# ANNUAL **REPORT &** ACCOUNTS 2019



#### THE NATIONAL CHARITY AWARDS

WINNER & Medical Research Charity of the Y

INSTITUTE OF FUNDRAISING YORKSHIRE & HUMBER AWARDS

Fundraising Team and Campaign of the Year



# CONTENTS

- Vision / Mission / Values
- Chairman's Introduction 04
- Income & Spend -05
- 2019 in Numbers -06
- 07-09 Research
- 10-11 Information
- 12-13 Awareness
- 14-15) Support
- Our Fundraising Approach
- Thank you
- Reference and Administrative Details
- 20-24) Report of The Trustees
- 25-43 Report of the Independent Auditors and Financial Statements

## **OUR VISION** A WORLD WHERE PRIMARY BONE CANCER IS CURED

**OUR MISSION** TO SAVE LIVES AND IMPROVE OUTCOMES FOR PEOPLE AFFECTED BY PRIMARY BONE CANCER

# **OUR VALUES**

- DYNAMIC WE DON'T STAND STILL, WE INNOVATE, WE CELEBRATE EVERY SUCCESS
- **SUPPORTIVE** WE LISTEN, WE UNDERSTAND, WE CARE.
- TRUSTWORTHY WE DO WHAT WE SAY.





• PIONEERING WE LEAD THE WAY, WE LEAVE NO STONE UNTURNED, WE ARE PREPARED TO TAKE RISKS. • KNOWLEDGEABLE WE KNOW OUR STUFF, WE ARE EAGER TO KNOW MORE.

# **CHAIRMAN'S** INTRODUCTION

# INCOME & SPEND

Welcome to our 2019 Annual Report & Accounts. What an incredible year it has been for the Bone Cancer Research Trust. With the unabated support of the primary bone cancer community we were able to continue driving forward our life-saving research whilst raising vital awareness and supporting thousands of patients and families here in the UK and abroad.

Since 2006, the Bone Cancer Research Trust has been at the forefront of the fight against primary bone cancer. Our patients and ultimate mission to finding a cure has always been our priority. When other organisations have not prioritised primary bone cancer, or given it the attention it requires, we have remained undeterred in our efforts.

So, what an honour it was that on 5th June, we were recognised for our work and were awarded National Healthcare & Medical Research Charity of the Year at the Charity Awards. An incredible honour and an absolute tribute to all our patients, supporters, volunteers and staff that have made the Bone Cancer Research Trust the world-leading organisation that it is today. From a small group of families driven by personal loss to a leading force for change, actively saving lives.

Over the last few years, we have continued to diversify our income sources to ensure we are more able and even better organised to deliver our 2017 - 2022 strategic aims and objectives. 2019 was no exception, we really cemented new income methods and expanded our fundraising team to ensure we are generating greater levels of net income that we can channel into our charitable work. Overall, we increased the efficiency of our fundraising for a fourth year, increasing by 13% from 2018.

The day-to-day operational management and delivery of the charity remains in the hands of our Senior Leadership Team. We continue to operate a unique and efficient management structure without the need for a Chief Executive. Throughout the year, we welcomed new individuals to our staff team, yet we have also continued to work hard on containing costs and making savings. Wherever possible we have ensured the highest possible percentage of supporter donations can go into furthering our charitable delivery.

2019 remained a strong and successful year for our research Grant Programme, with £580,252 spent on pioneering research. We have now delivered 58% of our 2017 – 2022 £2.8million research commitment. We are pleased to see that demand for primary bone cancer research funding continues to increase but our commitment to only funding the best research with maximum patient benefit remains; the overall success rate for applications in 2018 was 38%.

In 2018 I told you about the launch of ICONIC, our first ever Clinical / Translational Grant, I am delighted to tell you that in October, the project passed ethical approval and began recruiting osteosarcoma patients. This marks a huge step forward for osteosarcoma research in the UK and we will continue to report on it's progress over time.

Throughout the year our awareness activities reached the highest number of individuals yet; we continued to educate and increase awareness of primary bone cancers and tumours amongst the public and healthcare professionals. Plans are underway for a large-scale campaign in 2020 which we hope will make the biggest meaningful impact yet to improving earlier diagnosis for patients.

