

# ANNUAL REPORT & ACCOUNTS

2020



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## **OUR VALUES**

- PIONEERING WE LEAD THE WAY, WE LEAVE NO STONE UNTURNED, WE ARE PREPARED TO TAKE RISKS.
- DYNAMIC WE DON'T STAND STILL, WE INNOVATE, WE CELEBRATE EVERY SUCCESS.
- SUPPORTIVE WE LISTEN, WE UNDERSTAND, WE CARE.
- KNOWLEDGEABLE WE KNOW OUR STUFF, WE ARE EAGER TO KNOW MORE.
- TRUSTWORTHY WE DO WHAT WE SAY.

## CHAIRMAN'S INTRODUCTION

I would like to start my introduction this year with a tremendous thank you! It cannot be underestimated how grateful we all are at the Bone Cancer Research Trust to every member of the primary bone cancer community. 2020 was an extraordinary year for so many of us, in lots of ways, and never has our charity been put under such immense pressure and strain. But thanks to your unwavering support, we got through it. Today we are stronger and in a better place to continue our work towards finding a cure for this cruel disease.

Over the last five years we have worked hard to diversify and grow our income. This improved financial position allowed us more flexibility and options to plan and track a course through the challenges brought by the COVID-19 pandemic. Sadly, some roles within our charity were no longer viable and we had to say goodbye to four colleagues. However, we continued to be proactive, making use of all financial options available to us and testing new fundraising approaches. Our entire staff and trustee team became involved in our fundraising efforts and ultimately, with your support, we turned the tide on the impact of COVID-19 and raised £2,756,042 for our life-saving work.

Despite the challenges, throughout the year we wasted no time in ensuring we continued serving our beneficiaries and the whole primary bone cancer community as best we could. The increased pressure, uncertainly and stress put on our patients and their families meant our Support & Information Service saw huge increases in service users. As physical events were no longer possible, we turned to virtual solutions to reach and support all families that needed our help or dedicated information.

We continued to work hard building and developing collaborations with external organisations. One particular highlight was the Bone Cancer Awareness Initiative, which was informed by our 2020 Patient Survey report. This 100-day campaign allowed us to reach and educate more healthcare professionals on the signs, symptoms and referral pathways of primary bone cancer than ever before in our history. 368,642 education resources were sent to every GP, Radiology Department, Medical School, MACP Physiotherapist and Pharmacy across the UK.

At the heart of everything we do at the Bone Cancer Research Trust are our patients and their families. And our mission to save lives and improve outcomes remains focused on funding pioneering new research. Sadly, the COVID-19 pandemic did slow us down, with many of our research laboratories closed and some of our researchers being re-assigned to COVID-19 testing and treatment development. However, during that time we did all we could to ensure the funding and support is in place to allow our researchers to go back to their laboratories and pick up where they left off with the least disruption possible.

I am delighted to share with you that, because of your support, we have been able to designate over £450,000 to new research that will be awarded in 2021. Our unwavering commitment to our research programme is ensuring the treatments of the future are being developed now and no matter the challenges we face, we will remain steadfast in our fight against this cruel disease... Until there's a cure.

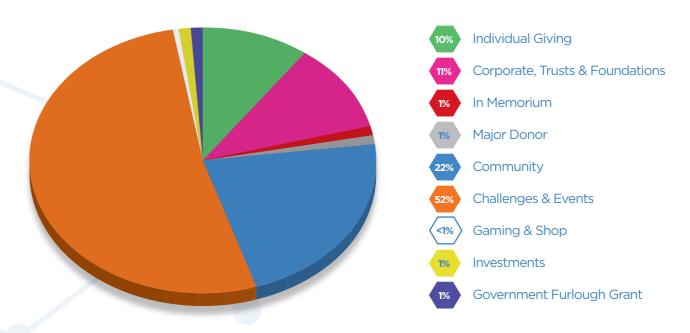


Andy Lewis Chairman

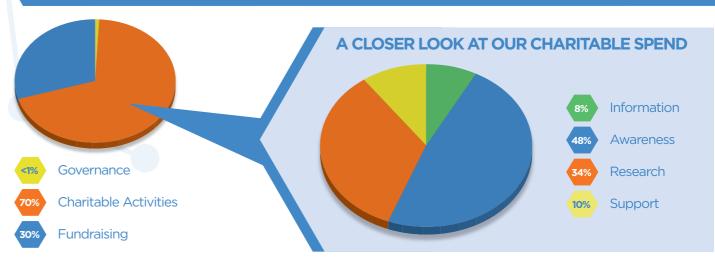


## INCOME & SPEND

#### Our income in 2020 totalled £2,756,042. This came from:



#### Our total expenditure in 2020 was: £1,349,681





During 2020 a further £489,000 (not included in the charts above) was committed to future research due to take place from 2021 onwards.

THIS TAKES THE AMOUNT THAT WE HAVE COMMITTED TO CHARITABLE ACTIVITIES IN 2020 TO £1,428,702

## 2020 IN NUMBERS





26,500,000		Our awareness activities reached over <b>26,500,000</b> individuals through social media around the world
20,000,000	£	Over <b>20,000,000</b> steps were completed during June for Step Up for Bone Cancer
13,500,000	<b>F</b> )*	Our press and media activities reached 13,500,000 individuals across the UK
2,102,152	也	We have now awarded <b>£2,102,152</b> to pioneering new research as part of our 2017-2022 Grant Programme
718,823	É	An incredible <b>718,823</b> miles were ran, jogged or walked to support our life-saving work
210,405	i	210,405 individuals accessed our online information pages
207,830		Our social media supporters grew to <b>207,830</b> from around the world
138,487	0	138,487 people accessed our patient stories as a source of information and support
25,000	É	A record number of over <b>25,000</b> individuals took part in our fundraising events & challenges
18,857	i	Our information resources were downloaded <b>18,857</b> times
5,000		Over <b>5,000</b> copies of United were distributed across the UK
4,828	Ī	Our Step-By-Step Guide for Patients was downloaded <b>4,828</b> times
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4,090		Our healthcare professional symptoms education webinars were attended or watched by <b>4,090</b> individual s
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1 incredible community made all of this possible - our supporters.

That includes amazing people like YOU!

In line with our strategy, **The Biggest Ever Commitment To Primary Bone Cancer**, in July 2017 we launched our new 2017 – 2022 Grant Programme. The below table demonstrates the progress of this programme to date:

#### 2017-2022 Grant Programme

GRANT TYPE/YEAR	2017	2018	2019	2020	2021	2022
CLINICAL / TRANSLATIONAL		1				
EARLY CAREER FELLOWSHIP						<b>✓</b>
PHD STUDENTSHIP		11		1		
INFRASTRUCTURE GRANTS	// //	111	/// //	111	<b>JJJ</b>	
EXPLORER	11	1	//	1	11	<b>✓</b>
IDEAS	11	<b>✓</b>	//	111	<b>✓</b>	<b>✓</b>
OTHER RESEARCH INVESTMENT	1	1	1	1	<b>✓</b>	<b>✓</b>

✓ AWARDED AS PLANNED ✓ ADDITIONAL UNPLANNED AWARD ✓ CALL CANCELLED DUE TO ADDITIONAL PHD STUDENTSHIP ✓ PLANNED ✓ GRANT AWARD DEFERRED TO 2020 ✓ GRANT AWARD DEFERRED TO 2021 DUE TO COVID-19 DISRUPTION

The COVID-19 pandemic affected the activities of our Infrastructure Grants, with partial or total pausing of patient recruitment and sample collection and processing; therefore the 2020 grant awards were moved to 2021.

#### **New Grants awarded in 2020**

LEAD RESEARCHER	PROJECT TITLE	GRANT TYPE	AWARD VALUE
Dr William Cross	Posthumous evaluation of a high-grade widely disseminated chondrosarcoma through analysis of its evolutionary history	Explorer	£70,000
Dr Katie Finegan	Targeting the MEK5-ERK5 pathway: a novel approach to treat Adamantinoma?	Ideas	£23,432
Dr Mark Morris	Identification of novel biomarkers for the management of Adamantinoma	Ideas	£21,000
Professor Alison Gartland	The Role of Oestrogen in Chondrosarcoma Using Patient-Derived Xenograft Mouse Models: A Pilot study	Ideas	£20,000
Professor Paul Cool	Sample collection support - Oswestry	Infrastructure	£21,295.29
Professor Sibylle Mittnacht	Bone-in-culture as an orthotopic platform for the study of patient-near tumour grafts and bone cancer initiation	PhD Studentship	£37,139

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## RESEARCH



2017-2022

As we entered 2020, we continued to build on the momentum from previous years. Our 2017-2022 Grant Programme continued as planned, and we were delighted to award an Explorer and PhD Studentship Grant. As our research community began to feel the impact of the pandemic, research laboratories closed and many researchers were furloughed or reassigned to support the national response to COVID-19. Our priority was to ensure our research would continue, therefore we worked closely with the Association of Medical Research Charities and engaged with all funded researchers to provide them with extensions to projects and ensure resources were in place when projects could re-commence.

Our first research grant award of the year was to Professor Sibylle Mittnacht to support a PhD Studentship. This work will be undertaken at University College London and aims to develop a new 3D model of bone to test the effectiveness of new drug treatments for osteosarcoma. Unfortunately, due to the unfolding situation caused by COVID-19, it was not possible to recruit a PhD student to start the work in 2020. A student will be recruited in early 2021 to undertake this project as they start their academic year from October. We would like to thank the Clive & Sylvia Richards charity for supporting this innovative new project and our aim to build the next generation of primary bone cancer researchers.

On World Cancer Day, we launched our new Skills Development Grants to enable researchers to gain new skills and experience in laboratories around the UK and internationally. Sadly, COVID-19 meant that none of these grants could be awarded in 2020, however, they will resume in 2021 when travel restrictions allow.

In March we were delighted to award our first ever tumour evolution project. This Explorer Grant was the first of its kind and was awarded to Dr William Cross at University College London to explore how chondrosarcoma develops and progresses. It is our hope that this project will improve the way we monitor chondrosarcoma patients and allow the identification of patients who may progress to advanced disease.

At the Bone Cancer Research Trust, we are passionate about bringing the primary bone cancer community closer to our research. We would normally approach this through lab open days and presentations, Q&As and discussions at our Bone Cancer Conference. Unfortunately, none of these were possible in 2020 and we had to innovate our approach. In response to the situation, we launched '#BiteSizeResearch', a series of 8 webinars with leading researchers from across the UK. These virtual events were a great success, attended by hundreds of individuals from across the UK and around the world. For the first time. this approach allowed us to remove geographical barriers and allow our supporters and members of the clinical and research community to engage with our research.

As part of our continued commitment to only fund the highest-quality research with maximum benefit for Ewing sarcoma patients, we recognised that to stimulate more research in the field, extending our grant applications to international applicants would be beneficial. Therefore, we launched our first ever international research grant call. This was a great success with 5 applications being

received from overseas and 8 applications overall. As a result, we began the process to award our first ever International Grant to Professor Aykut Üren from Georgetown University in Washington, DC, USA. The project is due to be awarded and commence in 2021.

Collaboration and coordination are key to accelerating progress in primary bone cancer research. In October, as part of Bone Cancer Awareness Week, we held our first ever International Ewing Sarcoma Research Symposium which was hosted by Professor Sue Burchill from the University of Leeds. The event brought together over 100 clinicians and researchers from across the world to understand the current research landscape and determine priorities for future collaborative research. The day culminated in the launch of our second international research grant call focused on Ewing sarcoma.

Due to the impact of the pandemic on the five NHS bone cancer surgical centres in England, it was not possible to continue patient consent and sample collection. As a result, our Infrastructure Grants were put on hold until such time that it is safe for NHS staff to resume this work. Despite this challenge, 2,852 samples that had already been collected from patients were still released to support 10 primary bone cancer research studies. In addition, one centre, The Nuffield Orthopaedic Centre, Oxford, successfully recruited a Clinical Fellow who will be dedicated to sample collection when the activity resumes.

