot express sufficient thanks for this wonderful gesture.

Worldwide membership grows

The EHE Facebook page now has 1,650 members spread across 68 countries worldwide, illustrating the very significant connectivity the group now provides to the worldwide EHE community.

National EHE oncology network proposed

We were thrilled to hear that an oncology surgeon in Ottawa, Canada, is hoping to establish a network of Canadian oncologists who are treating EHE, to share experiences, discuss cases, and provide each other with help in treating such a rare sarcoma. Our EHE community will provide any support it can to this excellent initiative.

USA Virtual 5K another great success

Extraordinary funding support for the EHE Group has once again continued through the quarter. This included the EHE Foundation's 2019 Virtual 5K event. 1,006 people participated, and together raised an amazing $45,000. We thank them all, and indeed all our other supporters worldwide who have continued to work so hard to keep the critical funds we need for EHE research flowing.

EHE research expanding in several places

The ongoing funding and awareness of EHE is leading to a growing, collaborative research effort across the USA, Australia, the UK, and Canada.

Further details on these stories, and much more, can be found in this edition of The Pledge.

01

Patient Support and Advocacy

Supporting those diagnosed with EHE

One of our core objectives is ensuring that we provide support to all those diagnosed with EHE. We will do this, wherever a patient may live. At the same time we will strive to increase awareness of EHE amongst the general public, government and in some cases the medical and research community. We will also work hard to make clear what the impact that living with a rare and frightening cancer has on a person's life. We thank all our supporters who have contributed to this critical part of our activity, examples of which are provided in this section.

EHE on the Catwalk!

Friends for Anchor is an organisation that every year holds a fashion show in Aberdeen, called Courage on the Catwalk, to raise funds to help treat cancer. It's a huge event and tickets sell out in minutes. The stars of this catwalk are cancer survivors with different forms of cancer, and for those taking part, it provides a great opportunity to talk about their particular cancer. So we were delighted when Adrianna Glennie posted to tell the EHE Facebook group that she had been selected to take part.

Adrianna was duly introduced through the Anchor publicity process. *"Today we introduce the lovely Adrianna Glennie from Stonehaven in our #BeInspired series. Diagnosed with an extremely rare form of cancer called Epithelioid Hemangioendothelioma, Ads is the only Scottish woman who has been given this diagnosis, and is one of around only 75 UK sufferers. She is on a mission to raise awareness and is passionate about research for all types of cancer. Her late brother also underwent treatment in the ANCHOR Unit and Adrianna says Friends of ANCHOR were a huge support to him".*

Her message to others? *"You've got this, and even if you don't - it's ok. Make memories, and always end conversations with 'I love you' so people know how much they mean to you." "We can't wait to see that smiling face up on the catwalk!".*

The actual event was a huge success, as in previous years. Adrianna said it was a really wonderful experience, and hugely inspiring. We congratulate Adrianna for being selected, for being a star on the catwalk, but most of all, for helping to spread awareness of EHE.

Oncologist Network Developing?

Our members are very aware of how even oncologists can have little knowledge or understanding of EHE, due to its rarity. That is why sarcoma patients are generally always advised to see a sarcoma specialist. We also hope that if EHE patients gravitate towards the same doctors and sarcoma centres, then those centres and the oncologists within them will gain greater exposure to and experience of EHE. The EHE foundations drive this process whenever we can. So we were delighted when Nadia Campanella in Canada posted news about contact she had from one specialist.

"Our oncology surgeon here in Ottawa, Ontario would like to create a Canadian network of doctors who have treated or are currently treating EHE patients in all different provinces. I told him I would help by trying to put together a list of doctors/hospitals from this group. Thanks for your help."

It's wonderful when we see this proactive approach to gaining experience of EHE from the medical profession. It's also wonderful when as a group, we can help deliver those contacts and the information required. We wish Nadia all success with helping to create the Canadian EHE doctors' network!

A Role Model

Delaney Wahl has been a leading light of the EHE group in the USA from the start, and she continues to spread awareness through local Green Bay, WI media outlets. Recently, Fox11 News of Green Bay, WI covered Laney's wonderful achievements. The story highlighted her Varsity Bay Port Soccer team, who won their regional title at the start of June.

Fox 11 explained Laney's attitude perfectly. *"Bay Port's Wahl is not backing down from cancer! It is scary, no doubt, but Delaney Wahl doesn't show she's afraid. Not knowing her health, you would look at her as just another high school girl playing soccer. She's much more than that. She has been a big figure in battling EHE and she will fight for as long as she has to."*

Laney was interviewed extensively and provided an amazingly honest and positive outlook of the future. *"I don't know if I'm going to be here for three years, I don't know if I'm going to be here for 30 years, but what you do when you have the time to do it matters and so that's what I focus on,"* Delaney said. *"I don't worry about what's in the future, but I work towards it if I can have it."*

Delaney recently graduated high school with high honors, "Student of Distinction" for graduating with a GPA over 4.0, the *"Superintendent Award for High Honors"*, for being an International Baccalaureate Full diploma student, and for being a member of the National Honor Society. Congratulations, Laney, and "thanks" from the EHE community for continuing to raise awareness.

