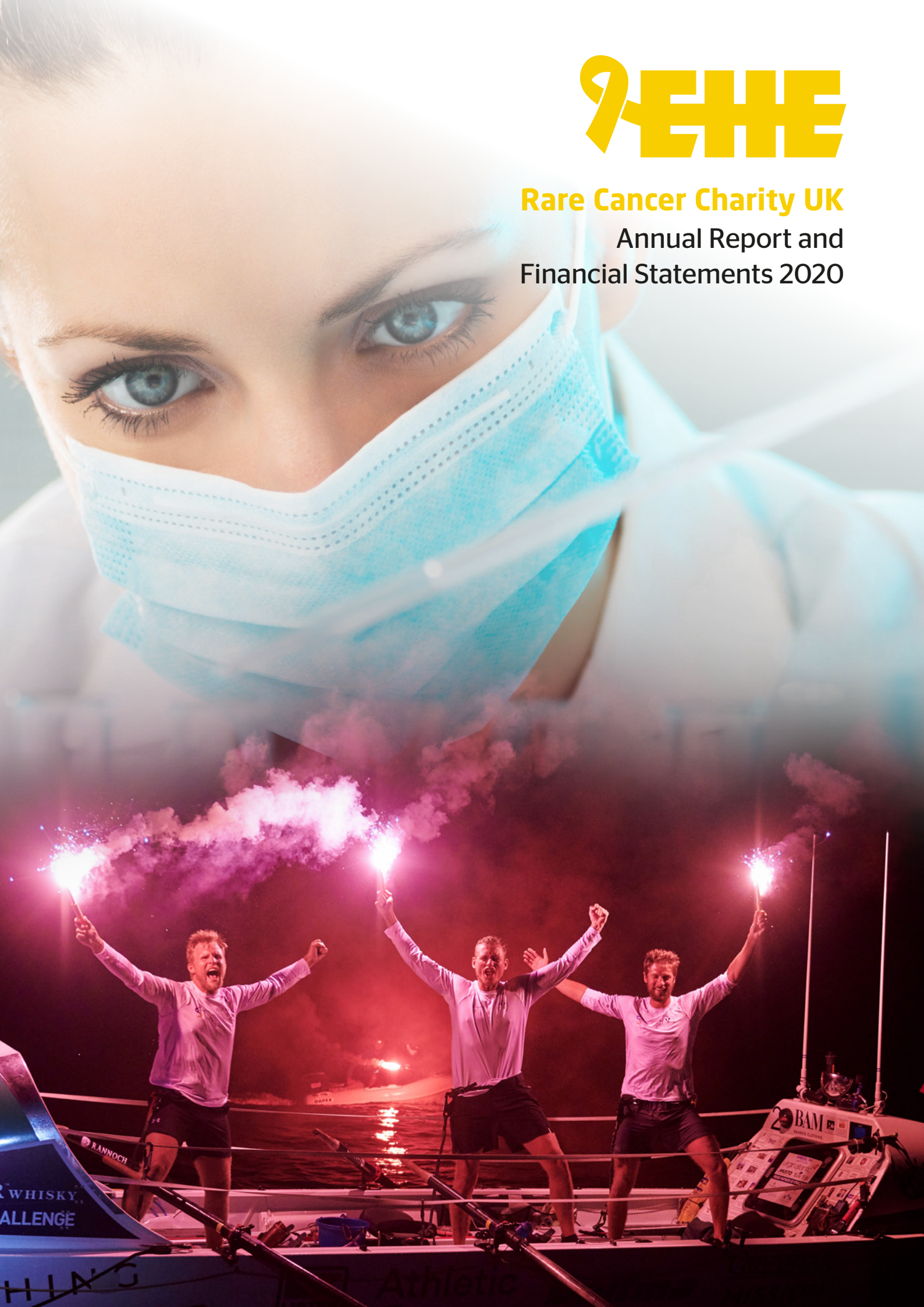




**Rare Cancer Charity UK**

Annual Report and  
Financial Statements 2020





## Epithelioid Haemangioendothelioma (EHE)

# EHE Facts

A **destructive vascular sarcoma** that is found in the walls of blood vessels

Commonly appears in **liver and lungs** but can appear anywhere

Can present as **indolent** (passive) or **aggressive**

Typically more aggressive in **young people**

**Can re-present** after long period with no disease

Often presents with **multiple tumours** called 'multifocal'

May turn **aggressive at any time** without warning

Clinical signal that onset may be tied to **pregnancy** and **puberty** in young women

Living with EHE causes **enormous psychological stress**

Affects women more than men in a ratio of about **5:1**

One of the **world's rarest cancers**, with 5 to 10 patients per year in the UK

**No recognised treatment**, so treatment is by trial and error

**No known cure.** Aggressive disease is **normally fatal**

Find out more at: [www.ehercc.org.uk](http://www.ehercc.org.uk)





ehe  
Biobank

At the end of 2020, the Royal Marsden Hospital had approved the UK National EHE Biobank, to be housed at the Royal Marsden Generic Tissue Bank.



Royal Marsden Hospital  
biobank technician.

# Annual Report and Financial Statements 2020

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# Progress despite COVID-19

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**With the world battling a truly global pandemic, 2020 was an exceptionally difficult year at every level. Our members and worldwide patient community were all impacted yet, across the globe, they managed to weather the COVID storm with the same determination and spirit we witness on a daily basis, fortified by the extraordinary support accessed through our EHE social media platforms.**

There were serious implications also for all our EHERCC activities. Research was largely suspended in the second and third quarters as lockdown took hold and research facilities were closed. Grassroots fundraising was impacted as many faced short-term uncertainty, while larger donors faced increased demand for their more limited funds. Major events such as the London Landmarks Half Marathon, in which we hoped to have 40 runners, were cancelled.

Faced with these circumstances, we chose not to prioritise fundraising as we felt this would be inappropriate and insensitive to the serious challenges that people were facing. We were confident that all our supporters would re-engage when some form of normality returned. We were delighted, therefore, when we did indeed see support for the charity's activities growing through the fourth quarter and into 2021.

In 2020, the fantastic support we always receive may have understandably reduced, but it never disappeared altogether. We hope it is clear, as you read through this report, that the enthusiasm and commitment to our activities was as strong as ever as we left 2020 behind. We cannot thank our supporters enough for all that they contributed through such a difficult year. We also are immensely grateful to the researchers and clinicians who have continued their work with EHE through 2020. Finally we want to say thank you to Liz Milligan, who resigned in March 2021, for all she contributed as a valued Trustee and colleague through 2020. To them all we want to say a huge

## Thank you!

**Left to right:**

Hugh Leonard (Chair of Trustees),  
Jeff Collins (Trustee),  
Kate Hooper (Trustee),  
Liz Milligan (Trustee, resigned 10.3.2021)  
Dr Oliver Pearce (Trustee).



## 01 Patient Support and Advocacy

Patients with ultra-rare diseases like EHE often feel isolated at the best of times. Layer on top of that 2020 issues like social distancing, lockdown and the uncertainty of how COVID might affect your rare disease, and patients can feel overwhelmed. Our patient support activities, largely delivered through the global EHE Facebook patient support pages, have perhaps never been more needed than they were in 2020.

It was with this background that the support, advice and encouragement of our global community, shared through social media, was so important. This was especially true for our members who had undergone organ transplant, and faced exceptionally challenging isolation levels due to their suppressed immunity. As always the support given was delivered tirelessly, by so many in our community, and provided with care, empathy and deep affection.

Of course, EHE does not stop during a global pandemic. Newly diagnosed patients still continued to engage with the charity through 2020. We are never pleased that new people have to embark on their own EHE journey, but we of course welcome them to our group, where we will always try to help answer any questions they may have, provide useful advice and information but perhaps most of all offer them support, encouragement and love within a group of fellow EHE patients.

Towards the end of the year, with the UK EHE community expanding, we decided that in addition to global social media, it was time to launch our own UK-focused EHE social media. Facebook, WhatsApp, Instagram and Twitter accounts were all launched. We hope that this will help foster an ever-stronger UK EHE community, together with delivering greater awareness and support for our work.

## 02 Research

Despite a COVID-related slowdown in research, our existing projects continued to deliver exciting results. At the same time, project expansions are under review, new research is being proposed and important infrastructure such as the UK National EHE Biobank is close to being finalised and going live. In short, COVID19 may have slowed us down for a short while but immediate and longer term EHE research possibilities are exciting.

The PhD we are funding at the University of Manchester, under Prof Valerie Kouskoff, has continued to shed light on how EHE is impacting the biology of endothelial cells.