Following our first Chondrosarcoma Trial Development Workshop in 2019 and our dedicated chondrosarcoma research grant call, we were pleased to award an Ideas Grant to Professor Alison Gartland at the University of Sheffield. For some time, there has been anecdotal evidence suggesting a link between levels of Oestrogen and chrondrosarcoma development. Professor Gartland has assembled a team of experts to explore the topic further and give us new insight into chondrosarcoma biology.

Despite all the challenges throughout 2020, we are proud of the progress we were still able to make. A particular highlight was the launch of the first ever Adamantinoma Research Programme in November with the award of two exciting Ideas Grants. Dr Katie Finegan from the University of Manchester and Professor Mark Morris from the University of Wolverhampton will lead this new research programme which aims to identify predictive biomarkers and new treatment options. This programme of research has been made possible thanks to The Liz Clarke-Saul Fund and is dedicated to her.

## WHAT WE SAID WE'D DO & WHAT WE DID.

#### We will commit over £2.8 million to pioneering research through an innovative new grant programme.

Our total investment into pioneering research in 2020 was £319.094, which includes the award of 6 new research grants. This brings our 2017-2022 total investment to £2,102,152.

#### We will support research at all levels, from initial idea through to clinical trial.

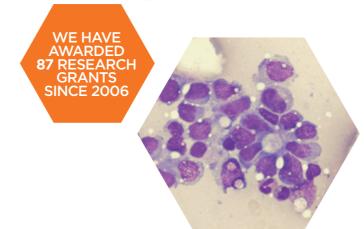
Throughout the year, we funded three Ideas Grants to start research into three new areas of study and an Explorer Grant to undertake an already developed and substantive project.

#### We will deliver the next generation of world class, primary bone cancer researchers.

During 2020, we were delighted to award our 9th PhD Studentship, bringing another talented individual into the field of primary bone cancer.

#### We will continue to support UK surgical centres to enable all primary bone cancer patients to contribute tissue samples for use in research.

Due to difficulties faced, only one Infrastructure Grant award was made in 2020 to The Robert Jones And Agnes Hunt Orthopaedic Hospital, Oswestry. All of our Infrastructure Grants will resume in 2021.



# WHAT WE'RE GOING TO DO IN 2021...

- We will regain ground lost in 2020 by investing at least £1million into research, more than ever before in our history.
- To celebrate our 15th anniversary in 2021, we will launch an unrestricted Anniversary Grant Call accepting wide ranging ideas and grant types to stimulate new and innovative research in the field of primary bone cancer.
- We're going to continue to support all stages of research by opening applications for PhD studentship funding and we will launch our first ever Early Careers Fellowship to support the most talented individual to start building their own research programme.
- Following the success of previous symposia. we will hold our second International Ewing Sarcoma Research Symposium, our second Osteosarcoma Symposium and a further workshop to continue driving forward research into chondrosarcoma.
- Following the successful initial stages of our PhD Studentship focused on improving Methotrexate as a treatment for osteosarcoma, we will fund the next stages of research bringing it ever closer to patient benefit.
- In response to our growing scientific community and demand for research funding, we will expand our Independent Scientific Advisory Panel and will look to include new international representation.



## INFORMATION



2017-2022

2020 was the first full year that our Support & Information Service was available for the primary bone cancer community. Throughout the year we saw unprecedented demand, with 210,405 individuals accessing our online dedicated information pages from around the world. We're proud to continue being the go-to organisation for accurate information for all forms of primary bone cancer and tumours.

As the impact of COVID-19 unfolded, it became clear that primary bone cancer patients and their family members needed up-to-date, clear information in light of the current situation. We joined weekly briefings delivered by NHS England specifically for cancer charities to understand the full impact on our community. We created a new dedicated information page on our website to disseminate clear and accurate information to inform individuals on the changes to cancer services and potential risks to current and former cancer patients. This page was accessed 8,118 times during 2020.

In February, we attended the annual Sarcoma Patients EuroNet Association Conference where we showcased our on work delivering the annual Bone Cancer Conference and ICONIC, our observational clinical trial focused on osteosarcoma in the UK. Additionally, we distributed our information materials to international delegates for dissemination in their home countries. We also continued to proactively send information resources to individuals overseas when requested.

Across the year, we continued to diversify the format of our information provision to reach as many individuals affected by primary bone cancer as possible. In July, we introduced a new series of 9 information webinars covering topics currently not within our information portfolio. These covered various themes, including late effects of treatment, financial support, palliative care and rehabilitation, understanding proton beam therapy, getting back into fitness, diet, body image and fertility. These webinars were made available online and distributed to healthcare professionals and other organisations. Across 2020, they were viewed 1,171 times.

As our Support & Information Service developed, our links with external organisations grew and strengthened. To ensure the primary bone cancer community had access to all assisting organisations, we undertook a full review of our online signposting hub and now actively provide this information through our Support & Information Line.

OUR STEP-BY-STEP GUIDE FOR PATIENTS WAS DOWNLOADED

4,828 TIMES IN 2020

To ensure our information is accurate and up to date with new emerging treatment protocols, we began an extensive review of our online and offline information resources. To complete the project we assembled a panel of researchers, clinicians, and patients. Part of this work also includes the discontinuation of the Information Standard kitemark. We expect this work will be completed by the end of 2021.

During Bone Cancer Awareness Week and as part of our continued commitment to provide information for the clinical and medical community, we developed 8 new information resources on the signs, symptoms and referral pathways for primary bone cancer and tumours.





WHAT WE SAID WE'D DO & WHAT WE DID.

## We will develop a Patient / Parent Pack to offer comprehensive information to all patients on their specific primary bone cancer or tumour type.

During 2020, our Step-By-Step Guide for Patients was downloaded 4,828 times from our website. Postal copies were also distributed upon request.

#### We will expand our existing portfolio of information for patients of all ages.

We saw unprecedented national and international demand for our two children's books in 2020. Harry has an Operation was downloaded 3,473 times and Abbie has Osteosarcoma was downloaded 3,690 times.

#### We will expand our basic information to ensure patients in other countries have access to relevant information.

Throughout the year, we actively disseminated our information resources internationally. Online, our information pages were access 810,501 times from individuals outside the UK. Top international countries accessing our information included the USA, South Africa, Ukraine, Russia, Italy and Germany.

## We will ensure that information is available for the clinical and medical community.

In 2020, we saw a 30% increase in usage of our online hub for healthcare professionals which was accessed 1,429 times.

During the year, our Support & Information Team proactively built new relationships with healthcare professionals across the UK and shared information webinars with our network to aid professional training and patient information provision.

## We will develop information for carers and families of patients with primary bone cancer.

We held 60 in-person and virtual support and information events throughout the year, providing direct information to hundreds of individuals affected by primary bone cancer.

### We will accurately signpost relevant information that falls outside our remit.

Our signposting hub was re-launched during the year, containing all known third-party organisations and charities that can further support members of the primary bone cancer community.

# WHAT WE'RE GOING TO DO IN 2021...

- We will launch our revised information resources throughout the year.
- We will conduct a full review of our online information and re-launch our digital-based resources.
- We will continue to deliver information-based webinars to help the primary bone cancer community.
- We will deliver new specific resources around amputation to aid patients and family members faced with this type of surgery.
- We will begin a review of our Step-By-Step Guide for Patients.





## **AWARENESS**



2017-2022

Increasing awareness of primary bone cancers and tumours remains of paramount importance, both amongst the public and healthcare professionals. Since 2006, we have continually been contacted by patients and family members reporting significant delays with diagnosis; 2020 was no exception.

As we embarked upon the year, we had intended to start a new large-scale project focusing on healthcare professional awareness in the UK. To lead the project, we recruited a new team member. However, as COVID-19 started to impact us as a charity, it became clear that this work could no longer continue as originally envisioned. Sadly, we said goodbye to our newly appointed Awareness Executive before work could really get underway.

During the year, we ran multiple campaigns to raise public awareness of primary bone cancer, including Sarcoma Awareness Month, World Cancer Day, Rare Diseases Day, Sarcoma Awareness Month, Childhood Cancer Awareness Month and our own event, Bone Cancer Awareness Week. Combined, our campaigns reached millions of individuals across the UK and internationally. Many families shared poignant personal experiences of their journey with primary bone cancer to educate on the signs and symptoms and improve understanding of the disease. Our thanks go out to all who got involved, shared their story and helped spread the word.

As part of Sarcoma Awareness Month, and in collaboration with Children with Cancer UK, we launched the Bone Cancer Awareness Initiative. This 100-day campaign aimed to reach and educate all GPs, medical students, radiology departments, musculoskeletal physiotherapists and pharmacies in the UK.

The first stage of the Bone Cancer Awareness Initiative was the launch of a survey, focusing on symptoms and routes to diagnosis experienced by patients. In total, 739 responses were received; 312 from the UK. This invaluable data went through thorough statistical analysis. Findings were compiled and included in our 2020 Patient Survey report - the most comprehensive analysis of presenting symptoms and routes to diagnosis for primary bone cancers & tumours in the UK to date.

Data from our findings was used to inform the development of 8 new information resources specifically for the 5 key healthcare professional groups included in the initiative. For the first time ever, data from our survey was used to create anatomical site-specific information and guidance for presenting symptoms of primary bone cancers and tumours. To ensure these new resources were robust, we assembled an expert Taskforce of clinicians and healthcare professionals representing each of the target groups.

Our 100-day campaign culminated in Bone Cancer Awareness Week. During the week, 368,642 education resources were distributed to 10,771 GP practices, 1,542 radiology departments, 44 medical schools, 586 MACP registered musculoskeletal physiotherapists and 12,811 pharmacies across the UK. This was the single largest primary bone cancer awareness campaign ever in the UK. To reinforce the information in these packs, we held 4 healthcare-specific webinars with our Taskforce members. These were attended by 2,038 healthcare professionals. The webinars were also made available online after the campaign where they have been watched a further 3,374 times.

I thought it was excellent. I have never received training in this area in 20 years of practice. I think your resources are very helpful and will be sharing with management.

A physiotherapist who attended one of our webinars

Alongside educating healthcare professions, our Bone Cancer Awareness Week campaign reached over 5 million members of the public across the UK and internationally.

In November, the British Orthopaedic Oncology Society invited us to present findings from our campaign to update members of the clinical community on the in-depth symptoms reported in our survey and the current situation being faced by patients when seeking a diagnosis.

368,642

**EDUCATION RESOURCES WERE SENT TO:** 

10,771

**GP SURGERIES** 

**RADIOLOGY DEPARTMENTS** 

44

**MEDICAL SCHOOLS** 

**MUSCULOSKELETAL PHYSIOTHERAPISTS** 

12.811

**PHARMACY PRACTICES** 



We will ensure all GPs in the UK have access to the training and tools they need to identify and diagnose primary bone cancer.

As part of the Bone Cancer Awareness Initiative, 172,336 education resources were sent to every registered GP practice in the UK. These resources are now also available online as well as educational webinars delivered during Bone Cancer Awareness Week.

We will develop tools to allow radiographers, physiotherapists, and other medical professionals to identify the symptoms of primary bone cancer.

We worked with a Specialist Orthopaedic Oncology Physiotherapist and a Consultant Musculoskeletal Radiologist to develop new education resources that will improve understanding of the presenting symptoms of primary bone cancer. During Bone Cancer Awareness Week, 26,276 of these resources were distributed across

#### We will continue to fund and develop training options for medical students in the field of primary bone

As part of the Bone Cancer Awareness Initiative, we created new flashcards and posters to aid medical student education on the presenting symptoms of primary bone cancer and onward referral pathways. These were shared with all 44 medical schools in the UK.