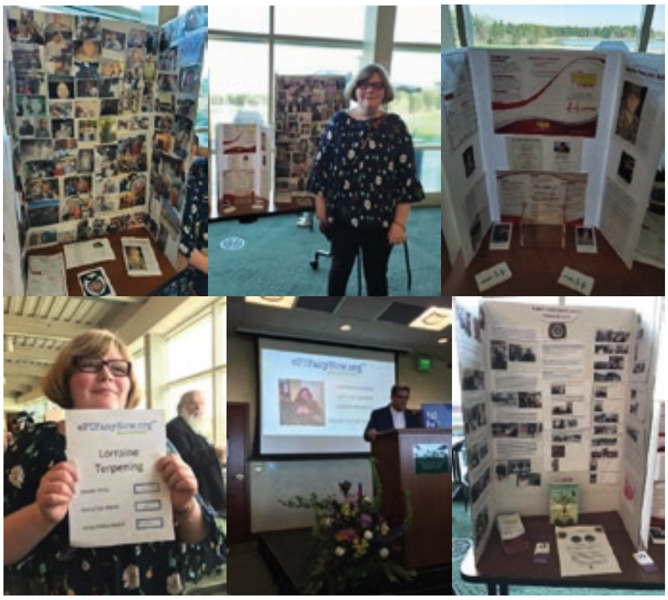
01 Patient Support and Advocacy

International Connections

Connecting people to each other for support and resources, even when they are based overseas and English may not be their first language, is a priority. In April, EHE Foundation's Director of Patient Services, Lisa De Young, was able to do this for a newly diagnosed EHE patient from Romania, welcoming her to our cherished EHE community, and helping her to connect with other Romanian EHE members. Online or in-person, we strive to represent the worldwide EHE community. We will always welcome new members, regardless of race, religion, gender, ethnicity or any of the other characteristics that so often create barriers in normal life. These differences are invisible to EHE, and they shall remain invisible to us as we continue to support EHE patients wherever they are.

A Brother Honoured and Remembered

It takes amazing character to be willing to help others especially while grieving a loved one. Rainey Terpening lost her brother, Tim, to EHE in April 2019. Rainey is 14 years old and was nominated for the ePIFany Y-PIF Award for youths doing random acts of kindness, paying it forward, and making a difference in their communities. Rainey chose The EHE Foundation for her charity, in honor of her brother Tim Webb who was diagnosed only 4 years before passing. Tim was only 32 years old and left behind his wife and three young children. Ellen Terpening stated, *"Although Rainey didn't win, she was able to spread EHE awareness and raise $475.00 for The EHE Foundation!"* That is an amazing amount and we are sure that Tim would have been very proud of his little sister. We appreciate your compassion and amazing character, Rainey! Thank you from the entire EHE community.



Telling Her Story

In mid-April Mariana Coutinho posted news of her first ever public speaking engagement. *"Last Friday, I was invited to share my experience as a cancer patient at a psyco-oncology event. I told them all about EHE, IRE (Nanoknife), what it is like to have a rare type of cancer, the value of a second opinion, the importance of finding a specialist in your disease, to stay informed, and the impact it had on my mental health. I feel very grateful that I had this opportunity."* Congratulations Mariana on a great job, and for ensuring that an entire audience, who had almost certainly never heard of EHE, left better informed and aware of the challenges of living with an ultra-rare cancer.

Experiences Shared

A significant part of our patient support comes from patients themselves. Not only can patients share their EHE stories and experiences in a group with others that can relate, but they can also help others learn more about the rare cancer. Although each journey is unique with different challenges, patients and caregivers are often the best support system available. Michael Proctor wanted to help others with EHE when he shared his honest account of his EHE journey so far. The power of shared experiences is often commented upon, and Michael was no exception. *"I am thankful for family and friends who have helped me through this so far and for the road ahead. I want to thank this group, the EHE foundation and the admins and everyone who is here sharing information and stories because it helps so much not going through this alone. I hope posting a little detail of what my experience was will help someone else if they have an upcoming procedure."*

Michael also posted this wonderful photo with his daughter, and went on *"Just remember we all react differently and go at your own pace. Please stay positive no matter what you may be facing because keeping your mind sharp and the right attitude will do so much for your overall recovery. Stay as positive as you can!"* We agree, and want to thank Michael for sharing his experiences so honestly.

01 Patient Support and Advocacy

Wonderful Support

As an EHE patient, some of our members have to face the fact that they may no longer be able to do things that once would have been easy. In such situations, patient support can come from unexpected sources. Carl Dickson shared a lovely story of just such an occasion, when he found himself unable to unload a 40 lb bag of dog food. To his amazement, his son Broxdon who only weighs about 50 lbs himself said *"I will carry it for you." Carl said "he picked it right up and carried it out of the store. What a helper".* Thank you Broxdon for helping your Dad, and providing such a precious moment

A Hero Met

There are not many upsides of being diagnosed with EHE, but Delaney Wahl perhaps experienced one when she was given the chance, through Make-A-Wish, to have dinner with Aaron Rodgers, quarterback for the Green Bay Packers.

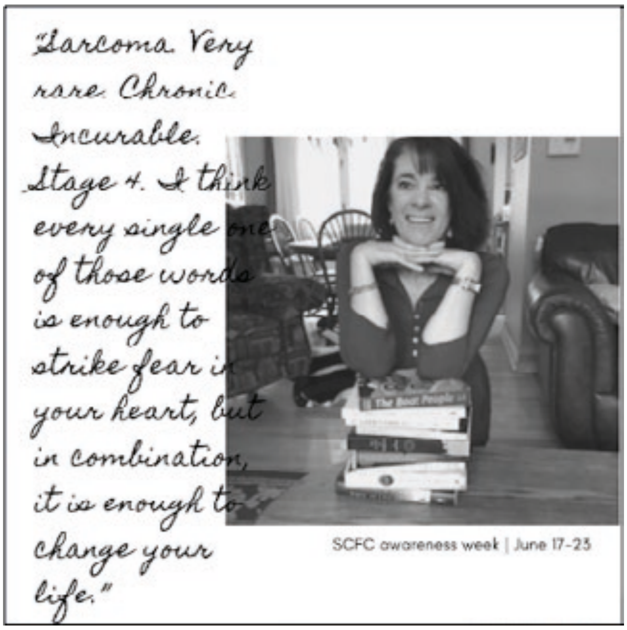
Laney gave him a Team Laney shirt and said, *"I wear a lot of shirts with your name on them, I think it's about time you wear one with my name on it."* He said *"Absolutely!"*

We love the idea that such a mega-star spent time with Laney, and left dinner well informed about EHE. Well done Laney and Olivia, who was also there to support her sister.