The project team we are funding at the Bateson Centre at the University of Sheffield are continuing to attempt to develop an EHE zebrafish model. Led by Dr Fredericus Van Eeden, this work is proving to be challenging, with the TAZ-CAMTA1 construct still not expressing in the zebrafish endothelial cells. A full and broad review of progress and results with other experts in the field has led to the identification of several possible solutions to the current difficulties.

At the end of the year we had also seen good progress towards the start of two new projects. The first of these is the set up and start of the National EHE Biobank which will be centred at the Royal Marsden Hospital. This biobank will finally allow us to start to collate EHE tissue and fluid samples to support EHE research. At year end, ethics approval had been received and final operational approvals were being sought.

The second project is a collaboration between INT in Milan and the ICR in London. With Dr Silvia Stacchiotti and Prof Robin Jones acting as the respective Principal Investigators, this project is looking to identify possible cytokines and hormones as biomarkers of EHE, which in turn may provide an early sign of disease progression, helping clinicians decide on the appropriate treatment regimens.

At the end of 2020, we were also delighted to see ESMO coordinate a virtual consensus meeting, bringing together more than 90 multidisciplinary experts to collate, agree and document best practice for treating EHE.

## 03 Fundraising

2020 started with the great support we have always enjoyed, from our amazing EHE community, their supporters, and the general public. The second and third quarters were very different, however, as the COVID pandemic and social restrictions impacted every part of our society. Yet by the end of the year, the commitment to help raise funds for critical EHE research had reignited and was clearly growing as we moved into 2021.

The year started with the climax of Charlie Medwin's row across the Atlantic. This amazing 2,900 nautical mile adventure was completed when Charlie and his two team mates reached Antigua on 20th January. The row not only provided an excellent platform to raise EHE awareness over months of preparation and publicity, but also raised more than £25,000 for the charity, an amazing result.

With COVID hitting hard in the second quarter of the year, and with core events like the London Landmarks Half Marathon being cancelled, our fundraising focus was obviously impacted. We also made a policy decision not to push our supporters as we knew that many of them were facing their own challenges and significant uncertainty.

But the fourth quarter saw renewed interest in grassroots fundraising as many of our supporters began to reach out and re-engage with the charity. We therefore decided to run a matched-funds campaign over Giving Tuesday, with a single donor offering to match up to £10,000 in donations. With great support from many we were able to exceed that target and raised more than £20,000 for EHE research.

There are of course still COVID-related uncertainties ahead, so we will continue to undertake our fundraising activities with care and consideration for the current situation. However, the energy and renewed support we have seen suggests that many of our supporters are once again determined to assist in raising the funds we need to keep our exciting EHE research programme moving forward.

# Objectives and 2020 Achievements

We believe it is important that we report openly and honestly how we did against the objectives that we set ourselves for the year, so that all those who support us can see how the charity is performing. On this page we have provided a summary of our achievements against our 2020 objectives. Of course, our 2020 objectives have been heavily affected by COVID19, and in some cases have therefore been rolled over into 2021.

## What we said we would do... ...and what we achieved

### 01 Patient Support and Advocacy

Promote National EHE Biobank and engage with patients.	Biobank delayed by COVID. Final approval awaited at year end.
Promote international collaboration.	Regular EHE international group meetings held.
Engage with European patients.	Deferred to 2021 due to COVID.
Promote profile of EHERCC.	All UK sarcoma centres contacted.
Increase engagement with UK patient community.	Zoom call held. New Exec Director engaging with volunteers. New social media accounts established.



### 02 EHE Research

Promote international collaboration including evaluating new proposals.	Largely deferred to 2021 due to COVID. Focus on supporting existing research during COVID.
Assist with finalisation of UK National EHE Biobank.	Assisted with all required input. Final approval awaited at year end.
Conclude PEACE project engagement and enrolment into biobank.	Deferred to 2021 due to COVID.
Communicate research progress with patient community.	Achieved through Zoom call, The Pledge quarterly newsletter, and Facebook posts.



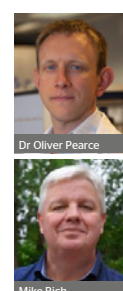
### 03 Fundraising and Finance

Support and encourage grassroots fundraising.	Adopted passive approach during COVID crisis.
Complete fundraising strategy.	Abandoned due to COVID. We will re-assess once we see the post-COVID fundraising landscape.
Develop strategy with RMH-ICR for funding of key biobank resource.	Deferred to 2021 due to COVID.
Seek to secure fundraising expertise through voluntary sector.	Temporarily suspended as we wait to see post-COVID landscape.



### Charity Organisation

Evaluate Board of Trustees expertise to support future growth.	Dr Oliver Pearce joined Board of Trustees.
Engagement of an experienced charity professional.	Engaged Mike Rich as part-time Executive Director.
Expansion of the Research and Medical Advisory Team.	Deferred to 2021 due to COVID.
Review organization goals.	Deferred to 2021 due to COVID.





# Our Forward Focus for 2021

Because rare cancers are not rare to those who have them

Our forward focus continues to be on the four key areas that will deliver a robust, vibrant and dynamic charity creating real progress in the battle against EHE.

Objectives for 2021 and beyond are listed below. Several of these objectives are the same as those that we listed for 2020, due to their deferral because of the COVID19 pandemic.

## 01 Patient Support and Advocacy

- Promote UK National EHE Biobank and maximise patient engagement
- Join appropriate European patient umbrella groups and expand European patient and clinical/research engagement
- Engage with regulators concerning tissue management and EHE treatment approvals
- Maintain contact with sarcoma centres

## 02 Research

- Promote EHE research and international collaboration
- Assist with launch of UK National EHE Biobank
- Conclude PEACE project engagement and enrolment into biobank
- Support existing research projects
- Promote and evaluate new research initiatives

## 2021 AND BEYOND

## 03 Fundraising

- Support and encourage grassroots activity
- Review fundraising strategy post COVID, including recruiting volunteer fundraising professional
- Develop strategy for longer-term EHE biobank financing
- Assess possible European grant award to assist with European strategy

## Charity Organisation

- Identify and invite patient representatives to join the Board of Trustees
- Continue to seek to expand Research and Medical Advisory Team
- Continue review of appropriate policies
- Review organization goals and conclude strategy and support required for success in post-COVID environment

# Consensus paper

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**In spite of COVID19, which made the last two years a terrible time for all of us, in 2020 the EHE community reached the goal of building the first consensus document on the clinical management of EHE, in collaboration with the worldwide community of experts and patient representatives, including particularly the EHE Rare Cancer Charity UK (EHERCC).**

**This consensus paper is now published as an open access paper available to all doctors, researches, and patients and their caregivers who need it. We really hope that this document will help increase the knowledge of the disease, harmonizing the treatment of EHE patients all around the world, minimising misdiagnosis, mistreatment and discrimination, and will provide a strong foundation for the years ahead. Thank you to everyone who made this achievement possible!!!**

**Dr Silvia Stacchiotti** is a medical oncologist, working in the Adult Mesenchymal and Rare Tumor Medical Treatment Unit, at the Fondazione IRCCS Istituto Nazionale Tumori (INT), Milan, Italy. She is involved in all institutional research activities on adult bone and soft tissue sarcomas (STS), with a specific focus on ultra-rare sarcomas, among which, in particular, EHE. Her research includes identification of new targets and new anticancer treatments for specific sarcoma types, studies on the immune-profile of sarcomas as well as on mechanisms of resistance to therapy and the development of preclinical models of sarcomas. She is the current president of the Italian sarcoma Group and collaborates with the Italian Network on Rare Tumors. She is the faculty coordinator of the Sarcoma track of the European Society for Medical Oncology (ESMO) and the subject editor of the ESMO guidelines committee for sarcoma and GIST. She is a member of the Board of Directors of the Connective Tissue Oncology Society (CTOS) and is the chair of the systemic therapy subcommittee of the EORTC Soft Tissue and Bone Sarcoma Group. She collaborates with several sarcoma Patients Advocacy Groups, among which in particular the EHE Rare Cancer Charity (UK) and The EHE Foundation in the USA, for both of whom she serves as a member of the respective medical advisory boards.





# Foreword

## Dr Silvia Stacchiotti

(Oncologist at The Istituto Nazionale dei Tumori (INT) in Milan, Italy)

**In December 2020, we promoted a consensus meeting on this rare tumor under the umbrella of the European Society for Medical Oncology (ESMO), because guidelines for diagnosis and treatment were currently lacking and EHE patients are treated inconsistently across the world resulting in suboptimal outcomes.**

Potential treatments include a number of loco-regional therapies, systemic agents, and also liver transplantation, but the degree of uncertainty in selecting the most appropriate approach remains high. Prior to the herein-presented consensus, the meeting was preceded by a comprehensive literature review and retrospective efforts to collect data on systemic treatments used to cure EHE patients, including sirolimus, and to identify prognostic factors. The consensus document is now signed by an international community of more than 80 sarcoma experts from several disciplines and from the major referral institutions in Europe, North America and Asia, with the contribution and the sponsorship of the Epithelioid Hemangioendothelioma foundations.