#### We will increase national and where possible, international public awareness of primary bone cancer and the Bone Cancer Research Trust

Throughout the year we delivered various national and international public awareness campaigns via social media and press. In total, we achieved a reach in excess of 40.000.000 in 2020.

# WHAT WE'RE GOING TO DO IN 2021...

- We will work with new partner charities to continue educating healthcare professionals.
- We will begin a second phase of the Bone Cancer Awareness Initiative which will focus on educating healthcare professionals that are likely to encounter patients with primary bone cancer in the head and neck.
- We will request and analyse Public Health England data to understand primary bone cancer incidence, survival and the routes to diagnosis. This information will be used to inform our onward campaigns and public information.







## **SUPPORT**



2017-2022

As the country dealt with the COVID-19 pandemic, our primary focus was to support our patients and their families. Through our Support & Information Service, we responded rapidly to changing circumstances and reimagined our delivery methods. Turning to online solutions and through greater promotion of our Support & Information Line, we saw an 82% increase in enquiries from the primary bone cancer community.

At the annual Sarcoma Patients EuroNet Association Conference in February, we were delighted to be awarded a Silver Advocacy in Action Award for the Bone Cancer Conference, our flagship support event. To allow more people to attend, in 2020 we were planning on holding two Bone Cancer Conferences; one in the north of England and one in the south. Whilst we were still able to hold two Support & Information Days at the Robert Jones And Agnes Hunt Orthopaedic Hospital and the Freeman Hospital, unfortunately, due to COVID-19 no further events could take place.

To ensure we could continue offering direct support to our community, we turned to online solutions and established a weekly virtual support group as well a series of patient-centered webinars. These events removed geographical barriers and provided vital peer-to-peer support for hundreds of individuals. As ongoing sources of support, our webinars were made available online where they were watched a total of 2,649 times in 2020. Our virtual support groups were also attended 305 times.

We'd both really like to thank you for all the support you've given us, especially during lockdown. It's made a huge difference being able to have the Virtual Cuppa every week to know that we can talk to and learn so much from the rest of the group that are also so affected.

During 2020, our Support & Information Line had contact with 646 patients and family members. Amongst others, a continued theme reported by our community was the cost of travel when undergoing proton beam therapy treatment. In response to this, we launched our Travel Assistance Grants, a one-off financial support grant for patients undergoing proton beam therapy treatment at The Christie Hospital, Manchester. Since their launch in June, we have awarded this grant to 21 patients.

The BCRT grant has been a massive help for patients travelling to the proton centre in Manchester.

In addition to supporting adult patients and family members during the pandemic, our Support & Information Team partnered with Henry Dancer Days to deliver 'Virtual Storytime' sessions for children between the ages of 5 and 11. These sessions were available to patients and children of patients to provide a fun and engaging experience. One patient, whose children took part in a Virtual Storytime said:

They were so happy after the stories.
They loved it so much, especially the funny books and my son keeps asking when he's having another story.

During 2020, we also tested virtual support formats specifically for teenage & young adult audiences. After consultation with key professionals and patients, we launched a three-monthly evening social event offering an escape and chance to engage with others of similar ages. These are now part of our ongoing service.

In addition to direct users of our Support & Information Service, 138,487 people accessed our online patient stories, and 1,007 individuals are now members of our 9 online digital support groups. This is a 120% increase in membership since 2019. These aspects of our service offer individuals a chance to connect with others who have faced similar experiences and reduce feelings of isolation and anxiety of the unknown.

# WHAT WE SAID WE'D DO & WHAT WE DID.

#### We will provide a listening ear service that allows current patients or family members to talk with someone that has been through a similar experience.

As part of our Support & Information Service, our dedicated phone line, virtual support groups, digital support groups and live webinars all offer the chance for individuals to connect with others and have an opportunity to talk and share their personal experiences with people who understand.

#### We will develop digital 'community' support groups.

In 2020 we launched a 9th digital support group specifically for ameloblastoma patients. At the end of 2020, we had 1,007 members across all of our groups.

## We will deliver an annual conference aimed at uniting and supporting our community.

Unfortunately, due to the COVID-19 pandemic, we were unable to hold a Bone Cancer Conference. We are hopeful that we will be able to hold at least one in 2021, with the possibility of this event being virtual should social distancing measures still be in place.

## We will actively promote the sharing of patient stories and experiences.

In 2020 the number of patient stories available on our website grew to 159, covering almost all types of primary bone cancer and tumour. These were actively shared with our community throughout the year. In addition, we held 8 patient story webinars which are now also available online as ongoing support resources.

## We will ensure robust signposting to other support groups and charities where we cannot provide assistance.

We continue to work with third parties, referring to their services where we cannot provide assistance or where their service will be of benefit to our Support & Information Service users.

# WHAT WE'RE GOING TO DO IN 2021...

- We will expand our range of Financial Assistance Grants for patients and their families.
- We will hold a Bone Cancer Conference if social distancing restrictions allow.
- We will continue to provide new digital-based services to the primary bone cancer community, ensuring no one has to face a diagnosis or treatment of primary bone cancer alone.



## OUR FUNDRAISING APPROACH & RESPONSE TO COVID-19

2020 was a year like no other for our fundraising. From a situation which could have put unprecedented and long-lasting strain on our charity, we responded quickly with innovative new approaches that enabled us to continue fundraising throughout the pandemic. Our incredible supporters stayed by our side and through their inspirational efforts, £2,756,042 was raised for our life-saving work.

We started the year in a strong position, by mid-March our income increasing 24% on the same period from 2019. However, following the introduction of the UK's first national lockdown, we saw our income drop dramatically as supporters could no longer undertake their fundraising activities. During the second quarter of the year, our income had fallen by 69% compared to the same period in 2019 and we were forecasting a potential £690,000 loss of income by the end of 2020.

As the impact of the pandemic began to affect our finances and ability to fundraise, we quickly started research into new fundraising approaches and testing of new activities. We also participated in new national campaigns, created in response to the pandemic. Hundreds of our supporters took part in the 2.6 Challenge alone, where they were able to raise over £34,000. We hosted new online quizzes, and launched new ways to get involved, including #LifeShavers – a way for individuals to turn home haircuts into vital funding. We also applied to all possible third-party income sources and were fortunate enough to receive a grant from the Coronavirus Community Support Fund distributed by the National Lottery Community Fund, for our Support & Information Service. Every idea and opportunity was explored and tested.

In addition to raising funds, we also took every step to defer or reduce costs wherever possible. However, despite our best efforts, by April it was clear that we were not yet able to return our fundraising to pre-pandemic levels. To protect the funds already raised by our supporters, we made the sensible decision to use the government's Coronavirus Job Retention Scheme and began furloughing members of staff from our Fundraising, Communications and Awareness Teams.

By mid-year, we abandoned plans to expand our Special Fundraising Events and it was necessary to scale back our Community fundraising. We also re-structured our Supporter Care provision in response to our new ways of working. As a result, we sadly said goodbye to four colleagues, three from our Fundraising Team.

In the coming months, as our research and testing continued, we started seeing a lift in income from our new approach to virtual fundraising. We continued to learn and optimise our testing and ultimately created viable and robust new sources of income, attracting thousands of new supporters to the charity.

To deliver the activity, we brought all staff back from furlough and focused all efforts on our virtual fundraising.

By the end of 2020, over 25,000 individuals from across the UK took part in our fundraising challenges. Because of their efforts, we not only made up the shortfall we had experienced earlier in the year but exceeded our original annual income targets and delivered a 65% year-on-year growth in our income.

The dedication, passion and love shown by our supporters throughout 2020 was awe-inspiring. It is because of their commitment to our work and endless support for our fundraising efforts that we managed to turn 2020 into a record-breaking year, not only in fundraising terms, but in the number of patients and families we were able to support through the pandemic.

Our fundraising programme continues to follow individual and community-led fundraising methods. Our approach is supporter centric and does not include higher cost, and sometimes more intrusive fundraising methods such as door-to-door or telemarketing fundraising. We continually assess the costs of our fundraising activities and work hard to find savings to invest back into our charitable work.

The Bone Cancer Research Trust continued to be a member of the Fundraising Regulator. During 2020 we received no complaints from the regulator relating to any of our fundraising activities.





## **THANK YOU**

Thank you to everyone who supported us throughout 2020! We value everyone who got involved to make our life-saving work possible. Whether you fundraised for us, worked collaboratively with us, or gave your time to help us achieve our goals – you really helped to make all the wonderful work detailed in this report possible!

#### **Special Funds**

We would like to thank all our Special Funds and their supporters for their unwavering support & dedication...

Abigail's Ambition, Adam Dealey, Adam Hassall Tribute Fund, Adam Panther Tribute Fund, Alexander Albiston Tribute Fund, Al Dawson Tribute Fund, Alex Lewis Memorial Fund, Anthony Pilcher Bone Cancer Trust, Campaigns for Caroline, Chloe's Fight, Chris Fairley Fund, Christopher Hardman (CHORF), Christopher Spratt Tribute Fund, Daniel Bridle Memorial Fund, Daniel Humphreys Tribute Fund, The Darren Wilkinson Amelo Warrior Fund, Dila's Fund, Emily Barker Tribute Fund, Fitzy's Fund, Frank's Fund, Freddie's Future, Gemma Pickering Tribute Fund, Guy Francis Tribute Fund, James Stewart Tribute Fund, Jennifer Carvell Tribute Fund, Jessica Gower My Blue Heart Fund, Jordon Wilson Tribute Fund, Josh Williamson Tribute Fund, Jude's Fund, Kenny McCabe Tribute Fund, Ken Davies Tribute Fund, Krystle Smith Tribute Fund, Laura Connolly Tribute Fund, Liberty's Legacy, Liz Clarke-Saul Fund, Lol's Legacy, Mary Collard Tribute Fund, Matt's Beacon Fund, Menafest, Nick Pollard Tribute Fund, Pushing for a Cure, Rhodri Jones Memorial Appeal, Ruth Grace's Battle, The Scott Abbruzzese Memorial Fund, Tom Stead Tribute Fund, Zack Foley Fund

#### **Our Active Ambassadors**

Laurence Whiteley, Peter Lloyd, Dr Phillip Green

#### **Corporates, Trusts and Foundations**

29th May 1961 Charitable Trust Balcombe Trust Barbour Foundation Caddick Construction Caddick Construction (in twice) Children with Cancer UK Clive & Sylvia Richards Charity Edward Cadbury Trust Ewing's Sarcoma Research Trust Friends for Dinner Garfield Weston Foundation Giddo's Gift James Tudor Foundation Leeds City Council Manning Staton Miss Margaret Butters Reekie Charitable Trust Murray Harcourt National Lottery Community Fund P F Charitable Trust **QBE** Foundation Shard Media Group Takeda UK Walker Morris LLP Wesleyan Foundation

#### **Volunteers**

Adam Bowers, Aimee Hunter, Felicity Smith, Terri Bush

...as well as all the many individuals who have supported us at fundraising events and are taking part in our Stamp Appeal.