Sarcoma Awareness Week

Fiona Louise has become a driving force and true champion for EHE in Canada, establishing an EHE-dedicated fund within the Sarcoma Cancer Foundation of Canada. So it was perhaps no surprise that Fiona would be one of those chosen by the SCFC to spread awareness of sarcoma as part of the Sarcoma Awareness Week activities.

In Fiona's words, *"Soft tissue sarcomas are the quiet kids, left to themselves in the corner of the classroom".* It's a great description, and perhaps not so surprising from a teacher. We congratulate Fiona on her ongoing campaign to raise both awareness and funds for EHE in Canada. We hope that other members of our Canadian EHE community will also join in and support EHE research through their own activities.



Sarcoma. Very rare. Chronic. Incurable. Stage 4. I think every single one of those words is enough to strike fear in your heart, but in combination, it is enough to change your life."

SCFC awareness week | June 17-23

Stormy Inspiration

Often our members will post positive thoughts and ideas for the group that can be triggered by unexpected events. John Lamb was in this very situation when driving in Arkansas after terrible storms, and happened across a lovely rainbow which he photographed. John observed *"It was a terrible day. Kind of like we all have from time to time ourselves, and as of late, as an EHE family."*

The situation reminded him of the text of an ancient book. *"We are troubled on every side, yet not crushed, we are perplexed, but not in despair, persecuted, but not forsaken; struck down, but not destroyed".* John noted *"It sounds to me like the man who wrote that understood about the storms of life".* He went on *"I hate the storms of life, I wish we didn't have them, but we do. We need to remember while dodging the flood to "look up" and we might just see a rainbow in the sky."* We think that is an apt philosophy for our EHE community, and hope that everybody will find their own rainbow.

02 EHE Research

Only through research can we answer questions and defeat EHE

We will ultimately defeat EHE because the research we fund will answer questions and generate new drugs and treatments to manage and defeat this cancer. The following notes provide an update of some of the research we are involved with.

Research Update

Jane Gutkovich provided a summary of the research that the EHE Foundation are currently supporting, thanks to grass-roots fundraising throughout our international EHE community.

1. Dr Brian Rubin's Lab at the Cleveland Clinic has been working on multiple EHE projects for several years. These have received significant funding and support from our international community. Dr Rubin's main focus is the development of targeted therapies for EHE;

2. A number of different projects are continuing to look at the development of in vivo models for EHE. These include mice models and drosophila flies in the USA, and zebrafish in the UK;

3. A comprehensive, multi-step EHE project has recently been initiated at Sloan Kettering which will look at EHE, genetics, the immune-microenvironment, their correlation with EHE behavior and identification of targets for immunotherapy;

4. Several independent EHE projects are focusing on EHE at the molecular level, both in the UK and USA.

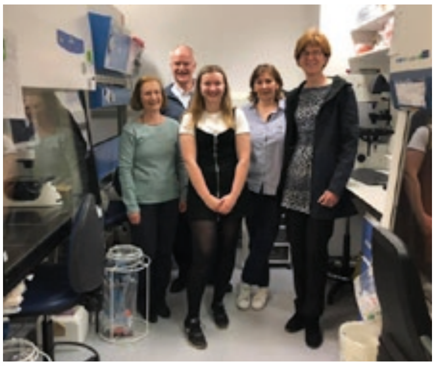
5. An international retrospective study involving medical records of several hundreds of EHE patients is planned with the objective of analysing patient data to identify best available treatments. Planning is in the final stages and we hope will be launched soon; and

6. The development of an EHE cell line is underway at the Broad Institute. If successful, we hope that the cell line can be used to screen for effective drugs. This project has not only benefitted from your financial support but is also progressing thanks to your active participation in fresh tissue donation through **pattern.org**.

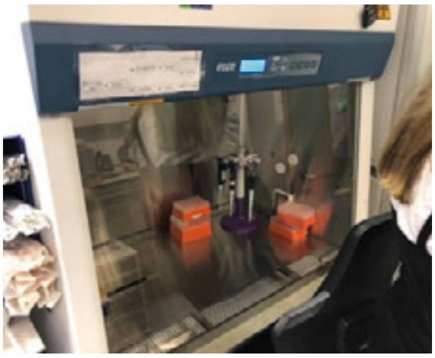
Jane noted "everything in research takes much longer than we all want, but we are beginning to see great momentum! We, as a community, as a team, as a family, are slowly but surely pushing forward to JUST LIVE! Thank you very much for all your support!!!".

UK Trustees Visit Manchester PhD

2019 saw the start of the second EHE-dedicated piece of research to be commissioned by the EHE Rare Cancer Charity in the UK. Led by Dr Valerie Kouskoff at the



Department of Developmental Biology and Medicine at the University of Manchester, the project is hoping to help understand how EHE is affecting the development of endothelial cells. In late April, Hugh Leonard, Kate Hooper and Elizabeth Milligan, all trustees of the EHERCC, visited the department to meet the team and spend half a day reviewing the science.



The trustees were very impressed. *"Three of us went to Manchester for a presentation of the PhD we are funding"* commented Kate. *"Emily Neil is the PhD student and she has made a great start. I think this team are going to turn up some very interesting results on how the TAZ-CAMTA1 fusion works and as a result, help us deliver more ideas on how to manage and defeat EHE".*

The project has only just begun, but already some interesting observations have been made. We look forward to reporting more results in the near future.