We do expect this paper to become the state of the art of diagnosis and treatment of EHE and the basis to build any future study. It will be disseminated by scientific networks and social media. A lay version for patients in many different languages will also be prepared. While EHE is indeed a rare tumor, we hope that this publication will help the EHE community and avoid the discrimination that patients with rare cancers often have to face. We do believe that this will help harmonise EHE management worldwide and ultimately benefit the most number of patients possible. In addition we do expect this report to be of great value in ongoing negotiations with the regulatory bodies (FDA, EMA and the like) about the process to develop and approve new agents for this disease. This is even more important since new compounds for treatment of EHE are now happily under development and new clinical studies are about to start.

In addition, the collaboration and support of the EHERCC and The EHE Foundation is making it possible to fund collaborative translational studies aimed at the identification of prognostic factors and mechanisms of disease progression, particularly including investigation into the role of inflammatory cytokines and hormones. 2020 has seen also the establishment of the first PDX model of EHE and of its corresponding cell line. This is of the highest importance in a rare disease, like EHE, in which it is so difficult to conduct clinical studies. New compounds and combinations can indeed be tried in the preclinical model and then translated into clinical studies once we see preliminary promising signs of anti-tumor activity. Indeed, this type of experiment is already under way.

Finally, a new platform to prospectively collect data on EHE patients is being considered and we hope will be established in Europe. This will be the basis for a prospective, international registry, fully dedicated to EHE, opening the way to a better understanding of the disease and its natural history.

All this would never, ever be possible without the strong and effective collaboration between EHE Patients and the experts, the exponential growth of which is probably the best news of 2020 and for the years to come.



Dr Stacchiotti

The EHE Rare Cancer Charity (UK) would like to thank Dr Stacchiotti, and her team at INT in Milan, for the wonderful support and care they provide for EHE patients globally. We are also very grateful for the time given by Dr Stacchiotti to write this foreword for our 2020 Annual Report.

# 01 Patient Support and Advocacy

For many people, the social restrictions imposed by COVID19 on everyday life in 2020 came as a huge shock. People felt isolated and frightened, and many talked of the psychological stress they now faced. Indeed, our national media have rightly been shining a spotlight on the impact this is having on so many individuals. Yet for EHE patients, living with an ultra-rare cancer, these feelings of fear and isolation, and dealing with the relentless psychological stress of their diagnosis, are things they live with year in, year out, without any immediate hope of a treatment that will bring a swift and happy end to their situation. For all EHE patients, particularly those who have transplants or are undergoing treatments where their immune system is suppressed, the fear of how COVID19 may impact their EHE has added yet greater anxiety.

So 2020 proved to be a year in which the patient connectivity that our social media forums provide was even more valuable than ever before. Already established over the preceding six years, and with a global community involving more than 2000 people across more than 75 countries in the world, participants quickly engaged on all issues that concerned them about COVID and EHE. Questions were posted and responded to, and although answers were not available for all questions, the sharing of concerns and the discussion of the issues helped so many quickly come to terms with the pandemic. We once again must thank everybody that contributed to the forums for giving their time and energy and, through that, for the care and comfort they helped provide.

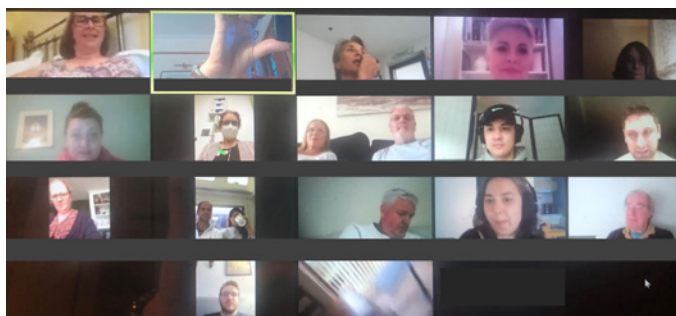




## Review by Hugh Leonard

As outlined on the facing page, 2020 was an exceptional year for EHE patients across the globe. Yet the support that was provided tirelessly by so many people, many of them EHE patients themselves, was inspiring and wonderful to watch. This is particularly important for isolated patients who may be living in places with less developed medical care, and where feedback and information can be so important.

But the pandemic also had surprise benefits. One of these was the almost global acceptance and exposure to virtual meeting platforms, such as Zoom, Teams and Skype, to name just a few. With almost everybody becoming comfortable with these systems, the EHERCC was delighted to hold its first Zoom meeting in July. This proved to be a lively discussion with a lot of energy and ideas exchanged. We were also delighted to be able to introduce Mike Rich to the UK patient community. Mike has many years experience working in the charity sector and agreed to join us as Executive Director on a voluntary and part-time basis, bringing huge amounts of experience into the group.

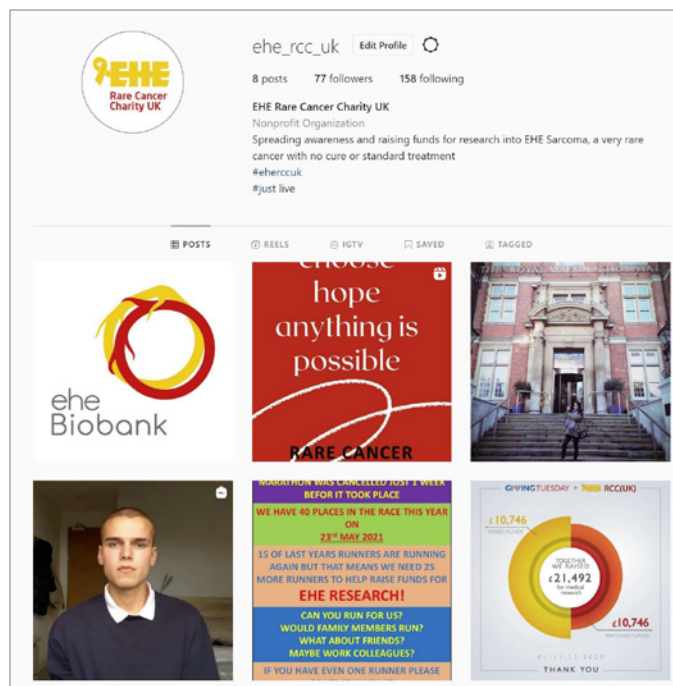
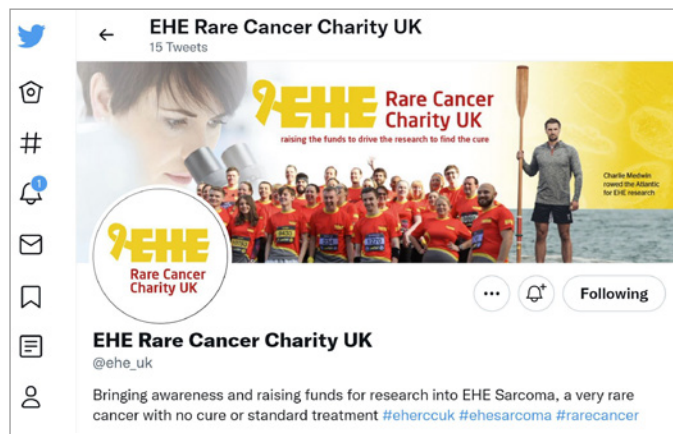


EHERCC Zoom call in July

One of the key issues agreed on this group call was the intent to establish volunteer groups to assist in key areas of the EHERCC's activity, including awareness, fundraising, and improved communications.

While the pandemic continued to create problems in areas such as fundraising and research, the EHERCC communications group, led by Allana Parker, were not the slightest bit curtailed in their thinking and foresight. Discussions with the UK patient community quickly identified that introducing UK-specific social media was not only sensible but that it was now necessary and something the UK patient community wanted.

The team set about building four new UK-focused EHE sites, on Facebook, Instagram, WhatsApp and Twitter. By the end of the year all four were successfully launched and are now active.



There have been some programmes casualties, however, to the COVID pandemic, and one of these has been the planned engagement and reach-out to the European community. Although the process did not progress far, we have completed our evaluation of the European-focused patient support groups we will apply to join in 2021, prior to beginning the process of creating a European EHE patient network. We are excited about this next phase of activity, hopefully allowing us to engage with, and support, an even larger group.