#### **Information Review Panel**

Dr Darrell Green, Dr Elizabeth Roundhill, Dr Katrina Ingley, Dr Lucia Cottone, Dr Phil Green, Dr Sandra Strauss, Geraint Davies, Millicent Lipshaw, Mr Kenneth Rankin, Mr Muzzammil Nusrath, Pete Lloyd, Professor Bernadette Brennan, Professor Paul Cool

## Members of the clinical and research community who provided help or assistance

Anita Killingworth, Caroline Ward, Clare McKenzie, Dr Adam Cribbs, Dr Rajesh Botchu, Hannah Spencer, Jennifer Fulton, Krista Bose, Lucy Bishton, Professor Adrienne Flanagan, Professor Susan Burchill, Tyler Barr

## Other people or organisations that helped or supported our work in 2020

Allen & Overv LLP Amputation Foundation Becki McGuinness Carol Hughes Charlene Young Dave & Barbara Harley Dr Cheryl Fitzgerald Emma Hallam Gemma Hillier-Moses Henry Dancer Days Julie Carr Kate Surman Keda Consulting Mark Reed Middlechild Productions Monika Siemicka Parveen Chatha Professor Richard Harding RNB Group Sarah Dransfield Sarcoma UK

# REFERENCE AND ADMINISTRATIVE DETAILS FOR YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

#### **Trustees:**

Andrew Lewis (Chair)
Roger Paul (Deputy Chair)
Gillian Elizabeth Johnston
Sarah Bernadette Dawson
Malcolm Matthews (resigned 6 April 2021)
James Maffin
Arlene Eves
Jonathan Stephenson
Bernadette Brennan
Alison Gartland
Damian Harper
Darrell Green

#### **Clerk to the Trustees:**

Liz Eatock

#### **Independent Scientific Advisory Panel:**

Hannah Millington (resigned 20 November 2020)

#### Chair: Professor Pam Kearns,

MBChB, BSC (Hons), PhD, FRCPCH, Professor of Clinical Paediatric Oncology and Honorary Consultant in Paediatric Oncology, University of Birmingham

#### **Deputy Chair: Professor Robert Brown**

Chair in Translational Oncology, Impreial College London and The Institute of Cancer Research

#### Lay Member: Mr Simon Allocca

Lay member of Independent Scientific Advisory Panel

#### **Member: Dr Richard Grose**

BSc, PhD, Barts Cancer Institute

#### **Member: Professor Andy Hall**

MBBS, FRCP, PhD, FRCPath Newcastle University

#### **Member: Piers Gaunt**

BSc MSc, Senior Biostatistician, University of Birmingham

#### Member: Dr Paulo Ribeiro

BSc MSc PhD, Senior Lecturer and Group Leader, Bart's Cancer Institute

#### **Member: Professor Thomas Grunewald**

MD, Division Head, Translational Paediatric Sarcoma Research, German Cancer Research Center, Heidelberg, Germany.

#### **Member: Dr Nathalie Gaspar**

Paediatric Oncologist, Department of Oncology for Child and Adolescent, Gustave Roussy Cancer Campus, France

#### **Member: Dr Didier Surdez**

Senior Researcher in the lab of Olivier Delattre, Institut Curie, Paris

#### **Principal Address**

Unit 10, Feast Field Horsforth, Leeds, LS18 4TJ

#### **Registered Charity Number**

1159590

#### **Independent Auditors**

Thomas Coombs Limited Statutory Auditor, Chartered Accountants 3365 The Pentagon, Century Way Thorpe Park, Leeds West Yorkshire, LS15 8ZB

#### **Solicitors**

Browne Jacobson LLP Mowbray House Castle Meadow Road Nottingham, NG2 1BJ

#### **Bankers**

CAF Bank Ltd 25 Kings Hill Avenue, Kings Hill West Malling, ME19 4JQ

Lloyds Bank 65-68 Briggate, Leeds West Yorkshire, LS1 6LH

#### **HR Consultants**

The HR Dept Ltd First Floor 3 Brook Office Park Emersons Green Bristol BS16 7FL

#### **Investment Managers**

Brewin Dolphin 10 Wellington Place Leeds, LS1 4LX





## REPORT OF THE TRUSTEES FOR YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

The trustees present their report with the financial statements of the charity for the year ended 31st December 2020. The trustees have adopted the provisions of 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).

#### **Objectives And Activities**

#### **Objectives and Aims**

The Bone Cancer Research Trust (BCRT) became a Charitable Incorporated Organisation (CIO) on 1st January 2015 and is a trust that is governed by a Trust Deed and managed by a Board of Trustees. The Constitution states that the object of the CIO is the relief of sickness generally and in particular, but not so as to limit the generality of the foregoing:

i) promoting research into the causes and treatment of primary bone cancer and publishing useful results thereof; and

ii) providing support and information services for persons suffering from primary bone cancer and their treatment.

Our vision is a world where primary bone cancer is cured. Our mission is to save lives and improve outcomes for people affected by primary bone cancer by being:

- The catalyst for pioneering research
- The trusted source of information
- The voice of the primary bone cancer community
- A supportive network for the people affected.

The Trustees have complied with the duty set out in Section 4 of the Charities Act 2011 and have paid due regard to the public benefit guidance published by the Charity Commission.

#### **Board Of Trustees**

#### **Andy Lewis - Chair**

Andy has 40 years' experience in technology, project management and consultancy. He has worked as a Founding Board Member (BBC Technology), a Company Director and a Programme Director (NCR, BBC, Siemens, ITV, Coopers and Lybrand, Sainsburys, RBS). Andy's son, Alex, passed away from Osteosarcoma in February 2011.

#### **Roger Paul - Deputy Chair**

Roger's business life was in telecommunications, working in an executive position with AT&T. His daughter, Claudia, died at the age of 17, following a three-year battle with Ewing sarcoma. Her final wish was for Roger to help children in her position in the future, and consequently, he has been a Trustee for 10 years.

#### **Bernadette Brennan**

Bernadette is a Professor in Paediatric Oncology and Consultant Paediatric Oncologist at Royal Manchester Children's Hospital and The Christie NHS Foundation Trust.

She is a NCRI Sarcoma Chair and member of the YOSS. Bone and STS subgroup, she chairs the CCLG (Childhood Cancer and Leukaemia Group) Rare Tumour Group and is a member of EXPeRT European Rare Tumour Group. She has given a number of invited lectures for learned societies and research groups both in the UK and overseas.

#### Sarah Dawson

Sarah is a Coach and HR Training Consultant who became a trustee after her son Al died in November 2007. Sarah lectures on related topics and spreads awareness of primary bone cancer to a wide range of audiences including students in nursing and other allied healthcare professionals.

Arlene is a pensions lawyer experienced in advising trustees of occupational pension schemes. She joined BCRT as a trustee in 2018.

#### **Gillian Johnston**

Gill has 40 plus years' experience in bookkeeping, payroll and general administration. Her son, Anthony, passed away following a battle with Osteosarcoma in October 2002, and she was a founding trustee of BCRT.

#### **James Maffin**

James is a finance professional and an associate member of the Chartered Institute of Management Accountants. He is Chief Financial Officer for an award-winning manufacturing business.

#### **Malcolm Matthews**

Malcolm has experience as a charity trustee and 25 years as a director at national charities. He had leadership roles providing services and information, creating policy, campaigning and fundraising. He became involved with BCRT after his youngest son died in 2007 as a result of a Ewing sarcoma that was misdiagnosed.

#### **Hannah Millington**

Hannah was diagnosed with Osteosarcoma at the age of 25 and provides us with an invaluable insight into the experience of going through primary bone cancer as a patient.

#### **Jonathan Stevenson**

Jonathan is a Consultant in Orthopaedic Oncology at the Royal Orthopaedic Hospital, Birmingham, managing adult and paediatric bone and soft tissue tumours of the limbs and pelvis. He became involved with BCRT in 2019 to help promote research and awareness.

#### **Darrell Green**

Darrell's best friend passed away from primary bone cancer when they were teenagers. Darrell is now a Lecturer and Researcher at Norwich Medical School, University of East Anglia. Darrell trained in molecular genetics at Addenbrooke's Hospital in Cambridge before obtaining his PhD in molecular biology at UEA. His research combines genetics, cell and molecular biology with bioinformatics to study gene silencing in primary bone cancer. Darrell sits on the editorial board of scientific journals and on grant review panels for other cancer charities. He is a member of Norwich Cancer Research Network. He has appeared several times on TV and Radio and has presented his research across the UK and in the USA. In 2019, he was listed as a Universities UK Top 100 People "The Nation's Lifesavers". In 2020, Darrell joined BCRT as a trustee.

#### **Damian Harper**

Damian was diagnosed with Osteosarcoma in 1986 at just 17 years old. He has had a successful career, initially as a biomedical scientist, working in a pathology laboratory. then moving into project and programme management.

#### **Alison Gartland**

Alison is a Professor of Bone and Cancer Biology at The University of Sheffield and has a background of over 20 years of research into bone biology including primary bone cancer. Alison currently heads up a team of researchers looking at mechanisms of primary and metastatic bone diseases and is regularly involved in education of Medical Students at The University of Sheffield. As such Alison has knowledge of the current research landscape and also the medicine curriculum and teaching priorities for the doctors of the future. Alison is passionate about raising awareness about primary bone cancer.

#### **Sub-Committees**

The Management and Finance Committee has delegated responsibility for overseeing financial, strategic and HR matters, and also acts as the remuneration committee, making recommendations to the Board of Trustees in respect of employee salaries. The Management and Finance Committee meets at least 4 times per year. The committee members in 2020 were:

- Gillian Johnston (Committee Chair)
- Andy Lewis
- Roger Paul
- James Maffin

#### **Recruitment and Appointment of New Trustees:**

The CIO constitution requires the Board of Trustees to have at least 8 members. BCRT reviews the skills mix of the existing Board when recruiting new Trustees, to ensure that their skills, personal and professional experiences are complementary to the existing board. On their appointment, new trustees are provided with, or have online access to the following documents:

- Latest audited Annual Report and Statutory Accounts
- · Management accounts for the current year
- Minutes of trustee meetings for the current year
- BCRT's conflict of interest policy
- BCRT's financial procedures
- "Charity Governance Code for Larger Charities" published by the Good Governance Steering Group
- · "The Essential Trustee", published by the Charity Commission.

Following their appointment, new Trustees have a planned induction process during which they meet the staff team, spend time with other trustees, and get to know more about BCRT's activities. Trustees serve a 3-year term, after which they are eligible for re-election.

During 2019, a recruitment process was undertaken to appoint additional trustees with specific skills, which complemented the existing Trustee board. The opportunity to become a trustee was advertised widely, on social media, the BCRT website and by relevant industry bodies. Recruitment took place towards the end of the year, and the successful applicants were appointed at the start of 2020.

#### **Organisational Structure**

The Board of Trustees meets at least 4 times a year to set the strategic direction of the charity, review ongoing operational and financial performance, approve the awarding of new grants, and review the risks faced by the charity. The Trustees give their time freely and no trustee remuneration was paid during the year. Details of trustee expenses and related party transactions are disclosed in notes 10 and 24 of the accounts.

Responsibility for the day-to-day running of the charity is delegated to the Senior Leadership Team, which comprises:

- Head of Fundraising and Communications
- Head of Research, Information and Support
- Head of Finance

The pay of the Senior Leadership Team is benchmarked against appropriate roles in similar charities in the same geographic area. The charity is committed to achieving a balance between paying market rates to attract the most competent staff, and careful management of our funds. A policy for staff remuneration is in place and applies to all staff employed by the charity.

The total number of staff employed at 31 December 2020 was 17 (including 6 part-time).

The charity has a Conflict of Interest Policy for Trustees and Staff, and a register of interests is maintained for Trustees and the Senior Leadership Team. Trustees are required to disclose all relevant interests to the Clerk to the Trustees and are required to withdraw from any decisions where an actual or potential conflict of interest may arise. Any individual with an interest in a matter being discussed at a meeting must immediately declare the interest to the meeting. The Chairman of the meeting will then decide whether that individual will be entitled to vote on the matter.

#### **Grant Making**

We recognise that our ability to fund research is limited by our physical and financial resources. We aim to maximise the impact of our grants by encouraging research which is likely to win support from larger funding bodies in due course.