EHE Foundation at ASCO 2019

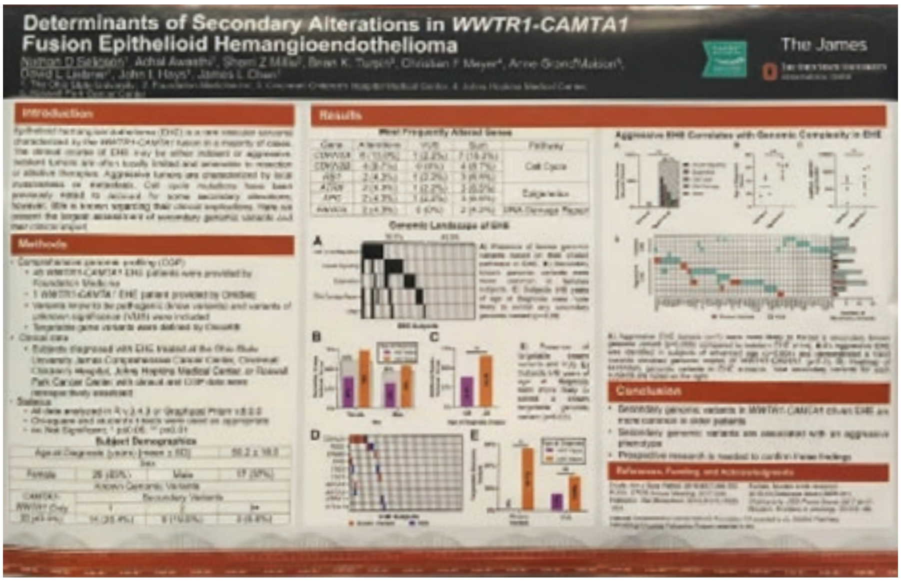
Once again, EHE Foundation joined over 30,000 cancer experts from around the world in Chicago, IL in early June to learn of the latest clinical cancer research impacting patient care. The 55th Annual Meeting of the **American Society of Clinical Oncology (ASCO)** highlighted advances in targeted therapies as well as new approaches to overcoming limited access to cancer care. The theme of this year's conference was *Caring for Every Patient, Learning From Every Patient.*

EHE Foundation board members and staff participated in the patient advocate track and were given access to all scientific sessions and viewed posters focusing on sarcoma and EHE research. In addition, the Foundation attended the **2019 Annual SARC meeting** – a four-hour meeting that includes scientific translational medicine presentation on new emerging science in the field of sarcoma and engages the sarcoma investigator community in the review of ongoing clinical research and discussion of opportunities for future research. All sarcoma advocacy organizations were also invited to an informal mixer to network and share resources. Also during ASCO, The EHE Foundation organized the annual **Medical Advisory Board** lunch meeting. Big thanks to AD Board members Drs. Okuno, Wilky & Burgess for the robust discussion with updates on fundraising, current research project portfolio, patient services, programmatic activities, and ideas for future directions.

Attendees at the EHE Foundation Advisory Group meeting at ASCO 2019
Standing (left to right): Denise Robinson, Julia Wahl, LeeAnn Conner, Dr Guy Weinberg, Dr Scott Okuno; Sitting (left to right): Jenni Kovach, Medha Sutliff, Dr. Melissa Burgess, Dr Breelyn Wilky.

02 EHE Research

Growing Recognition of EHE at ASCO



Determinants of Secondary Alterations in *WWTR1-CAMTA1* Fusion Epithelioid Hemangioendothelioma

The James

Introduction

Results

Methods

Conclusion

Jane Gutkovich posted news from the 2019 ASCO conference that for the first time ASCO had recognised EHE by providing space for four EHE posters. Jane noted two key facts: (i) the importance of data sharing and collaboration; and (ii) while the news from the posters was not necessarily new, the fact that the posters are there is huge.

The four posters were:

1. Determinants of secondary alterations in WWTR1-CAMTA1 fusion Epithelioid Hemangioendothelioma - (2019 ASCO Annual Meeting Abstracts)
2. Activity of sirolimus in advanced Epithelioid Hemangioendothelioma (EHE): A retrospective analysis within the Italian Rare Tumor Network (RTR) - (2019 ASCO Annual Meeting Abstracts)
3. Prognostic factors and therapeutic options for Epithelioid Hemangioendothelioma (EHE): A multi-center analysis of a series of fifty-seven cases - (2019 ASCO Annual Meeting Abstracts)
4. Advanced Epithelioid haemangioendothelioma: Fever, pain, and pleural effusion predict a worse outcome. (2019 ASCO Annual Meeting Abstracts)

If anybody would like to have copies of these papers please contact your local EHE foundation or Jane Gutkovich or Lisa de Young through the EHE Facebook group.

Dr John Lamar is Funded by the EHE Group

The EHE foundations were thrilled to conclude arrangements to sponsor a new research proposal in the USA. The grant application was submitted by Dr John Lamar, based at the Albany Medical College, and came through Dr Guy Weinberg's Telluride YAP, TAZ & TEAD workshop. The research is looking to test the hypothesis that the TAZ-CAMTA1 fusion protein that is core to EHE is subject to regulation by Hippo-pathway independent mechanisms that could be exploited to inhibit TAZ-CAMTA1 function and so treat EHE. Dr Lamar intends to use his extensive expertise in developing mouse xenograft models to assay cancer growth and progression *in vivo* (see objective 2 below).

Dr Lamar's project has two core objectives:

1. To identify regulators of the TAZ-CAMTA1 fusion protein and assess their therapeutic potential; and
2. To establish model systems to assay TAZ-CAMTA1 function *in vitro* and *in vivo* and use to test therapeutic potential of candidate TAZ-CAMTA1 regulators.