# 02

# EHE Research

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**2020 was a strange year for research. The first quarter was unaffected by COVID, and yet, at the end of March, the national lockdown brought all projects to a standstill. The second quarter was lost almost completely, but the third quarter saw research labs reopening tentatively, with a more sustained return through the fourth quarter. At the end of the year we also began to receive enquires about new projects, and extensions of those we are already funding. This is very encouraging and leaves us once again excited about the future.**

**We have provided a summary of the main projects we are sponsoring on these pages, together with some thoughts and observations about the future. We hope that you will also find these exciting.**

## **Project 1:**

### **Developing an EHE zebrafish model**

Over the past two years, a small team in Sheffield has been working hard, trying to generate an EHE zebrafish model. A zebrafish model would be a wonderful addition to EHE research as these fish are far cheaper and quicker to produce, and therefore far lower cost, than mice. However, the project has proved difficult with TAZ-CAMTA1 expression not presenting in endothelial cells. This was surprising as a parallel construct using GFP (green fluorescent protein) had been successfully introduced.

Dr Fredericus van Eeden, the Principal Investigator for the project, believes that a number of possible causes for this failure to achieve TAZ-CAMTA1 expression can be hypothesised. There could, for example, be sequence elements in the construct that lead to repression of expression. Codon optimisation was used to try and address this issue but does not change the sequence completely and although the team used two different approaches, it may not have “hit” the relevant bases. If the mechanism of this repression can be identified and understood, the team also hope that it might perhaps be therapeutically exploited in EHE tumours in humans. A detailed understanding of this mechanism is therefore warranted. In addition, understanding of the precise reasons may allow us to relieve this repression and gain epithelial expression. A new, four element, one-year project extension is under consideration.

The first approach will be to examine if there are sequence elements in the construct that prevent expression under control of the *flil*a promoter that has been used.

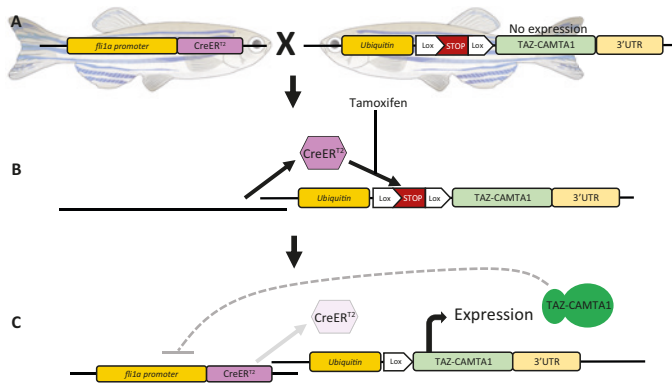
The second approach has arisen following dialogue with Dr Valerie Kouskoff in Manchester who is also working on EHE. Importantly, Dr Kouskoff found that in embryonic stem cells the TAZ-CAMTA1 expression can lead to downregulation of endothelial markers including *flil* expression (the mammalian equivalent of *flil*a). To provide the best model of the disease, the same promoter should be used as is actively driving TAZ-CAMTA1 in the human condition. In addition, the team will clone a similar element from the zebrafish and test both of these for driving expression in zebrafish and endothelial cells, initially using GFP as a reporter.

The third element of this year’s work will address the issue faced with previous assays where the team only established that lines were not behaving as expected after creating a line, which takes a significant amount of time (3-4 months). It is clear from the team’s previous attempts that TAZ-CAMTA1 requires more checks. Therefore, they will also do *in vitro* experiments before progressing with transgenesis in fish.



## Review by Kate Hooper and Oliver Pearce

Assuming that the results of the first three elements are positive, the fourth element will be to apply these findings to hopefully create an EHE zebrafish model. Only when the team are convinced from their *in vivo* and *in vitro* experiments that the construct is working as expected, will they progress and raise transgenic lines.



**Fig:** Strategy for driving TAZ-CAMTA1 in endothelial cells. Fish containing a flilA driven CreERT2 and a silenced TAZ-CAMTA1 expression construct are crossed together (A), the resulting larvae containing both constructs express an inactive form of Cre in the endothelial cells -when activated with tamoxifen the Cre will remove the stop cassette (B) and lead to expression of TAZ-CAMTA1 under the control of a constitutive ubiquitin promoter. If subsequent feedback of TAZ-CAMTA1 leads to downregulation of the flilA promoter activity and CRE production, this is irrelevant, as removal of the stop cassette is permanent (C).

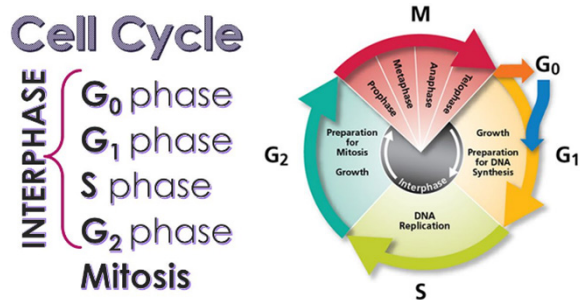
### Project 2: Understanding the biology of how EHE affects endothelial cells

Despite university laboratories being completely shut down early in the year and then reopened, but with restricted access through a large part of the rest of the year, Emily Neal who is undertaking the EHE research PhD at the University of Manchester in Dr Valerie Kouskoff's laboratory, has been able to make good progress through the last quarter of the year.

Emily's PhD is seeking to show how EHE affects endothelial cells, and, in particular, to determine how TAZ-CAMTA1 activity and expression is regulated in endothelial cells. During the fourth quarter Emily was focused on three different approaches:

The first approach was to evaluate the transcriptomics of different endothelial cells. Transcriptomics is the identification of genes, using RNA sequencing, which are expressed during the transcription process in cells. This analysis was undertaken by inducing TAZ-CAMTA1 in endothelial cells at 10 days old. The cells were then separated into four different groups with different levels of TAZ-CAMTA1 expression. These are: (i) uninduced cells; (ii) cells with no TAZ-CAMTA1 expression; (iii) cells with low TAZ-CAMTA1 expression, and (iv) cells with high TAZ-CAMTA1. RNA sequencing will be used to identify the genes expressed, and the resultant differences for the four different groups of cells will be used to begin to understand what biological processes within the cell are altered as a result of TAZ-CAMTA1 expression. This final RNA sequencing is planned for the start of 2021.

The second approach was to use cell cycle analysis, as naturally-occurring TAZ is known to be involved in the cell cycle. The cell cycle is the name for the process by which our cells grow and proliferate, with different phases of the cycle given different names. The G1/G2 phases relate to cell growth periods. The S phase is the part of the cycle where the cell nucleus replicates and divides. The M phase is where the cells divide to produce two identical cells. The G0 phase is a sort of 'holding pen' where cells that have not yet fully synthesised their DNA are held until they are ready to move on to the S phase.



The objective of this part of the research is to see if TAZ-CAMTA1 affects the cell cycle. By analysing endothelial cells where TAZ-CAMTA1 was induced at 10 days, and then stained and analysed using flow cytometry, the number of cells in the different phases could be seen for different levels of TAZ-CAMTA1 expression. Early results have shown that in cells expressing TAZ-CAMTA1, a higher proportion are in the S phase than in cells with no TAZ-CAMTA1, but a lower proportion are in the G0/G1 phase. There was, however, no obvious difference in the proportions in the G2/M phases between all cell types. This suggests that TAZ-CAMTA1 expression increases the ability of cells to enter the S phase of the cell cycle. The question remains as to whether this leads to greater cell proliferation, or whether the cells remain arrested in the S phase, something that may be indicated by the lack of difference in cell proportions in the G2/M phases. Emily will be undertaking further research to try and answer these questions.

The third approach involves determining whether, in cells that are exposed to external mechanical stimuli, TAZ-CAMTA1 localisation and/or expression is affected. This is of interest as it is known that normally occurring (wild-type) TAZ is affected by such stimuli. This is also an interesting point because the mechanics within tumour tissue are quite different to surrounding non-tumour tissues.

The experiment took endothelial cells at 10 days old, induced TAZ-CAMTA1, and then introduced three different inhibitors of three proteins that are known to communicate mechanical stimuli to wild-type TAZ. The inhibitors used in these experiments are altering the internal cell cytoskeleton, so the current approach isn't actually altering the mechanics of the environment directly, but is replicating the effect that such mechanical stimuli might have on the target cells.

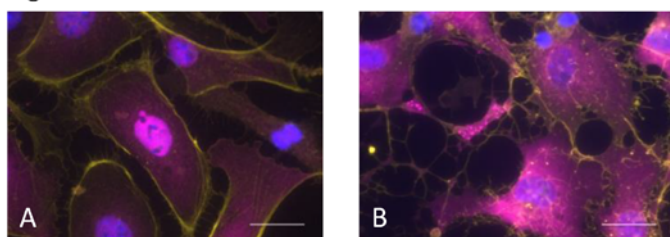
## 02 EHE Research Continued

The effect of these three inhibitors was then investigated by analysing where the TAZ-CAMTA1 appeared in the endothelial cells.