We believe that there is great value is collaborative research. Finding a cure depends on the cooperation of many experts, some of whom may not have worked in primary bone cancer research to date. Therefore we place special emphasis on the importance of:

- Creating the opportunity for researchers to work within primary bone cancer research
- Nurturing the careers of early-stage researchers with an interest in primary bone cancer
- Working with research teams to develop their research ideas through an innovative pilot grant scheme
- Supporting proposals which are likely to win support from larger funding bodies
- Encouraging collaboration between research groups
- Encouraging interdisciplinary team work and partnerships
- Facilitating access to primary tissue and clinical data
- Working with other charities to fund research costs

BCRT has established its grant making policy, which adheres to the recommendations set out by the Association of Medical Research Charities (AMRC) and National Institute for Health Research (NIHR) for peer review, to achieve its objects for the public benefit, and this policy is reviewed periodically. Applications are invited through calls for proposals, which then undergo a thorough review process including both review by our Independent Scientific Advisory Panel (ISAP) and external expert reviewers where necessary. The ISAP make recommendations to the Trustees on the award of research grants, and the Board of Trustees approve the grants to be awarded. The ISAP consists of research professionals who are from respected centres of research throughout the UK and Europe. We also have one lay member of ISAP. BCRT is an active member of the AMRC.

The role of ISAP is to:

- Assess the validity of all research applications, taking into account the results of the external peer review process
- Interview candidates for studentships and fellowships
- Make recommendations in respect of funding projects to the Board of Trustees.

BCRT works with the primary bone cancer community and ISAP to develop our strategy to respond to areas of unmet or urgent need. BCRT works collaboratively with researchers and places emphasis on the ongoing monitoring of the impact of the research that we fund.

#### **Risk Management**

The Trustees have a duty to identify and review the risks to which the charity is exposed, and to ensure that appropriate controls are in place to provide reasonable assurance against fraud and error. BCRT has a risk management policy, which reflects the commitment of the Trustees to maintaining a strong risk management framework.

The Trustees have examined the major strategic, business and operational risks which are faced by the charity, and confirm that there are suitable systems and procedures in place to enable those risks to be appropriately mitigated managed and monitored. The Senior Leadership Team has a day to day responsibility to highlight any major risks that they may become aware of during the course of their duties.

ANNUAL REPORT AND ACCOUNTS 2020

The majority of BCRT's income is from voluntary donations and income from investments derived from voluntary contributions, and so there is a significant risk in being unable to maintain and grow income, in a cost-effective manner, in order to fund our charitable objectives and our 5-year strategy. To manage this risk, the charity continues to invest into the diversification of income streams and to reduce reliance on a small number of core sources of income.

#### Volunteers

The Trustees are very appreciative of the work carried out by numerous volunteers throughout the UK and overseas and thank them for their tireless work in organising fundraising activities. There are also many volunteers that have played a role in other BCRT activities such as office administration, supporting challenges and events, conferences and Bone Cancer Awareness Week. In accordance with accepted practice, no value has been included in the financial statements to reflect the work undertaken by volunteers.

#### **Financial Review**

#### Income and Expenditure

We achieved our highest ever level of income in 2020 at £2.756m, an increase of 64.6% over the previous year. The global pandemic has curtailed many of our usual fundraising activities, but we have been able to capitalise on virtual fundraising opportunities, gaining new supporters and raising awareness of primary bone cancer as well as raising funds. Many of our supporters have continued to organise fundraising activities during the pandemic. We have received grants and donations from a number of Trusts and Charitable Foundations. We gratefully thank every single fundraiser who contributed in 2020, no matter how large or small, your donation makes such a difference in enabling us to fulfil our charitable objectives.

During the year we spent £950K on charitable activities, including awarding grants totalling £183K. This figure was much lower than planned as the global lockdowns caused research activity to be paused for much of the year. Fundraising costs were £400K, 14.5% of total income. We ended the year with a surplus of £1,440K.

#### **Investment Policy**

BCRT's investment policy requires that there must be no direct investment into tobacco or vaping companies. The charity's investments are held in a combination of fixed interest securities, UK and overseas equities and alternative investments. The funds are held in two portfolios and managed by Brewin Dolphin. The Portfolio No.1, which comprised 58% of the total fund at 31 December 2020, has an investment mandate of 'income and capital growth with moderate investment risk', whilst the mandate for Portfolio No.2 42% of total value at year end is 'income and capital growth with low investment risk'.

During 2020 Portfolio No.1 made a total return of +5.34%. This compared to a total return in the MSCI WMA Balanced index of +1.95%. The market value of the investment portfolio was £1,218,024 at 31 December 2020.

During 2020 Portfolio No.2 made a total return of +3.82%. This compared to a total return in the MSCI WMA Conservative index of +2.97%. The market value of the investment portfolio was £874,089 at 31 December 2020.

As a result of the success of the fundraising campaigns in the latter part of the year the Trustees were able to transfer £750,000 of funds from current bank accounts into the investment portfolios in December 2020. A total of £250,000 was added to portfolio 1 and £500,000 into portfolio 2. The Trustees are reviewing their plans for future charitable activities in the light of this better than anticipated reserves position.

The Trustees hold regular review meeting with Brewin Dolphin, and they remain satisfied with the overall performance of both the investment managers and the investment portfolio performance.

#### **Reserves Policy**

BCRT has a policy of maintaining sufficient reserves to enable the charity to meet, as a minimum, its operational costs for six months, estimated to be £1,490,000.

At the end of 2019 there was a designated reserve of £120,000 towards the costs associated with infrastructure grants, travel grants and the clinical trials accelerator grant over 2020 and 2021. £21,295 was released against one infrastructure grant awarded in the year, leaving a balance of £98,705.

During the year the Trustees agreed to designate a further £390,295 towards multi-year grants, including the second phase of funding for the ICONIC clinical study, and other charitable support and information costs. The total funds designated at 31 December 2020 were £489,000.

Restricted reserves at 31 December 2020 were £640,089, whilst free reserves were £1,675,127. This exceeds the level required by the reserves policy. The Trustees regularly monitor and review the reserves hold within the context of the funds required to fulfil the objectives of the charity.

#### **Going Concern**

The Trustees believe that the charity is a "going concern" based on the current financial status, the ongoing funding streams, the planned expenditure and research strategy.

#### **Trustees Responsibility Statement**

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales 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 and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the charity SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- 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 that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the Board of Trustees on 24th April 2021 and signed on its behalf by Roger Paul - Trustee

## Report of the Independent Auditors to the Trustees of Bone Cancer Research Trust

We have audited the financial statements of Bone Cancer Research Trust (the 'charity') for the year ended 31st December 2020 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- Give a true and fair view of the state of the charity's affairs as at 31st December 2020 and of its incoming resources and application of resources, for the year then ended:
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

#### **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### **Conclusions relating to going concern**

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

#### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

#### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- The information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- Sufficient accounting records have not been kept; or
- The financial statements are not in agreement with the accounting records and returns; or
- We have not received all the information and explanations we require for our audit.

#### **Responsibilities of Trustees**

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

#### Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of noncompliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the entity and sector in which it operates, we identified the principle risks of non-compliance with laws and regulations related to charitable trusts and the application of charitable funds. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Charities Act 2011.

We evaluated managements and those charged with governance, incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined the principal risks were related to management bias in accounting estimates, especially accrued income.

In a response to these risks, audit procedures performed by the engagement team included:

- Discussions with management of known or suspected instances of non-compliance with laws and regulations and fraud.
- Challenging assumptions and judgements made by management in determining significant accounting estimates, in particular in relation to accrued income.
- Identifying and testing journal entries.
- Reviewing minutes of meetings of those charged with governance.

There are inherent limitations in the audit procedures described above and the further removed non compliance of laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement relating to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

#### **Use of our Report**

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Thomas Coombs Limited
Statutory Auditor
Chartered Accountants
Eligible to act as an auditor in terms
of Section 1212 of the Companies Act 2006
3365 The Pentagon
Century Way
Thorpe Park
Leeds, West Yorkshire
LS15 8ZB

Date: 24th April 2021



# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

	UN	RESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL FUNDS 2020	TOTAL FUNDS 2019
N	OTES	£	£	£	£
INCOME AND ENDOWMENTS FROM Donations, legacies and grants	2	2,148,648	569,360	2,718,008	1,634,229
Other trading activities Investment income	3 4	6,292 31,742	-	6,292 31,742	2,663 37,673
Total		2,186,682	569,360	2,756,042	1,674,565
EXPENDITURE ON Income generation	5	400,027		400,027	494,696
Charitable activities Research Awareness	6	181,074 429,377	138,020 20,000	319,094 449,377	580,253 203,393
Information Support Governance		76,254 23,624 9,952	71,353	76,254 94,977 9,952	41,246 113,195 13,772
Total		1,120,308	229,373	1,349,681	1,446,555
NET INCOME/(EXPENDITURE) BEFORE INVESTMENT GAINS/(LOSSES)		1,066,374	339,987	1,406,361	228,010
Net gains/(losses) on investments		33,991	-	33,991	126,512
NET MOVEMENT IN FUNDS		1,100,365	339,987	1,440,352	354,522
RECONCILIATION OF FUNDS Total funds brought forward		1,072,071	300,102	1,372,173	1,017,651
TOTAL FUNDS CARRIED FORWARD		2,172,436	640,089	2,812,525	1,372,173

## STATEMENT OF FINANCIAL POSITION 31<sup>ST</sup> DECEMBER 2020

	U	NRESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL FUNDS 2020	TOTAL FUNDS 2019
	NOTES	£	£	£	£
FIXED ASSETS					
ntangible assets	13	-	-	-	5,048
Tangible assets	14	8,309	-	8,309	,
Investments	15	2,090,680	-	2,090,680	1,283,057
		2,098,989	-	2,098,989	1,299,68
CURRENT ASSETS					
Stocks	16	128,742	-	128,742	52,404
Debtors	17	224,174	-	224,174	219,289
Cash at bank and in hand		408,753	640,089	1,048,842	553,177
		761,669	640,089	1,401,758	824,870
CREDITORS  Amounts falling due within one year	18	(669,408)	-	(669,408)	(627,623)
NET CURRENT ASSETS		92,261	640,089	732,350	197,247
TOTAL ASSETS LESS CURRENT LIABILITIES		2,191,250	640,089	2,831,339	1,496,928
CREDITORS					
Amounts falling due after more than one year	r 19	(18,814)	-	(18,814)	(124,755)
NET ASSETS		2,172,436	640,089	2,812,525	1,372,173
FUNDS	21				
Unrestricted funds	21				
- Free reserves				1,675,127	935,447
- Fixed asset reserve				8,309	,
- Designated reserve	23			489,000	
Restricted funds	22			640,089	
TOTAL FUNDS				2,812,525	1,372,173

The financial statements were approved by the Board of Trustees and authorised for issue on 24th April 2021 and were signed on its behalf by:

**Roger Paul - Trustee** 

**Andrew Lewis - Trustee** 

## STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

		2020	2019
	NOTES	£	£
Cash flows from operating activities: Cash generated from operations	1	1,237,873	306,781
Cash flows from investing activities Purchase of tangible fixed assets Purchase of fixed asset investments Sale of fixed asset investments Investment income		(318) (1,095,887) 322,255 31,742	(12,618) (296,664) 170,256 37,673
Net cash used in investing activities		(773,950)	(139,026)
Change in cash and cash equivalents in the reporting period		495,665	205,428
Cash and cash equivalents at the beginning of the reporting period		553,177	347,749
Cash and cash equivalents at the end of the reporting period		1,048,842	553,177

# NOTES TO THE STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

	2020	2019
	£	£
Net income/(expenditure) for the reporting period		
(as per the statement of financial activities)	1,440,352	354,522
Adjustments for:		
Depreciation charges	3,584	1,432
Amortisation charges	5,048	9,547
Loss/(gain) on investments	(2,840)	2,970
Loss on disposal of fixed assets	-	
Unrealised loss/(gain) on investments	(31,151)	(129,482)
(Increase)/decrease in stocks	(76,338)	13,717
(Increase)/decrease in debtors	(4,885)	33,634
Increase/(decrease) in creditors	(64,155)	58,114
Investment income	(31,742)	(37,763)

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

#### 1. ACCOUNTING POLICIES

#### Basis of preparing the financial statements

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, with the exception of investments which are included at market value, as modified by the revaluation of certain assets.