On receiving news that his grant application had been successful, Dr Lamar commented *"Thank you very much for the good news. We are excited about the project and are very grateful for the support of the USA, UK and Australian EHE groups."* We are also excited by this project and of course wish Dr Lamar and his lab every success in their research effort.

International Sarcoma Kindred Study (ISKS) Focus

In May Jane Biddlecombe posted news about the ISKS which is being run from the Garvan Institute in Australia, led by Prof David Thomas. Jane went on, *"why do some seniors age in good health and other seniors suffer with multiple chronic conditions? A new genetic database is using whole-genomic sequencing (WGS) to answer that question in ways that may benefit medical laboratories. For Rare cancers such as EHE this study could allow researchers to use EHE patients' WGS to look for and identify what might drive genetic changes in EHE cancer cells."*

The study is open to all international patients, and the EHE foundations are all working to enrol as many EHE patients as possible. If you want to take part, and want to receive an ISKS kit, please email the study group in Australia at: isks@garvan.org.au

Jane Biddlecombe and the EHE-RCFA also want to express their gratitude to Lindsey at Masters Studio in Darwin for generously providing pro bono use of their recording studio to allow Jane to record the voice over for an information animation that the EHE-RCFA and Anna Wrydo (UK supporter, and animator) have been working on to support and advertise ISKS.

The video will explain the International Sarcoma Kindred Study which Australia will take worldwide soon. We look forward to viewing the complete animation and hope that all patients get behind this important initiative.

Jonathan Granek, EHE-RCFA Director, was also delighted at the progress they are seeing generally. *"More people have signed up to participate in Australian research initiatives including CART-Wheel, the Stafford Fox Rare Cancer Program (including tissue banking), ISKS and MoST Study which will support further insights and research opportunities into EHE"*. We congratulate Australia on their continuing progress.

02 EHE Research

Dr Wilky's Publication Celebrated

Dr Breelyn Wilky is a great friend of the EHE community and a special oncologist to all her EHE patients. So we were delighted when Lisa de Young posted a congratulatory message celebrating Dr Wilky's 'first author' publication on May 8, 2019.


THE LANCET
Oncology

Log in

Axitinib plus pembrolizumab in patients with advanced sarcomas including alveolar soft-part sarcoma: a single-centre, single-arm, phase 2 trial

We also want to join Lisa in sending congratulations to Dr. Wilky.

YAP, TAZ and TEAD Workshop

Dr Guy Weinberg who set up the Cravat Foundation established a workshop that meets each year in Telluride, Colorado, to discuss advances and developments in understanding YAP, TAZ and TEAD, the genes affected by the translocation responsible for EHE. These genes contribute to many common types of cancer and the overarching goal of the workshop is to bring experts in that field into the study of EHE. This leverages the recognized biological importance of YAP, TAZ and TEAD to increasing the value in studying a rare cancer - one that is important to us, but would otherwise be under the radar.

The EHERCC was pleased when Dr Fredericus van Eeden from the Bateson Centre at the University of Sheffield, PI in the EHE zebrafish modeling project, was able to attend and present the results of their work. Continuing the international participation, Professor Kieran Harvey, a recognised expert in the Hippo Pathway and advisor to the EHE-RCFA, also attended from Australia.

We were particularly pleased to see the EHERCC and EHE-RCFA, together with the Cravat Foundation in the USA, contribute to the costs and so help enable Dr van Eeden and Professor Harvey to attend this important group. Professor Harvey noted *"the Telluride YAP/TAZ meeting was fantastic and very valuable"*. Jonathan Granek agreed; *"part of dealing with a rare disease is getting the relevant experts together occasionally to discuss a range of issues, share experiences, and hopefully develop new ideas. So Professor Harvey participating was an obvious objective for the foundation"*.

Tissue Manager Role Agreed

The EHE Rare Cancer Charity has been trying for over two years to establish an EHE biobank in the UK. This has proved to be frustratingly hard due to the limited resources available within the NHS. But following discussions with the Institute of Cancer Research and the Royal Marsden Hospital in London, the EHERCC was delighted to sign a two year funding arrangement with the Royal Marsden Cancer Charity to fund the role of a dedicated Tissue Manager in The Joint Royal Marsden-ICR Sarcoma Research Unit.

"We hope that this new role will allow us to progress with a number of key functions" said Hugh Leonard, Chair of Trustees at the EHERCC. *"We want to establish a bio bank and sampling protocols to start to collect EHE tissue and blood samples from all UK patients. This is important as tissue availability is a key limitation in several areas of research. We hope by developing the biobank we will in the future be able to provide real and meaningful biological samples to interested researchers."*

The EHERCC will also be coordinating the collation of historic data for the up-coming EHE international retrospective study. *"This will be the first major collation of international EHE patient data. A key part of that study will be accessing, collating and cataloguing the large number of historic data sets held across the UK. We hope that the new Tissue Manager can play a key role in this process."*

And these objectives are not restricted to the UK. Hugh Leonard explained *"with such a rare disease we want ultimately to have a European-wide data catalogue with multiple centres contributing to the overall EHE data and sample sets."* We wish the UK every success as they embark on this important programme.

03 EHE Fundraising

We are raising funds to support critical EHE research

The EHE Group is completely focused on raising the critical funds needed to finance, drive and accelerate our expanding EHE research programme. We thank all our members, their supporters and members of the public for their fundraising efforts, some of which are described below.

Major Gift Secured from Margie and Robert E. Petersen Foundation

We are thrilled to be able to start the Fundraising section of this edition of The Pledge with the news that the Cleveland Clinic and the EHE Foundation have secured a major gift from the Margie and Robert E. Petersen Foundation. The $1 million gift will be donated to the Cleveland Clinic to support EHE research conducted by Dr. Brian Rubin.