Early results showed that these inhibitors did have an effect on the TAZ-CAMTA1 expression. In one case the inhibitor seems to have reduced the overall number of cells expressing TAZ-CAMTA1. The other two inhibitors did not reduce the overall number of cells expressing TAZ-CAMTA1, but did seem to reduce the level of TAZ-CAMTA1 expression in those cells.

Finally, fluorescence microscopy techniques were used to visualise where the TAZ-CAMTA1 is situated within the endothelial cells. This revealed that TAZ-CAMTA1 was predominantly located in the nucleus of uninhibited endothelial cells. The addition of each of the inhibitors however increased TAZ-CAMTA1 presence within the cell cytoplasm, but did not completely remove it from the nuclei (see Fig 1). Taken together, this provides preliminary evidence that mechanical stimuli may have a role in TAZ-CAMTA1 regulation, resulting in its degradation and relocation into the cytoplasm.

**Fig 1**



**Slide A** shows endothelial control cells expressing TAZ-CAMTA1 but with no inhibitor treatment. The pink/purple areas show the location of TAZ-CAMTA1, almost exclusively in cell nuclei.

**Slide B** shows endothelial cells treated with inhibitor (blebbistatin). Again the pink/purple areas show the location of TAZ-CAMTA1 which is now predominantly present in the cell cytoplasm, but with some presence remaining in the nuclei.

All three of the approaches taken are delivering very interesting results about TAZ-CAMTA1 and its effects on the biology of endothelial cells. These of course are preliminary results, with further experiments required and planned to understand the implications to endothelial cells, and therefore EHE disease, and ways we may treat the disease. This will form the focus for 2021.

### **Project 3:**

#### **Launching the National EHE Biobank**

In August 2019 the EHERCC initiated funding for the role of Tissue Manager at the Institute of Cancer Research in London. Managed by Dr Paul Huang, this new role, filled by Emma Perkins, was focused on developing the UK National EHE Biobank to capture and store samples from EHE patients for use in research.

As for many other projects, progress through 2020 was delayed by COVID19, but the EHERCC was delighted to be able to report at the end of the year that final ethics approval for the biobank had been received. Work was underway to complete all procedural approvals prior to the biobank going live in early 2021. When it does go live, participation in the biobank will be open to everybody in the UK, regardless of location, as this will be a national biobank, and will therefore allow patients to ask for their samples to be included wherever they live. Patients will be able to achieve this by either asking their hospital and doctors to enrol them and send the samples, or they will be able to enrol directly with the Royal Marsden team who 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.

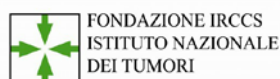
The EHERCC wants to thank the Royal Marsden Hospital who have been instrumental in helping set the biobank up, and who will be managing and storing the samples at the Royal Marsden Generic Tissue Bank. We also want to thank the ICR for their involvement. We could not be more grateful for their brilliant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

### **Project 4:**

#### **Identifying cytokines and hormones as possible biomarkers of EHE**

The EHERCC was also delighted to be able to report that they had completed the signing of their first joint EHE project in Europe. This is an exciting project as it is the first time the EHERCC has signed a funding agreement with a European research facility. It is also the first collaborative research project the EHERCC has supported that involves a collaboration with three different organisations.

The European entity is The Instituto Nazionale dei Tumori (INT) in Milan, Italy. Researchers there will be collaborating with The Institute of Cancer Research (ICR) in London, UK. The third entity is Memorial Sloan Kettering (MSK) in New York, USA. The EHERCC funding, in combination with funding from the EHE Foundation in the USA, is for INT and the ICR only, as the MSK work is being funded by a private donation in the USA.



FONDAZIONE IRCCS  
ISTITUTO NAZIONALE  
DEI TUMORI



The project has two key objectives. The first is to assess: i) the profiles of circulating cytokines, hormones and micro-RNAs; and ii) hormone expression and activation of YAP/TAZ in tumour tissues; both as a function of 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 three subgroups according to disease behaviour (non-growing disease, slow-growing disease, highly aggressive disease with evidence of pleural effusion and systemic symptoms). The second objective is to identify and validate novel biomarkers to inform patient management (prognosticators and predictors of response to medical agents) as well as potential therapeutic targets.

Work on the actual research will start in early 2021. The EHERCC is thrilled to have three such prestigious institutions engaged in this important research. We look forward to providing further updates in our quarterly newsletter, The Pledge, and in our future annual reports.

### ESMO (European Society of Medical Oncology) holds major EHE event

At the start of December, Dr Silvia Stacchiotti, based at INT in Milan, chaired a virtual ESMO meeting on the *"Development of the Consensus and Guidelines for EHE treatment"*. This is a standard ESMO procedure where disease experts are brought together to discuss all aspects of the disease with a view to agreeing the *"Consensus and Guidelines for EHE Treatment"*. Hugh Leonard from The EHERCC in the UK and Medha Deoras Sutliff and Jane Gutkovich from The EHE Foundation in the USA were invited to attend the meeting as patient representatives.



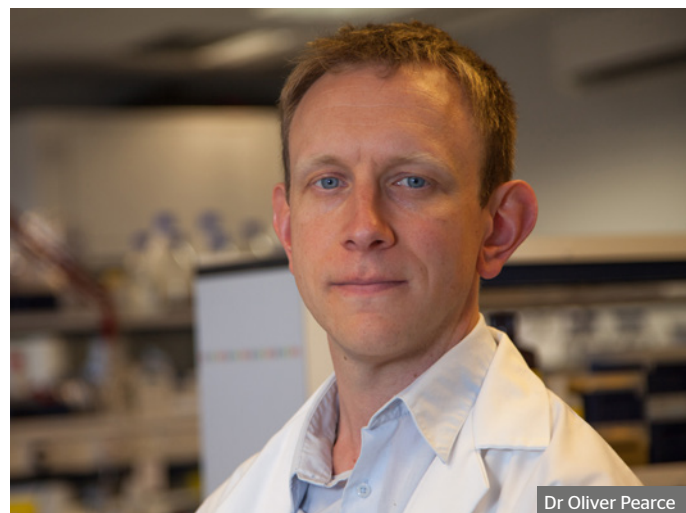
The 6-hour meeting involved 90 oncologists, surgeons, radiation oncologists, and palliative care specialists, mostly from Europe, but also included guest specialists from the USA, Japan, Canada, and India. The main body of the meeting consisted of an extraordinarily thorough discussion of all aspects of EHE management including proper diagnosis, prognosis, treatment of EHE in different organs, the role of systemic therapy, etc. Doctors developed a preliminary consensus on the proposed clinical approaches.

The edited draft will be circulated when ready for final comments, and the final draft will be submitted to the journal *"Annals of Oncology"* for publication.

We could not be more grateful to Dr Stacchiotti, ESMO, and all those who took part, for their time, dedication and the focus given to EHE in this amazing process. We look forward to seeing the final paper once approved.

### Dr Oliver Pearce joins the charity

One of the key objectives of the charity in 2020 was to enhance the research understanding and capabilities of the Board of Trustees. The charity is therefore delighted to be able to confirm that Dr Oliver Pearce, Group Leader at the Barts Cancer Institute in London, joined the Board of Trustees during the third quarter of the year.



Dr Pearce's research group at Bart's is focused on the tumour microenvironment (TME); they are particularly interested in understanding the composition and function of the tumour extracellular matrix in immunosuppression. Dr Pearce brings state-of-the-art cancer research experience onto the Board of Trustees.



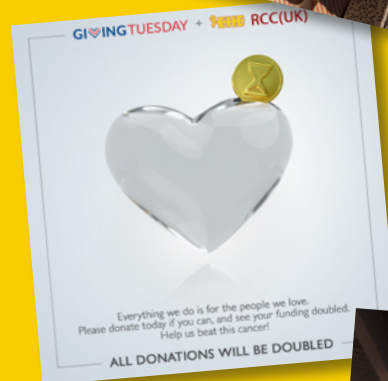
# 03 Fundraising and Finance

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**2020 was a significantly challenging year for all charities. The concept of group activities was no longer possible, bringing a temporary halt to the major fundraising events on the annual calendar. Even small and personal fundraising became very difficult. More importantly, many people faced significant uncertainty regarding their own, immediate future. Even the largest foundations were heavily affected, with their fundraising significantly reduced; meanwhile, for those still able to support important causes, demand for their limited funds became far greater.**

In this environment, the Trustees recognised that it would be extremely difficult for our supporters to continue to fundraise, and that to continue to encourage them to do so was not therefore acceptable. We would of course encourage and assist anyone who chose to fundraise for us, but this would only be in cases of fundraising initiated by our supporters.