The Trustees consider that there are no material uncertainties about the charity's ability to continue for a period of not less than 12 months from the date of approval of the financial statements. Accordingly the financial statements have been prepared on the going concern basis.

#### Income

Donations and sponsored events are included in the Statement of Financial Activities when:

- the charity is told it is to receive the gift or donation
- the Trustees are reasonably certain of the amount to be received
- the Trustees are reasonably certain they will receive the money and
- any conditions for receipt are met

Income from challenge events is recognised when the event takes place. Any income received in relation to events taking place in future years is held as deferred income until the event takes place.

Legacies are recognised when it is probable that they will be received. Receipt is normally probable when:

- there has been grant of a probate:
- the executors have established that there are sufficient assets in the estate after settling any liabilities to pay the legacy; and
- · any conditions attached to the legacy are either within the control of the charity or have been met.

Government grants are recognised at the fair value of the asset received or receivable when there is reasonable assurance that the company will comply with conditions attaching to them and the grants will be received using the accruals model.

#### Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Irrecoverable VAT is charged against the category of resources expended for which it was incurred.

The costs of generating income consist of investment management fees and those costs incurred attracting voluntary income and activities for generating funds, such as events.

Costs of charitable activities include grants made and an apportionment of overheads and administration costs.

Grants payable are payments made to third parties in the furtherance of the charitable objectives of the charity. Single or multi-year grants are accounted for where either the recipient has a reasonable expectation that they will receive a grant and the trustees have agreed to pay the grant without condition, or the recipient has a reasonable expectation that they will receive a grant and any condition attaching to the grant is outside of the control of the charity.

Governance costs comprise all costs involving the public accountability of the charity and its compliance with regulation and good practice. These costs include costs related to external inspection an legal fees together with an apportionment of overhead and administration costs.

#### **Critical accounting estimates and judgements**

In the application of the charities accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

#### **Critical estimates and judgements**

#### **Allocation of administration costs**

Administration costs are allocated between the various activities of the group based on the weighting each activity has within total expenditure. The allocation of these costs is considered to be critical to the accounts because they have the ability to materially alter the allocation of costs between expenditure on raising funds and expenditure on charitable activities.

The activities of the charity are categorised as follows:

Income generation

- expenditure incurred in order to raise funds for charitable purposes.
- Research
- grant funding research into funding a cure for primary bone cancer.increasing survival rates through raising awareness of primary bone cancer.
- Awareness Information
- providing accurate and reliable information across all forms of primary bone cancer.
- Support
- improving the access to primary bone cancer support for all patients, family members,
- carers and friends.

The breakdown of administration costs and how these were allocated between governance and other administration costs is based on the following rates:

 Income generation
 29% (2019:34%)
 Information
 6% (2019:3%)

 Research
 24% (2019:41%)
 Support
 7% (2019:8%)

 Awareness
 34% (2019:14%)

#### Intangible fixed assets

Amortisation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Website - 25% on cost

#### **Tangible fixed assets**

Tangible fixed assets are stated at cost (or deemed cost) or valuation less accumulated depreciation and accumulated impairment losses. Costs includes costs directly attributable to making the asset capable of operating as intended.

Depreciation is provided to write off the cost less the estimated residual of tangible fixed assets by equal instalments over their estimated useful economic lives as follows:

Fixtures and fittings - 25% on cost Computer equipment - 33% on cost and 25% on cost

#### Stocks

Stocks are valued at weighted average cost, after making due allowance for obsolete and slow moving items.

#### Taxatio

The charity is exempt from tax on its charitable activities.

#### **Fund accounting**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### **Investments**

Investments held by the charity are shares which are publicly traded. Investments are recognised initially at fair value which is normally the transaction price including transaction costs. Subsequently, they are measured at fair value with changes recognised in 'net gains / (losses) on investments' in the SoFA.

#### **Financial instruments other than investments**

The charity has financial assets and financial liabilities of a kind that qualify as basic and complex financial instruments. Basic financial instruments are measured at their settlement value in the case of current assets and liabilities and at discounted settlement value in the case of creditors falling due after more than one year.

#### Status

The Bone Cancer Research Trust is a Charitable Incorporated Organisation (CIO), the liability is therefore restricted If the CIO is wound up, the members of the CIO have no liability to contribute to its assets and no personal responsibility for settling its debts and liabilities.

#### **Volunteers**

The value of services provided by volunteers is not incorporated into these financial statements. Further details of the contribution made by volunteers can be found in the Trustees' annual report.

Where services are provided to the charity as a donation that would normally be purchased from a supplier, this contribution is included in the financial statements at an estimate based on the value of the contribution to the charity.

#### Pension costs

The charity contributes to defined contribution schemes on behalf of some of its employees. These contributions are charged to the SoFA when accrued.

#### 2. DONATIONS, LEGACIES AND GRANTS

	2020	2019
	£	£
Event income, including online activities Donations Grants	1,703,775 960,936 53,297	700,020 934,209
Total	2,718,008	1,634,229

Grants received, included in the above, are as follows:

		2020	2019
		£	£
Furlough grant		53,297	-
Total		53,297	-

#### 3. OTHER TRADING ACTIVITIES

	2020	2019
	£	£
Other trading income	6,292	2,663
Total	6,292	2,663

#### 4. INVESTMENT INCOME

	2020	2019
	£	£
Investment income	31,742	37,673
Total	31,742	37,673

#### 5. INCOME GENERATION

Raising donations and legacies

	2020	2019
	£	£
Staff costs	209,635	185,576
Event costs	70,391	134,953
Other trading costs	3,108	4,161
Other fundraising costs	28,686	88,026
Support costs	88,207	81,980
Total	400,027	494,696

#### 6. CHARITABLE ACTIVITIES COSTS

	DIRECT COSTS	GRANT FUNDING OF ACTIVITIES (SEE NOTE 7)	ADMINISTRATION COSTS (SEE NOTE 8)	TOTALS
	£	£	£	£
Research	71,590	183,027	64,477	319,094
Awareness	358,577	_	90,800	449,377
Information	60,943	-	15,311	76,254
Support	75,905	-	19,072	94,977
Admin	-	-	9,952	9,952
Total	567,015	183,027	199,612	949,654
Total 2019	378,206	419,388	154,265	951,859

#### 7. GRANTS AWARDED TO INSTITUTIONS IN THE YEAR

			2020	2019
			£	£
Research			183,027	419,388
The total grants paid to institutions during the year was as follows:	2020 Unrestricted Re	2020 estricted	2020 Total	2019
Prof Sibylle Mittnacht, UCL Cancer Institute, Department of Cancer Biology	-	37,139	37,139	-
Dr William Cross, Posthumous evaluation of a high-grade widely disseminated chondrosarcoma through analysis of its evolutionary history	61,432	8,568	70,000	-
Mr Paul Cool, Sample collection support - Oswestry	18,295	3,000	21,295	-
Dr Katie Finegan, University of Manchester Kids Research, Targeting the MEK5-ERK5 pathway		23,432	23,432	-
Professor Mark Morris, Research Institute of Health Science, Identification of novel biomarkers for the management of adamantinoma		21,000	21,000	٦.
Professor Alison Gartland, The Mellanby Centre For Bone Research, The Role of Oestrogen in Chondrosarcoma Using Patient-Derived Xenograft Mouse Models	17,332	2,668	20,000	
Mr Kenneth Rankin, Sample collection support - Newcastle	-	-	-	16,000
Professor Adrienne Flanagan, Royal National Orthopaedic Hospital, Sample collection support - Stanmore		-	-	19,873
Dr Graham Caine, The Royal Orthopaedic Hospital, Sample collection support - Birmingham	-		-	24,579
Mr Thomas Cosker, University of Oxford, Sample collection support - Oxford	-	-	-	9,000
Professor Graham Cook, University of Leeds, Oncolytic virus therapy for Ewing sarcoma	-	-	-	120,500
Dr Robert Falconer, University of Bradford, Development of a targeted methotrexate prodrug with enhanced therapeutic index for osteosarcoma	-	-	-	72,303
Mr Adam Cribbs, University of Oxford, Therapeutic targeting and understanding of oncogenic driver networks in chordoma	-	-	-	56,697
Dr Arshiya Banu, Kings College London, Haem oxygenase-1 a novel druggable target for prevention of osteosarcoma growth and metastasis	-	-	-	70,000
Iben Lyskjaer, University College London	-	-	-	15,000

#### Continued...

			2020	2019
			£	£
The total grants paid to institutions during the year was as follows:	2020 Unrestricted	2020 Restricted	2020 Total	2019
Sue Birchill, Ideas, Modelling Ewing's sarcoma heterogenity and tumour microenvironment to improve outcomes. PI Prof Sue Birchill	(2,198)	-	(2,198)	14,710
Dr Helen Owen, MicroRNA Regulation of Autophagy-Induced Chemoresistance in Osteosarcoma	(569)	-	(569)	-
Sue Birchill, Ewings, Can we reliably detect viable, dying or dead Ewing's sarcoma cells in peri-tumoural tissue following induction chemotherapy? PI Prof Sue Birchill	(1,902)	-	(1,902)	-
Prof Gartland, Osteo, Purigenic signalling in osteosarcoma. PI Prof Allie Gartland	(2,131)	-	(2,131)	-
Prof Heymann, Osteo, Early events of recurrent disease and metastatic dissemination in osteosarcoma: pre-clinical assessment and clinical proof-of-concept. PI Prof Heyman	(4)	-	(4)	-
Sue Birchill, Ewings Ideas, Identification of the lead candidate NRXN1 isoform as a prognostic biomarker and a novel target for therapy PI Prof Sue Birchill	y (4)	-	(4)	-
Dr Roberts, UCL Institute of Orthopaedics and Musculoskeletal Science, Royal National Orthopaedic Hospital, University College London "Mimicking the bone microenvironment to create a chimeric osteosarco modil (COM)"		-	-	(2,274)
Grant refund - Dr Sandra Strauss, investigation of CL67 as a first-in-class novel inhibitor of the HIF 1alpha pathway in osteosarcoma	s (5,232)	-	(5,232)	-
Patient Travel Support Grant	2,201	-	2,201	-
Restricted funding allocated to payments of existing grants meeting the specific restrictions	(42,213)	42,213	-	
	45,007	138,020	183,027	419,388

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#### 8. ADMINISTRATION COSTS

	MANAGEMENT	INVESTMENT MANAGEMENT COSTS	GOVERNANCE COSTS	TOTALS
	£	£	£	£
Research	64,477	-	-	64,477
Awareness Information	90,800 15,311			90,800
Support Income generation	19,072 78,979	9,228		19,072 88,207
Governance		-	9,952	9,952
Total	268,639	9,228	9,952	287,819
Total 2019	213,189	9,284	13,772	236,245

The analysis of administration costs, included in the above, is as follows:

	RESEARCH	AWARENESS	INFORMATION	SUPPORT
	£	£	£	£
NA/- WAS	15.070	21 517	7,000	4 501
Wages	15,279	21,517	3,628	4,521
Social security	1,293	1,820	307	382
Pensions	327	459	77	96
Redundancy costs	1,031	1,452	245	304
Rent, rates and water	5,552	7,818	1,318	1,642
Telephone	2,344	3,303	557	694
Postage and stationery	3,375	4,752	801	998
Sundries	1,896	2,670	450	561
Travel and subsistence	923	1,300	219	273
Software licences	7,689	10,828	1,826	2,274
Recruitment and human resources costs	2,047	2,884	487	606
Stock management	19,917	28,050	4,730	5,892
Bank charges	188	265	45	56
Legal fees	543	764	129	161
Amortisation of intangible fixed assets	1,212	1,706	288	358
Depreciation of tangible fixed assets	861	1,212	204	254
Portfolio management	-	-	-	-
Trustees' expenses and meeting costs	-	-	-	-
Auditors' remuneration	-	-	-	-
Accountancy and legal fees	-	-	-	-
Total	64,477	90,800	15,311	19,072
Total 2019	86,900	30,463	6,177	16,953