Another highlight for the year was the launch of our Support & Information Service. Originally unplanned in our 2017 – 2022 strategy, it became clear in recent years that our community wanted and expected to come to the Bone Cancer Research Trust for bespoke, primary bone cancer-specific help, support and information. In response to this increasing demand and unmet need, we launched our new service offering telephone, online and face-toface support.

Our dedicated staff team continue to drive forward our charity, making the biggest impact possible for our patients. Their expertise and diligent approach continue to take the Bone Cancer Research Trust from strength to strength. But it is YOU, our incredible community that are ensuring we can continue to offer hope to all those affected by this brutal disease now and for years to come.

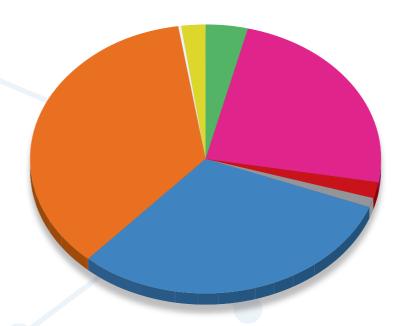
On behalf of all of us at the Bone Cancer Research Trust, thank you!

Until There's A Cure,

This

Andy Lewis Chairman

Our income in 2019 totalled £1,674,565. This came from:

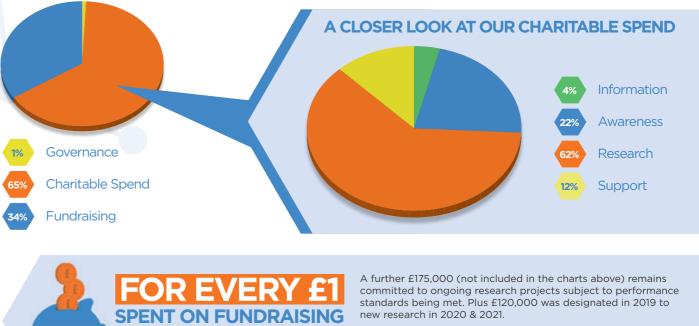


#### Our total expenditure in 2019 was: £1,446,555

WE RAISED £3.38

FOR OUR LIFE-SAVING WORK

£3.38



ANNUAL REPORT AND ACCOUNTS 2019



standards being met. Plus £120,000 was designated in 2019 to new research in 2020 & 2021.

THIS TAKES THE AMOUNT THAT WE HAVE COMMITTED TO CHARITABLE ACTIVITIES AT THE END OF 2019 TO £1,233,087



# **2019 IN NUMBERS**

36,000,000		Throughout 2019 we reached over <b>36,000,000</b> people internationally through our awareness activities
4,000,000	<b>\$</b>	Bone Cancer Awareness Week (our main awareness campaign) reached over 4,000,000 people
3,864,634	À	We reached 80 research grants awarded since 2006 totaling <b>£3,864,634</b>
1,233,087	0	We committed <b>£1,233,087</b> to fighting primary bone cancer
580,253	À	We spent <b>£580,253</b> on pioneering research
288,415		288,415 unique visitors accessed over 3,000,000 pages on our website
195,987		Our incredible social media supporters grew to <b>195,987</b>
166,272	2	Our patient stories were accessed <b>166,272</b> times as a source of strength and information
25,548	Q	A total of <b>25,548</b> Support & Information resources were distributed
23,000		Over 23,000 copies of our free supporter magazine, United, were distributed
18,598	8	A total of 18,598 hours was spent on our Support & Information pages on our website
8,401	Q	We distributed <b>8,401</b> information resources to hospitals across the UK
2,295	À	<b>2,295</b> primary bone cancer samples were collected for use in research through our Infrastructure Grants
1,392	<b>(3</b> )	<b>1,392</b> individuals ran, walked, trekked, cycled, swam and dived from the skies in support of our life- saving work
854		We offered direct support to <b>854</b> individuals
001	<u></u>	We oncled direct support to Gov individuals
828		828 copies of our Step-By-Step Guide for Patients were distributed
828		828 copies of our Step-By-Step Guide for Patients were distributed
828 644		828 copies of our Step-By-Step Guide for Patients were distributed We sent out 644 printed information resources that were requested by post
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## **STRATEGIC OBJECTIVES & ACHIEVEMENTS** RESEARCH