Of course EHE did not stop presenting or progressing in patients because of COVID19. EHE research therefore remains as critical today as it did before the COVID19 pandemic, and so fundraising to support that research will continue to be at the core of our activities. We were also confident that as soon as COVID19 restrictions began to ease, our wonderful supporters would re-engage. We were therefore delighted to see that re-engagement beginning as early as the fourth quarter of 2020. We leave the year therefore feeling very positive about 2021!



## Review by Jeff Collins

**2020 was a difficult year but, despite the challenges faced by everybody, fundraising continued, albeit at a lower level than previously enjoyed. We are also excited about the outlook for 2021 and will be working as hard as ever to assist and encourage our wonderful supporters.**

Although significantly curtailed by COVID19, our wonderful supporters were still able to raise an amazing £53,100 in 2020. Their support and dedication was even more important in such difficult circumstances.

Good examples of the challenges faced were the cancellations of both the London Landmarks Half Marathon in late March, and the Prudential RideLondon100 event in July, both core events in our fundraising calendar. While the RideLondon100 event has in fact been permanently cancelled, the London Landmarks Half Marathon will restart in 2021, and we are delighted to already have 40 runners signed up.

We were also delighted to see Charlie Medwin and his colleagues safely complete the Talisker Whisky Atlantic Challenge at the start of the year, rowing more than 2,900 nautical miles to raise more than £25,000 for EHE research, partly in 2019 and partly in 2020.

In 2020, we once again received the generous support of a single donor who funded 100% of the charity running costs. As in all previous years, we segregated these funds, donated for administration purposes, from those received from all other sources, which can therefore be allocated to fund our key objectives, and in particular, EHE research. It is the intention of the Trustees that the same will be true in 2021.

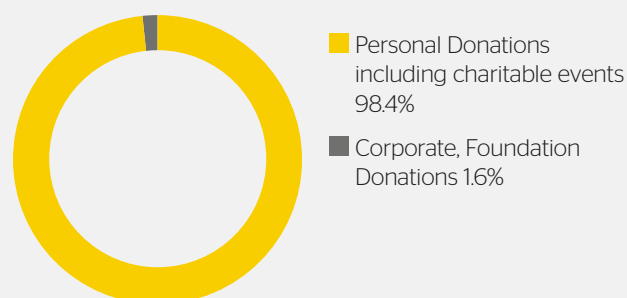
### Key Objectives

In the 2020 calendar year our supporters raised a total of £51,900 for the charity's key objectives.

During 2020, our EHE research projects were suspended for a period in the second quarter, and operated on a restricted basis thereafter. Where possible, the research institutes worked with us to reduce and defer costs during these periods, for which we are very grateful. However, despite these delays, key projects were able to advance and our investments during the year of £118,400 continued to produce interesting results through the year. In addition, we were pleased to receive final ethics approval for the National EHE Biobank, and sign agreements for combined biomarker research between INT in Milan and the ICR in London.

For existing multi-year research projects, the charity has recognised all funding obligations for future years (2021 and beyond). Details can be found in the notes to the financial accounts.

### Source of funds



### Administration/business running costs

The charity received funding of £1,200 for its administration and business running costs account. During 2020, £13,500 of expenses had been incurred, which included an accrual of £1,200 for the independent examiner's fee. The remaining £12,300 funded fundraising events scheduled for 2020, publications and other administrative costs and consulting fees to develop our fundraising strategy. The Charity had sufficient funding from prior year donations to meet these additional costs in excess of the current year donations.

*"Despite the challenges faced in 2020 due to COVID19, we were pleased that our supporters were still able to assist us in raising important funding for critical EHE research. We also worked hard to ensure that costs were minimised and/or deferred in any areas where activity was curtailed during the year, including the research we are funding, and would like to thank all the associated institutes for their support in managing this difficult period. We were also pleased that our underlying policy of ensuring we do not expose the charity to funding commitments beyond our means meant that the challenges faced in 2020 did not at any time threaten any of our activities. This is a policy we will continue to follow. As in all previous years, the wonderful support the EHERCC receives comes in many different forms. I would once again like to take this opportunity to thank all the volunteers who have donated their time so generously, and to the companies and organisations who have provided their services at no or reduced costs. Special mention again goes to SFC Bennett Brookes who for the sixth year running have donated their bookkeeping services to the charity. Thank you."*

**Jeff Collins**

# Wonderful support for EHE in 2020

**The following pages highlight the key fundraising events we were able to complete in 2020.**

## Rowing the Atlantic

Most people will have welcomed in 2020 with friends at a local party, or maybe with family at home, or even tucked up in bed asleep. Charlie Medwin, however, together with Lewis Matthews and Tom Whittle, welcomed the New Year sitting in a small boat in the middle of the Atlantic Ocean. Taking part in the Talisker Whisky Atlantic Challenge, under their team name All-Oar-Nothing, these three brave men were rowing in support of their respective charities. Charlie's chosen charity was the EHERCC, as his younger brother has EHE.

The All-Oar-Nothing team reached the finish line on 20th January after rowing more than 2,900 nautical miles. In the process, Charlie raised more than £25,000 for EHE research. We are so grateful for, and proud of, what these three fantastic men achieved.



## An amazing relay complete

It was on 1st January 2019 that Allana Parker posted news that her four wonderful friends, Natalie Ellis, Samantha Power, Ellen Cramoysan, and Sophie Kitchen, were embarking on a 400-day relay to raise funds for EHE research. These four very determined women each completed an amazing challenge over their 100-day section of the relay under the name EHERelayRaisers, all to help fund EHE research.

Their relay ended on 4th February 2020, and raised an amazing £4,424.49 which was presented to Hugh Leonard, Chair of Trustees, at their Masquerade Ball, held to celebrate the end of their relay. Allana thanked them for their wonderful support and noted that further donations had been promised. Indeed, when the final financial tally was posted by Allana on 19th February, the EHERelayRaisers total was confirmed at an extraordinary £4,964.49.



## Partying the night away

On 15th February Adrianna Glennie decided to celebrate her 40th birthday with a party and gig at the Station Hotel in Stonehaven, Scotland. Adrianna wanted to raise money for two charities that are close to her heart. These are the EHE Rare Cancer Charity and Clan Cancer Support. It was a truly brilliant event with great music into the early hours of the morning.





## Surprise for a mother

Tracey Betts shared news at the start of November of a huge surprise when, without telling her, her son Conor and 13 of his friends launched their campaign to grow moustaches through November in support of Tracey and EHE research.

Conor and his friends, with donations and gift aid, raised a staggering £3,031. That was doubled to more than £6,000 with our Giving Tuesday matched funding that included their campaign. Thank you so much guys! And here is the photographic proof of the moustaches grown!



## What a night!

Allana Parker wanted to do something special to celebrate the end of the amazing EHERelayRaisers 400-day relay. As a group, these five women of boundless energy decided that holding a charity ball shortly thereafter was a great idea. And so, on 8th February, their EHE Masquerade Ball took place. And what a night it was. The event was spectacular with a wonderful setting, fantastic energy and amazing fun had by all who were there. The ballroom was spectacular, and there was also an amazing video backdrop featuring EHE patients from all over the globe, which ran continuously. And soon after the event Allana posted the wonderful news that the Ball and the relay together had raised an unbelievable £11,447.54!



## EHE 2021 Wall Calendar

Our 2021 Wall Calendar initiative was started by Anna Wydro, to bring the EHE community together, but to also raise funds for EHE research. Using 12 photographs submitted by members of our worldwide EHE community, the final calendar looked spectacular. A total of 730 calendars were produced and distributed worldwide, to the UK, USA, Canada, Australia, Italy, Germany, Portugal, Finland, Poland, Greece, Ireland, Holland, Estonia, Hungary, and Belgium. Funds raised for EHE research totalled more than £6,300 or US\$8,500. We thank and congratulate Anna on a great campaign, and Artur Rozwalak who, with Anna, provided the photographic and artistic input that made the calendars so special.