#### Continued...

	INCOME GENERATION	GOVERNANCE	2020 TOTAL ACTIVITIES	2019 TOTAL ACTIVITIES
	£	£	£	£
Wages	18,716	-	63,661	87,095
Social security	1,583	-	5,385	6,115
Pensions	400	-	1,359	1,378
Redundancy costs	1,263	-	4,295	-
Rent, rates and water	6,800	-	23,130	32,411
Telephone	2,873	-	9,771	8,110
Postage and stationery	4,134	-	14,060	10,824
Sundries	2,322	-	7,899	3,274
Travel and subsistence	1,130	-	3,845	2,995
Software licences	9,418	-	32,035	25,486
Recruitment and human resources costs	2,509	-	8,533	13,513
Stock management	24,398	-	82,987	9,195
Bank charges	231	-	785	806
Legal fees	664	-	2,261	1,008
Amortisation of intangible fixed assets	1,484	-	5,048	9,547
Depreciation of tangible fixed assets	1,054	-	3,585	1,432
Portfolio management	9,228	-	9,228	9,284
Trustees' expenses and meeting costs	-	1,928	1,928	6,065
Auditors' remuneration	-	5,319	5,319	5,425
Accountancy and legal fees	-	2,705	2,705	2,282
Total	88,207	9,952	287,819	236,245
Total 2019	81,980	13,772	236,245	

#### 9. AUDITORS' REMUNERATION

	2020	2019
	£	£
Fees payable to the charity's auditors for the audit of the charity's financial statements	5,319	5,425

#### **10. TRUSTEES' REMUNERATION AND BENEFITS**

The average number of trustees in the year was 13 (2019: 11)

There was no trustee's remuneration or other benefits for the year ended 31st December 2020 nor for the year ended 31st December 2019.

All trustees give their time freely and no Trustee remuneration was paid in the year. During the year monetary donations made by Trustees to the charity totalled £1,142 (2019: £1,335). A number of trustees have connections to organisations which donate funds to the Trust. Further details are provided in note 24.

#### Trustees' expenses

Reimbursed expenses, which are all subject to the charity's processes of internal controls, do not form part of the remuneration and are not included above. During the period, travel and subsistence expenses of £1,634 (2019: £3,611) were reimbursed to six trustees (2019: six trustees).

#### 11. STAFF COSTS

	2020	2019
	£	£
Wages and salaries Social security costs Other pension costs Redundancy costs	526,537 45,088 13,769 4,295	410,799 33,206 7,408
Total	589,689	451,413

The average monthly number of employees during the year was as follows:

	2020	2019
Permanent staff	18	16

The average full time equivalent of employees during the year was 17.4 (2019: 13.8).

No employees received emoluments in excess of £60,000.

The Trust considers its key management personnel comprise the trustees and its Senior Leadership Team. The total employment costs to the charity of the key management personnel were £141,609 (2019: £130,093).

#### 12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	UNRESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL FUNDS
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations, legacies and grants	952,247	681,982	1,634,229
Other trading activities	2,663	-	2,663
Investment income	37,673	-	37,673
Total	992,583	681,982	1,674,565
EXPENDITURE ON			
Income generation	494,696	-	494,696
Charitable activities	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		, , , , , , , , , , , , , , , , , , , ,
Research	(140,945)	721,198	580,253
Awareness	201,884	1,509	203,393
Information	41,246	-	41,246
Support	91,724	21,471	113,195
Admin	13,772	-	13,772
Total	702,377	744,178	1,446,555
NET INCOME/(EXPENDITURE)			
BEFORE INVESTMENT GAINS/(LOSSES)	290,206	(62,196)	228,010
Net gains/(losses) on investments	126,512	-	126,512
NET MOVEMENT IN FUNDS	416,718	(62,196)	354,522
RECONCILIATION OF FUNDS			
Total funds brought forward	655,353	362,298	1,017,651
TOTAL FUNDS CARRIED FORWARD	1,072,071	300,102	1,372,173

#### 13. INTANGIBLE FIXED ASSETS

	WEBSITE COSTS
	£
COST	
At 1st January 2020 and 31st December 2020	38,187
AMORTISATION	
At 1st January 2020	33,139
Charge for year	5,048
At 31st December 2020	38,187
NET BOOK VALUE	
At 31st December 2020	-
At 31st December 2019	5,048

#### 14. TANGIBLE FIXED ASSETS

	FIXTURES AND FITTINGS	COMPUTER EQUIPMENT	TOTALS
	£	£	£
COST			
At 1st January 2020	11,170	20,075	31,245
Additions	318	-	318
At 31st December 2020	11,488	20,075	31,563
DEPRECIATION			
At 1st January 2020	1,939	17,730	19,669
Charge for year	2,493	1,092	3,585
At 31st December 2020	4,432	18,822	23,254
NET BOOK VALUE			
At 31st December 2020	7,056	1,253	8,309
At 31st December 2019	9,231	2,345	11,576

#### 15. FIXED ASSET INVESTMENTS

	LISTED INVESTMENTS	CASH AND SETTLEMENTS PENDING	TOTALS
	£	£	£
MARKET VALUE At 1st January 2020 Additions Disposals Revaluations	1,265,013 1,060,022 (319,413) 31,149	18,044 35,865 -	1,283,057 1,095,887 (319,413) 31,149
At 31st December 2020	2,036,771	53,909	2,090,680
NET BOOK VALUE At 31st December 2020 At 31st December 2019	<b>2,036,771</b> 1,265,013	<b>53,909</b> 18,044	<b>2,090,680</b> 1,283,057

At 31st December 2020 no individual investment represented more than 5% of the total investment portfolio valuation.

The historical cost at 31st December 2020 is £1,807,333 (2019: £1,114,887).

All investments are carried at their fair value. Investment in equities and fixed interest securities are all traded in quoted public markets, primarily the London Stock Exchange. Asset sales and purchases are recognised at the date of trade at cost (that is their transaction value).

The significance of financial instruments to the ongoing financial sustainability of the Trust is considered in the financial review and investment policy and performance sections of the Trustees' Annual Report.

The main risk to the charity from financial instruments arises from uncertain investment markets resulting in variable income and capital returns from the portfolio of assets.

Currency translation risks remain for those companies and bonds that are exposed to overseas earnings and assets.

Liquidity risk is anticipated to be low as all assets are traded on recognised exchanges with good liquidity and high trading volumes. The charity's portfolio has no material investment holdings in markets subject to exchange controls or trading restrictions.

The charity manages investment risk by appointing professional investment managers and operating an investment policy that provides for a high degree of diversification of holdings within investment asset classes that are quoted on recognised stock exchanges.

The charity does not make use of derivatives and similar complex financial instruments as it takes the view that investments are held for their longer term total return.

#### 16. STOCKS

	2020	2019
	£	£
Stocks of fund raising items	128,742	52,404

#### 17. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Other debtors	21,051	18,136
Accrued income	117,983	6,652
Prepaid event costs	85,410	194,501
Total	224,174	219,289

#### 18.CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Trade creditors	5,532	31,467
Taxation and social security	13,567	12,629
Grants payable	617,720	545,474
Deferred event income	5,876	24,928
Other creditors	26,713	13,125
Total	669,408	627,623

#### 19.CREDITORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR

	2020	2019
	£	£
Grants payable	18,814	124,755
Reconciliation of Grants Awarded	2020	2019
Opening liability obligation	670,229	626,843
Research grants awarded in the year	195,067	421,662
Research grants refunded in the year	(5,232)	-
Provisions no longer required	(6,808)	(2,274)
Paid during the year	(216,722)	(376,002)
Closing liability obligation	636,534	670,229
Split as: Due within one year	617,720	545,474
Due after more than one year	18,814	124,755

#### **20. OPERATING LEASE COMMITMENTS**

The following operating lease payments are committed to be paid:

	LAND AND BUILDINGS		OTHER OPERATING LEAS	
	2020	2020 2019		2019
	£	£	£	£
Expiring:				
Within one year	16,797	16,797	6,161	7,585
Between one and five years	35,121	51,918	1,394	7,555
Total	51,918	68,715	7,555	15,140

#### 21. MOVEMENT IN FUNDS

	NET MOVEMENT			
	AT 1/1/20	IN FUNDS	31/12/20	
	£	£	£	
Unrestricted funds				
General fund	1,072,071	1,100,365	2,172,436	
Restricted funds				
Ewing Sarcoma	0.100		0.100	
Ewing's Sarcoma Research Trust	2,198 109,798	- 78,257	2,198 188,055	
Liberty Schurer Frank's Fund	81,934	62,202	144,136	
Fitzy's Fund	-	41,979	41,979	
Freddie's Future	_	36,045	36,045	
Other funds restricted to research into Ewing Sarcoma	23,333	35,714	59,047	
Osteosarcoma				
Rhodri Jones	20	6,105	6,125	
Tom Hunt	13,149	(10,438)	2,711	
In support of Mary Collard	725	27,023	27,748	
Tom Stead Other funds restricted to research into estacearcome	786	6,901	7,687	
Other funds restricted to research into osteosarcoma	2,113	18,013	20,126	
Other research				
Miss Margaret Butters Reekie Charitable Trust	-	10,000	10,000	
The Liz Clarke-Saul Fund	22,498	(12,025)	10,473	
Christopher Spratt Other funds restricted to research	302 2,492	(302) 3,654	6,146	
Other fullus restricted to research	2,492	3,034	0,140	
Infrastructure Grant QBE Foundation	13,027	(12,290)	737	
PF Charitable Trust	1,000	10,000	11,000	
Doris Field Charitable Trust	5,000	2,500	7,500	
Other funds restricted to infrastructure grants	1,000	5,240	6,240	
Methotrexate prodrug				
Balcombe Trust	-	10,000	10,000	
The Charity of Stella Symons	-	10,000	10,000	
Support, information, and awareness				
Takeda	20,727	-	20,727	
My Blue Heart	-	4,309	4,309	
James Tudor Foundation	-	7,100	7,100	
	300,102	339,987	640,089	
TOTAL FUNDS	1,372,173	1,440,352	2,812,525	

#### 21. MOVEMENT IN FUNDS - CONTINUED

Net movement in funds, included in the above are as follows:

	INCOMING ESOURCES	RESOURCES EXPENDED	GAINS AND LOSSES	MOVEMENT IN FUNDS
	£	£	£	£
Unrestricted funds				
General fund	2,186,682	(1,120,308)	33,991	1,100,365
Restricted funds				
Ewing Sarcoma				
Liberty Schurer	85,725	(7,468)	-	78,257
Frank's Fund	72,139	(9,937)	-	62,202
Fitzy's Fund	41,979	-	-	41,979
Freddie's Future	36,045	-	-	36,045
Other funds restricted to research into Ewing Sarcom	a 35,714	-	-	35,714
Osteosarcoma				
Rhodri Jones	11,105	(5,000)	-	6,105
Tom Hunt	-	(10,438)	-	(10,438)
In support of Mary Collard	50,992	(23,969)	-	27,023
Tom Stead	9,901	(3,000)	-	6,901
Other funds restricted to research into osteosarcoma	23,183	(5,170)	-	18,013
Other research				
Miss Margaret Butters Reekie Charitable trust	10,000	-	-	10,000
The Liz Clarke-Saul Fund	32,407	(44,432)		(12,025)
Christopher Spratt	4,004	(4,306)	-	(302)
Other funds restricted to research	13,202	(9,548)	-	3,654
Infrastructure Grant				
QBE Foundation	-	(12,290)	-	(12,290)
PF Charitable Trust	10,000	-	-	10,000
Doris Field Charitable Trust	2,500	-	-	2,500
Other funds restricted to infrastructure grants	8,240	(3,000)	-	5,240
Methotrexate prodrug				
Balcombe Trust	10,000	-	-	10,000
The Charity of Stella Symons	10,000	-	-	10,000
Support, information, and awareness				
My Blue Heart	4,309	-	-	4,309
The National Lottery Community Fund				
(Coronavirus Community Support Fund)	66,015	(66,015)	-	-
Children with Cancer	20,000	(20,000)	-	-
James Tudor Foundation	7,100	-	-	7,100
Edward Gostling Foundation	4,800	(4,800)	-	-
	569,360	(229,373)	-	339,987
TOTAL FUNDS	2,756,042	(1,349,681)	33,991	1,440,352