Significantly, The Margie and Robert E. Petersen Foundation will provide an additional $1 million in research funding to match donations raised by The EHE Foundation Group over the next three years. These matching funds will be used to fund an EHE research team from around the globe that will be picked by Dr. Rubin to complement his own research. The EHE Foundation will be able to keep their funds to be used to strengthen its own infrastructure and support research independently of the Petersen funds. The EHE Foundation hopes this partnership will catalyze our already-energized worldwide grassroots fundraising of passionate supporters to support vital EHE research.

Formal press releases will soon be issued, and we hope to be able to provide more information in our next edition. We want to congratulate the EHE Foundation and Dr Rubin for this amazing success, but most of all, we want to thank The Margie and Robert E. Petersen Foundation for their transformational gift that will help EHE patients worldwide.

Great Support Continues

In March and April, a colleague of Fiona Louise in Canada performed a magic show titled Stomp Out Sarcoma and raised $3200. In addition, activities associated with the EHE April Awareness month led to another $2,500 being raised. Fiona Louise noted *"so that's about $5700 from my school community this past two months."*

Then in May Fiona Louise posted photos of a another event at her school, with several members of staff 'braving the shave' to raise funds for EHE research, while the maths teacher donated her long fair for wigs. This event raised over another $3,000, all of which will be going to fund EHE research.

Fiona is also very keen to build a broader support base for fundraising in Canada, especially as donations can be made with full tax benefits thanks to the donations being made to Sarcoma Cancer Foundation of Canada. *"Other Canadians, I would love to see what you can do. Other than our awesome patron I am feeling a little lonely. Message me if you want more information."*

Virtual 5K a Massive Success

As part of the April EHE Awareness Month program, The EHE Foundation organized and conducted the 4th Annual EHE Virtual 5K Run/Walk. They surpassed their goal by leaps and bounds with 1,006 participants and $47,538 raised of which 100% will be used to fund EHE research. Julie Rivers Wahl explained *"This run/walk is an all-ages and abilities event to raise money for EHE research. This event is "virtual", which means it can be done anywhere you are. You can complete the 3.1 miles by running, walking, crawling, roller skating or any other form of exercise. If everyone were able to get just one or two (or more) friends and family to register, not only would we raise much needed research funds, but every registration also means one more person raising awareness by wearing an EHE t-shirt and bracelet."*

The EHE Foundation was delighted as over 1,000 people participated in the annual event. "*Thanks those that hosted large groups to complete their 5K event together and those that encouraged friends and family to join their efforts across the nation. We measure the event's success by its growth each year and YOU really helped us propel our accomplishments this year!"* A "special" thanks to Kristen Carlton (Team Kristen Leigh), Joe (in memory of his wife, Yahaira), Jenni Kovach (#teamjenni), Katherine Czyzewski, and Julie Wahl (Team Laney) for hosting record sized groups for the event. No matter how or where you participated, we want to say a huge THANK YOU for your brilliant support

The Foundation also received wonderful support from a group of generous sponsors. We are grateful for the following sponsors of the 4th Annual EHE 5K.

Platinum: BWA South; Cushman & Wakefield; Giombetti Associates, Hansen Distribution Agency.

Gold: Ryczek Construction; V&P Hydraulic Products.

Silver: Monticello and Warren Animal Clinics; Team Laney; Team Kristen Leigh; #teamjenni

03 EHE Fundraising

A Marathon Marathon!

Allana Parker posted an update concerning her four wonderful friends, Natalie, Samantha, Ellen, and Sophie, who are taking part in a 400 day marathon to support Allana and raise funds for EHE research. Each of the four friends, calling themselves the 'EHErelayraisers' is taking on a different challenge for 100 days at a time. In April, the first leg which started on 1st January was completed by Natalie who went 100 days without alcohol, including social events, birthdays and other events already in her diary (now that is a challenge!).

Natalie commented, *"It's been a long 100 days and I've felt like caving so many times but the reason behind why I have done it, and seeing how strong our beautiful friend Allana is, I knew I couldn't let her down. I'm proud to say that I have raised in total £1,111 (with a few donations left to come in) which will all go towards the EHE charity!"* Natalie continued *"Today I hand the baton over to the lovely @ellensmith1387 who will be completing 568 miles in the form of a triathlon in the next 100 days! Good luck Elle we know you will smash it! "*.

Ellen explained, *"my challenge is to complete 568 miles by way of a virtual triathlon, which is about the same distance as 2 return trips from Allana's house to the Royal Marsden."* Ellen has already completed over 500 miles so is well ahead of her schedule. *"I have 5 more weeks to go so well on track. It's hard work fitting all the training in, but it's such a great cause! Had a couple of injuries but have not let it stop me training yet."* We think these photos show the effort that Ellen is throwing at her leg of the relay!

We cannot wait to see what Samantha and Sophie will choose as their challenges. Allana said at the start that there aren't enough words to express how proud she is of them all. And the whole team are bowled over by the amazing support they have been getting. *"Thank you to everyone for your support and donations. We're overwhelmed with the amount that's been raised so far"*. We agree. It's an inspirational effort, and we are so grateful. Keep going @EHErelayraisers.

Three ‘Super Women’

Karen Workenaour often hand-paints ‘kindness rocks’ which she leaves lying around normally for people to find and hopes that they make them smile. Karen ended up painting 64 of these, with a Super-Woman logo adaptation posted by Anna Wydro in the UK.