## Donna and Amy raise more than £500

October saw two of Allana Parker's fantastic support network, Donna Watson and Amy Mills, complete their fundraising event for the EHE Rare Cancer Charity ". Donna explained:

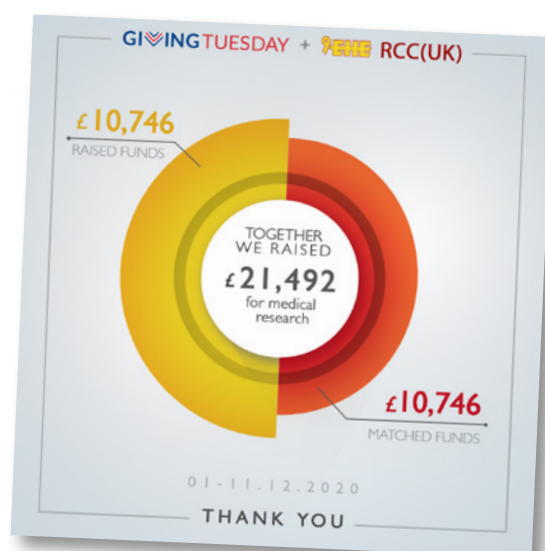
*"Last year was alcohol free for 1 month, and I raised £235! We would love to beat this. This year we are exercising before or after work for 31 consecutive days, biking, walking or running for 2 miles a day, a pretty big challenge for us as we haven't exercised for months."*

So in early November, Allana was thrilled to be able to report that her friends had finished their challenge, raising £502 for EHERCC, topping the £235 they raised last October. *"I'm a very lucky person to have wonderful friends like these!"*



## Giving Tuesday matched-funding a success

2020 was a tough year for charitable organisations across the globe, and the UK was no different. So we were delighted when, at the end of November, a kind benefactor offered to match all Giving Tuesday donations made to the EHERCC up to £10,000. We immediately brought this wonderful offer to the attention of all our supporters. Their generosity, including the donor agreeing that they would include Adrianna's gig in Stonehaven, and Connor's moustache growing buddies, meant that we reached our target, and secured £10,746 in matched funding. We of course send our sincere thanks to the donor who so generously provided the matched funding.



EHE Rare Cancer Charity UK

# Financial Accounts for 2020

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# EHE Rare Cancer Charity (UK)

## Independent examiner's report

### Independent examiner's report to the trustees of EHE Rare Cancer Charity (UK)

I report to the charity trustees on my examination of the accounts of EHE Rare Cancer Charity (UK) (the Charity) for the year ended 31 December 2020.

### Responsibilities and basis of report

As the Trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

### Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the Charity required by section 130 of the Act; or
- 2 the accounts do not accord with those records; or
- 3 the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

*(signed) "RJP LLP"*

**Simon Paterson FCCA**

RJP LLP  
Ground Floor  
Egerton House  
68 Baker Street  
Weybridge  
Surrey  
KT13 8AL

Date: 21 October 2021



# EHE Rare Cancer Charity (UK)

## Statement of Financial Activities

for the period ended 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	<b>Total 2020 £</b>	Total 2019 £
<b>Incoming resources:</b>					
Donations	2	51,867	1,200	<b>53,067</b>	158,445
<b>Total incoming resources</b>		<b>51,867</b>	<b>1,200</b>	<b>53,067</b>	158,445
<b>Resources expended:</b>					
Costs of generating donations		1,186	3,262	<b>4,448</b>	6,744
Charitable activities		118,365	-	<b>118,365</b>	115,653
Governance costs		-	1,200	<b>1,200</b>	1,200
Other administrative costs		99	9,011	<b>9,110</b>	7,148
<b>Total resources expended</b>	3	<b>119,650</b>	<b>13,473</b>	<b>133,123</b>	130,745
<b>Net surplus for the year</b>		<b>(67,783)</b>	<b>(12,273)</b>	<b>(80,056)</b>	27,700
Transfer between funds		-	-	-	-
Balance brought forward		447,339	12,623	<b>459,962</b>	432,262
<b>Funds carried forward</b>	8	<b>379,556</b>	<b>350</b>	<b>379,906</b>	459,962

Funds carried  
forward for 2020  
£379,906

# EHE Rare Cancer Charity (UK)

## Balance Sheet

as at 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	<b>Total 2020 £</b>	Total 2019 £
<b>Current assets</b>					
Debtors	5,9	229,408	1,361	<b>230,769</b>	255,430
Cash at bank and in hand		321,937	3,049	<b>324,986</b>	413,852
<b>Total current assets</b>		<b>551,345</b>	<b>4,410</b>	<b>555,755</b>	669,282
<b>Creditors: amounts falling due within one year</b>	6,9	(108,688)	(4,060)	<b>(112,748)</b>	(105,371)
<b>Net current assets (liabilities)</b>		<b>442,657</b>	<b>350</b>	<b>443,007</b>	563,911
<b>Creditors: amounts falling due after one year</b>	7,9	<b>(63,101)</b>	-	<b>(63,101)</b>	(103,949)
<b>Net assets (liabilities)</b>		<b>379,556</b>	<b>350</b>	<b>379,906</b>	459,962
<b>Funds carried forward</b>					
Unrestricted funds		379,556	-	<b>379,556</b>	447,339
Restricted funds		-	350	<b>350</b>	12,623
<b>Total funds</b>	8	<b>379,556</b>	<b>350</b>	<b>379,906</b>	459,962

The Charities Act requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity at the year end and of the surplus or deficit for the year then ended.

In preparing these financial statements, the Trustees are required to select suitable accounting policies, and then apply them on a consistent basis, making judgements and estimates that are prudent and reasonable. The Trustees must also prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure the financial statements comply with the Charities Act 2011. The Trustees are also responsible for safeguarding the assets of the charity and hence taking reasonable steps for the prevention and detection of fraud and other irregularities.

These accounts were approved by the Trustees Committee on 19 October 2021 and signed on its behalf by:

*(signed) "Hugh Leonard"*

**Hugh Leonard**  
Chairperson

# EHE Rare Cancer Charity (UK)

## Notes to the Accounts

### for the period ended 31 December 2020

#### 1 Accounting Policies

**Basis of preparation:** The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

#### Incoming resources

**Recognition of incoming resources:** These are included in the Statement of Financial Activities when:

- The charity becomes entitled to the resources;
- The trustees are virtually certain that they will receive the resources; and
- The monetary value can be measured with sufficient reliability.

**Deferred income:** Where grants are received in advance and specified by the donor as relating to specific accounting periods, these are deferred on an accruals basis to the period to which they relate.

**Tax reclaims on donations and gifts:** Incoming resources from tax reclaims are included in the Statement of Financial Activities at the same time as the gift to which they relate.

**Incoming resources with related expenditure:** Where incoming resources have related expenditure, the incoming resources and related expenditure are reported gross in the Statement of Financial Activities.

**Volunteer help:** The value of any volunteer help is not included in the accounts.

**Investment income:** Investment income is included in the accounts when receivable.

#### Expenditure and liabilities

Resources expended are inclusive of VAT where applicable which cannot be recovered.

**Liability recognition:** Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.

**Costs of charitable activities:** A research grant is recognised when the Charity formally notifies the recipient of the award following scientific review. The liability is measured as the total of expected payments for the award. Grant payments that are contingent on a successful outcome of and payable after a future scientific review are disclosed as commitments. Liabilities for awards payable more than one year after the balance sheet date are recorded at the value the Charity expects to settle the grant or award.

**Governance costs:** These include the costs of preparation and examination of statutory accounts, the costs of any general meetings and the costs of any legal advice to trustees on governance or constitutional matters.

#### Administrative fund

This fund has been established by the Trustees to fund all governance and administrative costs and is funded by a single donor for these restricted purposes.



## 2 Analysis of incoming resources

### Donation income:

	2020 £	2019 £
<b>Unrestricted funds:</b>		
Personal donations including fundraising events	51,055	88,098
Payroll Giving	-	8,813
Corporate and Foundation donations	812	38,848
	51,867	135,759
<b>Restricted funds:</b>		
Administration fund	1,200	22,686
	1,200	22,686

## 3 Analysis of resources expended

	Unrestricted funds £	Restricted funds £	Total 2020 £	Total 2019 £
<b>Costs of generating donations:</b>				
Just giving fees	425	562	987	1,580
Fundraising event entry and other fees	-	2,700	2,700	4,286
Credit card and other processing fees	761	-	761	878
	1,186	3,262	4,448	6,744
<b>Costs of charitable activities:</b>				
University of Manchester PhD Study	33,433	-	33,433	45,535
Royal Marsden Biobank	56,000	-	56,000	30,333
Zebrafish Study University of Sheffield	28,932	-	28,932	22,105
Contributions to Albany Medical College	-	-	-	15,789
Telluride Support	-	-	-	1,891
	118,365	-	118,365	115,653
<b>Governance costs:</b>				
Independent examiners' fee	-	1,200	1,200	1,200
	-	1,200	1,200	1,200
<b>Other administrative costs:</b>				
Design and publishing	-	3,810	3,810	4,193
Website maintenance	-	1,750	1,750	1,609
Other professional fees	-	3,348	3,348	1,116
Bank fees	99	103	202	230
	99	9,011	9,110	7,148

### Trustees' expenses

No expenses were paid to Trustees during the period (2019 - £363).