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#### 21. MOVEMENT IN FUNDS - CONTINUED

	NE AT 1/1/19	T MOVEMENT IN FUNDS	31/12/19
	£	£	£
Unrestricted funds General fund	655,353	416,718	1,072,071
Restricted funds			
<b>Ewing sarcoma</b> Ewing's Sarcoma Research Trust	86,541	(84,343)	2,198
Liberty Schurer	125,499	(15,701)	109,798
Frank's Fund	-	81,934	81,934
Jordon Wilson	-	5,102	5,102
Other funds restricted to research into Ewing Sarcoma	10,713	7,518	18,231
Osteoscarcoma	00.700	(00.077)	705
In support of Mary Collard Tom Stead	28,798 16,536	(28,073) (15,750)	725 786
Tom Hunt	10,550	13,149	13,149
Clive and Sylvia Richards Charity	_	-	-
Daniel Bridle	14	(9)	5
Other funds restricted to research into osteosarcoma	1,683	445	2,128
Infrastructure grant			
QBE Foundation	24,579	(11,552)	13,027
PF Charitable Trust Barbour Foundation	10,000 5,000	(9,000) (5,000)	1,000
Other funds restricted to infrastructure grants	6,000	-	6,000
Methotrexate prodrug Three Ells Trust	10,000	(10,000)	
Balcombe Trust	10,000	(10,000)	
Funds restricted to Methotrexate PhD awarded by BCRT in 2018	7,132	(7,132)	-
Other research			
Christopher Spratt	16,476	(16,172)	304
The Liz Clarke-Saul Fund	-	22,498	22,498
Other funds restricted to research	347	2,145	2,492
Non research			
Takeda	1,980	18,745	20,725
Other funds restricted to non-research charitable activities	1,000	(1,000)	
	362,298	(62,196)	300,102
TOTAL FUNDS	1,017,651	354,522	1,372,173

#### 21. MOVEMENT IN FUNDS - CONTINUED

Net movement in funds, included in the above are as follows:

	ICOMING SOURCES	RESOURCES EXPENDED	GAINS AND LOSSES	MOVEMENT IN FUNDS
	£	£	£	£
Unrestricted funds				
General fund	992,583	(702,377)	126,512	416,718
Restricted funds				
Ewing sarcoma				
Ewing's Sarcoma Research Trust	-	(84,343)	-	(84,343)
Liberty Schurer	145,775	(161,476)	-	(15,701)
Frank's Fund	105,557	(23,623)	-	81,934
Jordon Wilson	10,102	(5,000)	-	5,102
Other funds restricted to research into Ewing Sarcoma	21,503	(13,985)	-	7,518
Osteosarcoma				
In support of Mary Collard	72,694	(100,767)	_	(28,073)
Tom Stead	19,554	(35,304)	_	(15,750)
Tom Hunt	43,000	(29,851)	_	13,149
Clive and Sylvia Richards Charity	85,000	(85,000)	_	15,145
Daniel Bridle	19,209	(19,218)	_	(9)
Other funds restricted to research into osteosarcoma	19,509	(19,064)	-	445
Infrastructure grant QBE Foundation	25,317	(76.960)		(11,552)
PF Charitable Trust	25,517	(36,869)	-	
Barbour Foundation	5,000	(9,000) (10,000)	-	(9,000) (5,000)
Other funds restricted to infrastructure grants	3,000	(3,000)	_	(3,000)
Other fullus restricted to lilitastructure grants	3,000	(3,000)	_	_
Methotrexate prodrug				
Three Ells Trust	-	(10,000)	-	(10,000)
Balcombe Trust	10,000	(20,000)	-	(10,000)
Funds restricted to Methotrexate PhD awarded				
by BCRT in 2018	-	(7,132)	-	(7,132)
Other research				
Christopher Spratt	3,274	(19,446)	_	(16,172)
The Liz Clarke-Saul Fund	22,498	(13,440)	_	22,498
Other funds restricted to research	30,265	(28,120)	-	2,145
Non research	40.705	(01.000)		10.745
Takeda	40,725	(21,980)	-	18,745
Other funds restricted to non-research charitable activities	_	(1,000)	_	(1,000)
	681,982	(744,178)	-	(62,196)
TOTAL FUNDS	1,674,565	(1,446,555)	126,512	354,522

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#### 22. RESTRICTED FUNDS

#### **Ewing Sarcoma**

The Ewing's Sarcoma Research Trust Restricted Fund represents monies restricted for research into Genotype and Phenotype Self-renewing cancer-initiating Ewing Sarcoma, the National Ewing Sarcoma Multi-Disciplinary Team Meeting and oncolytic virus therapy for Ewing sarcoma.

The Liberty's Legacy Restricted Fund represents monies restricted for research into Ewing Sarcoma.

Franks fund represent monies restricted for research into Ewing Sarcoma.

The Jordon Wilson Restricted fund represent monies restricted for research into Ewing Sarcoma.

Fitzy's Fund represents monies restricted for research into Ewing Sarcoma

Freddie's Future Restricted Fund represents monies restricted for research into Ewing Sarcoma

Other funds represent monies restricted for research into Ewing Sarcoma.

#### Osteosarcoma

The Mary Collard Restricted Fund represents funds restricted for research into Osteosarcoma.

The Tom Stead Restricted Fund represents monies restricted for research into Osteosarcoma.

The Tom Hunt Restricted Fund represents monies restricted for research into Osteosarcoma

The Clive and Sylvia Richards Charity Restricted Fund represents monies restricted for research into Osteosarcoma.

The Rhodri Jones Restricted Fund represents monies restricted for research into Osteosarcoma

Other funds represent monies restricted for research into Osteosarcoma.

#### **Infrastructure grant**

The QBE Foundation Restricted Fund represents monies restricted to the 2018 Birmingham Infrastructure Grant.

The PF Charitable Trust Fund represents monies restricted to the Oxford Infrastructure Grant.

The Barbour Foundation Fund represents monies restricted to the Newcastle Infrastructure Grant.

The Doris Field Charitable Trust represents monies restricted to the Oxford Infrastructure Grant.

Other funds represent monies restricted to Infrastructure grants.

#### **Methotrexate prodrug**

The Methotrexate prodrug Fund represents monies restricted to the PhD awarded by BCRT in 2018 seeking to develop a targeted methotrexate prodrug.

The Three Ells Trust Fund represents monies restricted to the PhD awarded by BCRT in 2018 seeking to develop a targeted methotrexate prodrug.

The Balcombe Trust Fund represents monies restricted to the PhD awarded by BCRT in 2018 seeking to develop a targeted methotrexate prodrug.

The Charity of Stella Symons represents monies restricted to the PhD awarded by BCRT in 2018 seeking to develop a targeted methotrexate prodrug

#### Other research

The Christopher Spratt Restricted Fund represents monies restricted for research into chordoma and chondrosarcoma.

The Liz Clarke-Saul Fund represents monies restricted for research into adamantinoma.

The Miss Margaret Butters Reekie Charitable Trust represents monies restricted to the ICONIC research programme.

Other funds represent monies restricted to research

#### Non research

The Takeda Restricted Fund represents monies restricted to the BCRT annual conference and development of the BCRT website.

The National Lottery Community Fund (Coronavirus Community Support Fund) represents monies restricted to support and information activities.

The Children with Cancer fund represents monies restricted to information and awareness activities

The James Tudor Foundation fund represents monies restricted to a patient amputation resource

The Edward Gostling fund represents monies restricted to support groups.

The My Blue Heart fund represents monies restricted to support.

Other funds represent monies restricted to non-research charitable activities.

#### 23. DESIGNATED FUNDS

AT 1/1/20	PAID	DESIGNATED	AT 31/12/20
£	£	£	£
-	-	29,000	29,000
120,000	(120,000)	67,000	67,000
-	_	175,000	175,000
-	-	43,000	43,000
-	-	175,000	175,000
120,000	(120,000)	489,000	489,000
	120,000 - -	£ £  120,000 (120,000)	£ £ £ £  29,000 120,000 (120,000) 67,000 175,000 - 43,000 - 175,000

Our Financial Support Grants for patients, launched in January 2021, are available to help with the extra costs that bone cancer treatment can bring.

Infrastructure grants support tissue collection across treatment centres in the UK.

The ICONIC programme supports the collection of tissue samples from osteosarcoma patients, with the aim of improving future outcomes.

Information and awareness charitable activities support planned patient advocacy and the creation and distribution of targeted information resources.

Other designated grant funds relate to an open grant call, to celebrate the charity's 15th year of operation.

#### 24. RELATED PARTY DISCLOSURES

Trustees are required to disclose all relevant interests and register them with the Finance Clerk and in accordance with the charity's policy to withdraw from decisions where a conflict of interest arises.

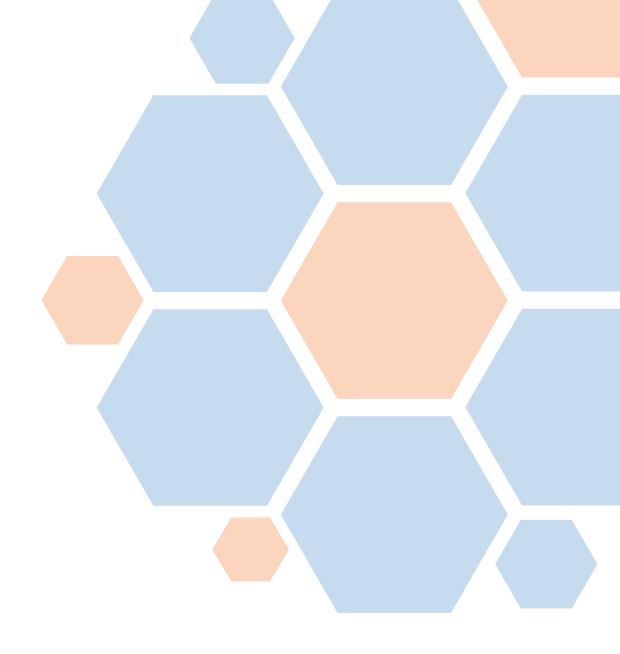
Any individual with an interest in a matter being discussed at a meeting must declare the interest to the meeting. The chairman of the meeting will then decide whether that individual should withdraw during the discussion and, if not, whether the individual should be entitled to vote on the matter under discussion.

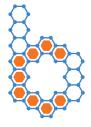
During the year ended 31st December 2020, consultancy services of £1,620 (2019: £1,080) were provided by one of the trustees to the charity.

#### **25. COMMITMENTS**

As at 31 December 2020 the charity as committed to funding the further research grants of £361,301. These commitments are subject to conditions and review within the control of the charity and accordingly not recognised as grant liabilities within notes 18 and 19.







#### ©Bone Cancer Research Trust 2021

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Charitable Incorporated Organisation (CIO) Number - 1159590

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