Karen Workenaour, used the stones as part of her fundraising activities associated with April EHE Awareness Month activities that were held in her local Emerald Preserve in Oak Creek. Together with her daughter, Dr Kristin Nyren and Heather Abasovski, these three ladies worked super hard to promote awareness and understanding of EHE. This included a raffle and a silent auction, her painted stones, and a lot of time producing her very own EHE information presentation materials. We congratulate them on a great effort and huge success in raising $130 so far.

Half Marathon Completed!

In early April, Michelle Benedettini Chmelko received fantastic news that after several years of treatment following her diagnosis of EHE, including extensive radiotherapy, she had another ‘clean report’ and was therefore starting to train again. She said, *“After keeping my training down low all winter, I’m excited to say I will be running the Bayshore Half Marathon in Traverse City later this month to support the EHE Foundation.”*

Michelle asked everybody to support her and the EHE Foundation. She said *“The EHE Foundation’s mission is to seek treatments and a cure for EHE by increasing awareness, pursuing scientific research, advocating for and supporting EHE patients. The Foundation also collects and bridges information between researchers, providers and patients.”*

Michelle summarised the task very well when she posted *“Goal: $2,500. Time to reach it: 23 Days. Bold? Maybe so. Attainable? YES!”* and went on, *“I want others that have been rocked by EHE to have hope and a cure. Please be as generous as your heart dictates. All proceeds go directly to the EHE Foundation and like all rare cancers, funding for research is limited. Thank you from the bottom of my heart for your love, support and generosity. I am blessed beyond measure!”*

In early May Michelle was able to update everybody with the great news that she had not only completed the race, but had smashed her fundraising target. Michelle said *“So everyone….the fundraising goal was accomplished plus some….and the race was completed. It wasn’t pretty, it wasn’t fast, but it was my way to Just Live! I know the funds will be put to good use!”* Michelle’s target of $2,500 was exceeded by some margin, raising over $3,000. We want to congratulate Michelle on a great comeback, and thank her for her wonderful fundraising result.

03 EHE Fundraising

All Oar Nothing

Over the last 12 months Sarah Medwin has posted several pieces about her son Charlie and his three friends, Tom, Chris and Lewis, who are going to be rowing the Atlantic Ocean, in the 2019 Talisker Whisky Atlantic Challenge, to raise funds for 4 charities. One of those charities is the EHE Rare Cancer Charity. Charlie is taking part in support of his brother Harry, who has EHE. The actual event starts in December this year, and on 30th May the All Oar Nothing team held their official launch party in London.

Hugh Leonard, Chair of the UK charity, and his wife Sally Baker, attended what was a wonderful event with so much support and positivity. Regular EHE Facebook contributor Sarah Medwin, Charlie's mother was there also, providing a lovely chance to meet. The charity had a display and Hugh was able to tell the guests about EHE, the EHE Rare Cancer Charity, and all we are trying to achieve.

We of course want to wish the All Oar Nothing team every success for the last six months of preparation, and for the event itself. And if you are wondering, the very small boat behind the six people standing side by side in the team photo is the actual boat that Charlie and his friends will spend around 45 days on crossing the Atlantic!

Aussie Aussie Aussie, Oy Oy Oy

In May, Jane Biddlecombe, President of the EHE Rare Cancer Foundation, posted news of an opportunity for the foundation to share a substantial pool of funding offered by one of the big banks in Australia. The task was simple. The foundation needed people to vote for it. The top foundations in Australia, based on the voting results, would share the jackpot of $50,000.

"Please vote for the EHE Rare Cancer Foundation Australia at mygivingcircle.org/biggestgive" said Jane *"and help us be in the draw to share in $50,000 - just search our name!"*

The EHE worldwide community was asked to help, and many voted and shared the posts, while others also donated to help gain greater votes. Voting closed at the end of June. We understand that the EHERCFA came 3rd which is a fantastic result. And with matching donations, the EHERCFA raised $7,965. A huge thank you to everybody who supported our Australian sister foundation.

Antonella Calrow Rocks in Australia

In the words of Jane Biddlecombe *"is there anything Ant Calrow can't do! Hosting EHE brunches, runway shows for EHE events, brain child behind our annual 10,000 steps challenge and our most consistent EHE fundraiser and supporter since 2015 is back at it."*

Antonella announced that she was participating in the 'Stadium Stomp', an event at the Adelaide Oval taking place on 16 June, which involves running up 6000 steps.... without training for it. Antonella set up a fundraising page and raised an amazing $934.

We congratulate Antonella on another great event, and we hope that her legs were not too sore.

STADIUMSTOMPAO2019.GOFUNDRAISE.COM.AU

Stadium Stomp Adelaide Oval 2019 | Antonella Rowse

Hi there, I have decided to make a difference by creating my very own fundraising appeal for charity for a friend , Jane , with a rare cancer. I will be…

Melissa Shares Her Story

In June, Fiona Louise posted Melissa Magnotta's story of love and devotion, a story about her life with her remarkable husband Joseph, who died in May 2018. Melissa wanted to tell their story and was able to do this through MyCityLife.ca. Melissa is setting up a Canadian Foundation in memory of Joseph to help in the fight against EHE. We hope to bring a lot more news in future editions of The Pledge, but at the moment want to simply join Melissa in celebrating Joseph's life.

MYCITYLIFE.CA

A Journey Of Love, Loss And Treasured Memories – Joseph & Melissa Magnotta

Birthday Fundraisers Continue

Australia continued the popular birthday fundraising theme when Jonathan Granek also used his birthday to ask people to donate to EHE research. Jono was thrilled to see his target of $1,000 well exceeded as his total reached $1,652. Our thanks go to Jono,

03 EHE Fundraising

Support From Workmates

In May, workmates of Bec Sherman in Australia, hosted a morning tea fundraiser to raise awareness of EHE and funds for EHE research. It was a wonderful morning, raising an amazing $244.35. Bec's boss wrote to Jane Biddlecombe to let her know that the write-up provided on EHE had really helped people to understand EHE, and that staff have been discussing EHE around the office. We want to thank Bec Sherman and the team at the National Centre of Vocational Education Research for their wonderful support and encouragement. We also hope they enjoyed the lovely cakes and snacks!