## 4 Taxation

The Charity is exempt from Corporation Tax on its charitable activities.

# EHE Rare Cancer Charity (UK)

## Notes to the Accounts (continued)

### for the period ended 31 December 2020

#### 5 Debtors

	Unrestricted funds £	Restricted funds £	<b>Total 2020 £</b>	Total 2019 £
Prepayment to the University of Manchester	94,269	-	<b>94,269</b>	127,702
Prepayment to Royal Marsden	51,333	-	<b>51,333</b>	81,667
Prepayment to Fondazione IRCSS Istituto Nazionale Dei Tumori	67,840	-	<b>67,840</b>	-
Prepayment to the University of Sheffield	-	-	<b>-</b>	28,932
Other debtors	15,966	1,361	<b>17,327</b>	17,129
	<b>229,408</b>	<b>1,361</b>	<b>230,769</b>	255,430

Included within the debtors figures above are amounts of £63,101 (2019 – £103,949) due after more than one year.

#### 6 Creditors: amounts falling due within one year

	Unrestricted funds £	Restricted funds £	<b>Total 2020 £</b>	Total 2019 £
University of Manchester	49,101	-	<b>49,101</b>	49,420
Royal Marsden	25,667	-	<b>25,667</b>	30,333
Fondazione IRCSS Istituto Nazionale Dei Tumori	33,920	-	<b>33,920</b>	-
University of Sheffield	-	-	<b>-</b>	21,699
Accrued independent examiners' fee	-	1,200	<b>1,200</b>	1,200
Other creditors	-	2,860	<b>2,860</b>	2,719
	<b>108,688</b>	<b>4,060</b>	<b>112,748</b>	105,371

#### 7 Creditors: amounts falling due after one year

	Unrestricted funds £	Restricted funds £	<b>Total 2020 £</b>	Total 2019 £
University of Manchester	29,181	-	<b>29,181</b>	78,282
Fondazione IRCSS Istituto Nazionale Dei Tumori	33,920	-	<b>33,920</b>	-
Royal Marsden	-	-	<b>-</b>	25,667
	<b>63,101</b>	<b>-</b>	<b>63,101</b>	103,949

#### 8 Details of funds

##### Administrative Fund

This fund has been established by the Trustees to fund all governance and administrative costs and is funded by a single donor for these restricted purposes.

## 9 Commitments and contingencies

In July 2018, the Charity contracted with the **Bateson Centre at the University of Sheffield** to develop an EHE zebrafish model. In August 2019, a second phase of the project was agreed with two payments required in August 2019 and February 2020 of £21,699 each. The first payment was made in 2019 and the second in 2020 as contracted. There are no further scheduled payments and the project came to a close in 2020 with total project expenses of £28,932 recorded in 2020 (2019 - £22,105).

In October 2018, the Charity contracted with the **Department of Developmental Biology and Medicine at the University of Manchester** for the carrying out of a four year PhD study to research the impact of EHE on endothelial cells. The total cost of the contract was £173,237 to be incurred over four years from January 2019 as follows:

2019	£45,535
2020	£49,420
2021	£49,101
2022	£29,181

In 2020, £49,420 of payments were made and recorded as charitable activity cost offset by £15,987 of amounts refunded as not spend during 2018 and 2019 (2019 - expense of £45,535). The amounts committed to for 2021 and 2022 have been included within Debtors and Creditors as appropriate.

In April 2019, the Charity contracted with the **Royal Marsden Trust** to fund a two-year position of Tissue Manager with the Royal Marsden and ICR Sarcoma Research Centre. The project commenced in 2019 with a total cost of £112,000 over two years commencing from the date of hire of the Tissue Manager on 17 June 2019. In 2020, the second payment of £56,000 was made and £56,000 recorded as charitable activity cost (2019 - payment of £56,000 and £30,333 as charitable activity cost). No further payments are required and remaining prepayments and expenditures have been included within Debtors and Creditors as appropriate, which will be recognized in the Statement of Financial Activities in 2021 when the expenditures to which they relate are incurred.

In December 2020, the Charity contracted with the Fondazione IRCCS Istituto Nazionale Dei Tumori in Italy and the Institute of Cancer Research: Royal Cancer Hospital, UK to fund a project to assess the presence of novel biomarkers in EHE patient blood and tissue samples to inform patient management as well as potential therapeutic targets. The total costs of the project is €115,000 (£104,020) to be incurred over a maximum of 30 months and separately, the Charity agreed that the EHE Foundation based in the United States would fund €40,000 (£36,180) of the total costs. The remaining €75,000 (£67,840) payable by the Charity has been included in Debtors and Creditors as appropriate.

## 10 Subsequent events

During 2021, it was confirmed that amounts forwarded to the Sarcoma Alliance for Research through Collaboration (SARC) in 2020 to fund a biopsy of US\$5,000 (£4,048) were not required and were therefore returned to the Charity in 2021. An amount of US\$5,000 (£4,048) has therefore been recorded as a Debtor in 2020 (2019 - £Nil).

In March 2021, the Charity agreed to fund costs associated with the establishment and administration of an EHE Biobank with the Royal Marsden Cancer Charity and the Royal Marsden NHS Foundation Trust with an estimated total cost of £38,750 over five years commencing in April 2021, when the first payment was made. As the commitment was not incurred as at the balance sheet date, no amounts have been recorded as liabilities in the 31 December 2020 financial statements.

In July 2021, the Charity contracted with the Bateson Centre at the University of Sheffield to fund a one-year, full-time MPhil student to further assess the EHE zebrafish model that the Charity had funded in 2018 through 2020. The total cost of the project is £52,965 and commenced in July 2021.

With the recent and rapid development of the Coronavirus outbreak, the Charity has considered the unique circumstances and the risk exposures of the Charity and has concluded that there is no immediate material impact to the Charity's financial position. The Charity will continue to monitor the situation closely and will re-assess in case the period of disruption becomes prolonged.



# Trustees' Declaration

As Trustees of the EHE Rare Cancer Charity (UK), the undersigned have fully reviewed the content of this Report of the Trustees and confirm that they each consider it to be a true and fair reflection of the EHERCC's activities and operations for the year ending 31st December 2020. They each confirm that there are, to the best of their knowledge, no exceptional or special events that have occurred or that should be reported.

The Trustees also confirm that they have undertaken their respective roles and responsibilities with due regard to the public benefit requirements of the charity, and have taken into account the Charity Commission's public benefit guidance when making any decision and producing any reports relating to EHERCC's charitable objects and its associated activities.

Signed this 22nd day of October, 2021

*(signed) "Hugh Leonard"*  
**Hugh Leonard** Chair of Trustees

*(signed) "Jeff Collins"*  
**Jeff Collins** Trustee

*(signed) "Kate Hooper"*  
**Kate Hooper** Trustee

*(signed) "Oliver Pearce"*  
**Oliver Pearce** Trustee

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## Charity Information

### Charity Name:

The EHE Rare Cancer Charity (UK),  
A Charitable Incorporated Organisation (CIO)

### Also known as:

Also known by its acronym, EHERCC

### Charity number:

1162472

### Web address:

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

### Registered address:

23 Geneva Road, Kingston Upon Thames,  
Surrey, KT1 2TW

### Charity Trustees:

Mr Hugh Leonard (Chair)  
Mr Jeffery Collins  
Dr Katharine Hooper  
Mrs Elizabeth Milligan (resigned 10.3.2021)  
Dr Oliver Pearce

Established in 2015.

One of three charities (UK, USA and Australia)  
working on EHE.

Managed and run by volunteers.

All running costs funded by single donor.

100% of all donations received therefore available  
to deliver core objectives.

# The Pledge

*The Pledge* is the quarterly newsletter of the EHE group of foundations. It is produced in London and provides details of the groups' worldwide activities in their key areas of advocacy and patient support, research, fundraising, and any other stories of interest. If you would like to be added to the distribution list to receive a copy of *The Pledge* each quarter, please contact your local EHE charity or foundation.





**EHE Rare Cancer Charity (UK)**

23 Geneva Road  
Kingston-Upon-Thames  
Surrey  
KT1 2TW

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

[contactus@ehercc.co.uk](mailto:contactus@ehercc.co.uk)

Registered charity: 1162472



A huge thank you to [eightcreate.co.uk](http://eightcreate.co.uk)  
for the graphics and design work in  
producing this report.



We would like to also thank SFC  
Bennett Brookes for providing  
bookkeeping services to EHERCC



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**Cover images**

Researcher in 2020 COVID pandemic  
Charlie Medwin and friends  
complete their Atlantic row, raising  
more than £25,000 for EHE research