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 Grai **GRANT TYPE/YEAR** 2017 201 **CLINICAL / TRANSLATIONAL** 1 EARLY CAREER FELLOWSHIP 11 PHD STUDENTSHIP $\checkmark$ **INFRASTRUCTURE GRANTS** 11 $\checkmark$ **EXPLORER** // **IDEAS** OTHER RESEARCH INVESTMENT /

🗸 AWARDED AS PLANNED 🗸 ADDITIONAL UNPLANNED AWARD 🗸 CALL CANCELLED DUE TO ADDITIONAL PHD STUDENTSHIP 🗸 PLANNED 🗸 GRANT AWARD DEFERRED TO 2020

#### Grants awarded in 2019

LEAD RESEARCHER	PROJECT TITLE	GRANT TYPE	AWARD VALUE
Dr Adam Cribbs & Dr Lucia Cottone	Therapeutic targeting and understanding of oncogenic driver networks in chordoma	Explorer	£59,696.72
Professor Agi Grigoriadis	Haem oxygenase-1 (HO-1), a novel druggable target for prevention of osteosarcoma growth and metastasis	Explorer	£70,000
Dr Iben Lyskjaer	Validation of DNA methylation-specific markers for circulating tumour Dna Analysis In Sarcoma Patients	Ideas	£15,000
Professor Susan Burchill	Identification of the lead candidate nrxn1 isoform as a prognostic biomarker and a novel target for therapy	Ideas	£14,709.86
Professor Adrienne Flanagan	Sample collection support - Stanmore	Infrastructure	£19,873.00
Mrs Carolyn Langford	Sample collection support - Birmingham	Infrastructure	£24,579.00
Mr Kenny Rankin	Sample collection support - Newcastle	Infrastructure	£16,000.00
Mr Tom Cosker	Sample collection support - Oxford	Infrastructure	£9,000.00

#### Second Stage Grants awarded in 2019

LEAD RESEARCHER	PROJECT TITLE	GRANT TYPE	AWARD VALUE
Professor Graham Cook	Oncolytic virus therapy for Ewing's sarcoma	PhD (Yrs 2-4)	£120,500
Professor Robert Falconer	Development of a targeted methotrexate prodrug with enhanced therapeutic index for osteosarcoma	PhD (Yrs 2-4)	£72,303



3	2019	2020	2021	2022
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	1	1	1	1

# **STRATEGIC OBJECTIVES & ACHIEVEMENTS** RESEARCH



Collaboration in research is becoming increasingly important, especially in rare cancers such as primary bone cancer, we take great pride encouraging, initiating and supporting collaboration at every opportunity at the Bone Cancer Research Trust, both between our researchers and with other like-minded charities and organisations and 2019 was an exemplary year for this.

In January, the Bone Cancer Research Trust collaborated with Children with Cancer UK to deliver the first International Osteosarcoma Research Symposium. The symposium, which took place at Goodenough College, London, attracted the most prominent academic and clinical researchers in the field, with Professor Richard Gorlick flying in from MD Anderson in Texas, USA, and Professor Stefan Bielack flying in from the Stuttgart Cancer Center, Germany, to give keynote speeches. In total, 66 delegates attended to discuss progress being made in osteosarcoma, both in the UK and further afield, and to identify future areas of priority.

This symposium highlighted the importance of collaboration in progressing our understanding of osteosarcoma and the development of new treatments. As a result, a group of 6 researchers were brought together by the Bone Cancer Research Trust after recognising their common areas of expertise. These researchers went on to establish OMeNet (Osteosarcoma Metastasis Network). another inspirational example of new collaboration.



2019 was an important and exciting year for the Bone Cancer Research Trust, with the opening of our first ever observational clinical trial ICONIC; a study focussed on osteosarcoma, and the first ever clinical study to include all osteosarcoma patients, irrespective of age and location of their tumour. ICONIC will offer the unique opportunity to learn from osteosarcoma patients, by capturing detailed medical data and comparing this to the biology of their tumour, which will hopefully allow clinicians to understand, for the first time, why some patients respond to treatment. yet others do not. We are hopeful that this project may bring us one step closer to personalised medicine.