Tell Your Story

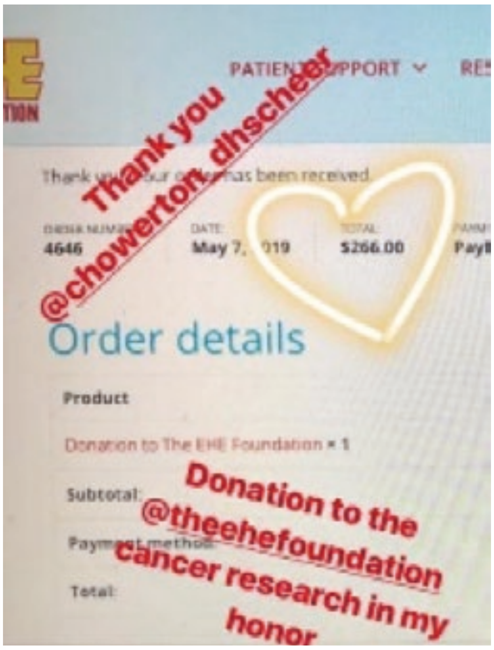
Fiona Louise from Canada wants to encourage all our EHE members to tell their story following her experience of amazingly positive support from two sources. *"Tell your story, please"* said Fiona Louise. *"I have stayed in touch with an up and coming Muslim author through Twitter and festival events. It is Ramadan and in the Muslim community it is a particular time for charity and good works. Her particular push this Ramadan is 1000 people to donate $25 to the Sarcoma Foundation/ EHE in my name. She is determined to raise 25K for EHE research here in Canada. Tell your story. You never know who is listening and who might decide to help."*

In June Fiona posted *"I had phoned my husband's boss at Dominion Securities about my situation and was looking at a specific fundraising event the bank did. He wasn't able to help but did promise to take my story forward. Today the boss stopped by my husband's desk to let him know that the board had just authorized a donation of $10,000 for EHE research in Canada."*

We totally agree with Fiona, as other members have also experienced these unexpected sources of support. We also want to say a huge thank you to her author-friend and to Dominion for such positive fundraising support.

We are All Cheering with You

Melissa Clark McPherson is a cheer coach in Azle. A friend of hers who cheers at a neighboring school asked their cheerleaders to donate all of their change for this year's EHE fundraising drive in April. The group donated $266 to The EHE Foundation. We cannot thank them enough for this fantastic gesture, and love their hashtag **#cheerforacure.**
We are all cheering with them.



Thank you @chowerton_dhscheer

PATIEN SUPPORT

Thank you has been received.

4646
DATE: May 7, 019
TOTAL: $266.00

Order details

Product
Donation to The EHE Foundation × 1
Subtotal:
Payment method:
Total:

Donation to the @theehefoundation cancer research in my honor

Dancing the Night Away

Tamzin Jones has been a tireless supporter of the EHE Rare Cancer Charity, and her close friend Kerry Hayman. So it was no surprise when Tamzin launched her next idea, a Dancer-thon for EHE research. And what an unbelievable success it was.

"We had the most amazing night/morning last weekend, with the most amazing people dancing and donating!" posted Tamzin. *"There is a little bit more to come in, but the total so far is mind blowing. My sleepy little town really pulled out all the stops, and it will be a night that is talked about for a long long time. Which also means in the backs of their minds will be EHE Rare Cancer Charity... awareness is spreading, and the support for the EHE family is growing. Totally awesome."*

tamzin jones

12 Hour Dancer-thon for EHE Rare Cancer Charity

Fundraising for EHE Rare Cancer Charity

243%

£3,659.10
raised of £1,500 target
by 61 supporters

We are amazed at the wonderful and inventive support that people like Tamzin continue to come up with. We are beginning to make a difference with several new EHE research opportunities, but this is only possible because of the generosity and energy of so many wonderful supporters. And as Tamzin noted above, that support not only results in funding but also in growing awareness of EHE.
We cannot thank Tamzin enough for her brilliant efforts. Keep going Tamzin Jones!!

04 And in other news...

Meeting Up

Many of our Facebook members have come to know each other and build close relationships without ever meeting. So when the chance to meet comes up, those involved are always thrilled. In April it was the turn of Jane Biddlecombe and Bec Sherman to meet in Adelaide, Australia. They had a great time, although the shared chocolate fondue apparently led to severe chocolate overload!!:

New Arrivals

The second quarter saw three new arrivals for families in our EHE group. These moments of joy are to be treasured, and we send our congratulations to:

Amanda Holland on the arrival of Hope Elizabeth on 14 April;

Livia Jauslin on the arrival of Vivien Sophia on 8 March; and

Sharan Sandhu on the arrival of Ajooni on 30 May.

Photo-therapy

As in previous quarters, Robinson Ortiz Jr shared inspiring photos with messages of support for all those with EHE. *"To those affected by EHE may you be filled with strength, peace, courage and hope."*

Because I have felt afraid
I understand courage.

Because I have been lonely
I appreciate love.

Because I have fallen
I can rise to my feet.

Because I have known despair
I believe in hope.

I am stronger because
I had to be.

~ Leonard Nimoy

Meanwhile, Malcolm Barrah in Scotland posted a photo for spring. *"Well spring is definitely on the move here in the UK. The river below me is bursting with love and new life, a nice reminder to us that we just need to push on and just live because at the end of every cold miserable winter there is a new beautiful spring, just like in life all horrible things come to an end eventually".*

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