We were excited to attend the launch event, along with our two patient representatives, Pete Lloyd and Dr Phillip Green, who provided a patient's perspective in the trial protocol and information sheets. The event took place in February 2019, as part of the British Sarcoma Group meeting in Glasgow and was attended by many of the collaborating centres and key partners of the study and generated much discussion. It was heart-warming to see the dedication of the lead investigator, Dr Sandra Strauss, and the clinical community uniting, from all parts of the UK, to make a difference for osteosarcoma patients. After successfully gaining ethical approval, the study opened

in October 2019 and subsequently recruited 12 patients in the remainder of the year.

In November, we hosted a Chondrosarcoma Trial Development Workshop, which took place as part of the National Cancer Research Institute's Bone Sub-group meeting. The workshop brought together 18 clinical and academic researchers with an interest in chondrosarcoma, to discuss the progress being made in current trials and biological studies and plan future projects. Chondrosarcoma is a priority for the Bone Cancer Research Trust as surgery remains the only approved treatment option for chondrosarcoma, something we are determined to change. At the workshop we launched a dedicated research funding call restricted to chondrosarcoma, in order to ensure continued progress is made.

2019 saw the Bone Cancer Research Trust award the highest number of new and second stage grants in a oneyear period; awarding 10 in total at a value of £421,662. Our total investment into research in 2019 was £580,253.

Our Infrastructure Grants to the five specialist Bone Cancer Centres in England ensured that the necessary resources were in place to continue patient sample collection. Because of our grants, bone sarcomas were one of the highest represented forms of cancer to be entered into the 100 Genomes Project. The data from this project represented an incredible opportunity to push forward understanding of cancer and stimulate new research, we had to ensure that primary bone cancer patients would benefit. In 2019, 2,295 patient samples were collected to support 16 pioneering research projects funded by the Bone Cancer Research Trust and other organisations. These grants have also enabled the collection of 1.533 patient samples to be bio-banked to enable future research.

It was for our innovative approach to supporting patient sample collection that we were awarded National Healthcare & Medical Research Charity of the Year at the 2019 Charity Awards.

Our supporters are passionate about the research we fund and we are always keen to show them the impact their donations make. In 2019, we held three laboratory open days: one in Bradford, to go behind the scenes in the lab of Professor Robert Falconer, who is currently attempting to chemically modify methotrexate to make it a more effective and less toxic treatment for osteosarcoma; and two in Leeds, with Professor Sue Burchill and her team who are trying to understand why some Ewing sarcoma cells evade treatment; and Professor Graham Cook and his team, who are developing an oncolytic virus therapy for the treatment of Ewing sarcoma.

# 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 2019 was £580,253, which includes the award of 8 new research grants.

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

In 2019 we awarded 2 Ideas Grants, which is 1 more than originally planned. These two projects will gather preliminary data on the epigenetics of osteosarcoma and a potential new target in Ewing sarcoma. We also awarded 2 new Explorer Grants, again, one more than was originally planned. These projects focus on the development of pioneering new treatments for osteosarcoma and chordoma.

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

After successfully completing their transition exam, we awarded funding for years 2-4 of our two current PhD studentships, initially awarded in 2018. Our Ideas and Explorer Grants are supporting post-doctoral researchers at all stages of their careers. One of these projects is supporting a junior postdoctoral researcher and the other is enabling a young research fellow to develop into an independent researcher.

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

In 2019, we provided Infrastructure grants to four of the five specialist Bone Cancer Centres to support sample collection, with the 5th deferred until 2020 due to staffing issues.

# WHAT WE'RE GOING TO DO IN 2020

1

- 2 Research Grant to support postdoctoral researchers wishing to stay in the field.
- We will launch a new type of Research Grant, aimed at research professionals, to support travel to research 3 conferences and other research laboratories to expand knowledge and learn new essential research skills.
- 2020 marks the 100th year anniversary of the identification of Ewing sarcoma, by James Ewing. To mark this





We're going to continue to support all stages of research by funding a PhD studentship to allow a graduate to specialise and start their career in the field of primary bone cancer. We will also fund an Ideas and an Explorer

occasion, we will hold an International Ewing Sarcoma Research Symposium to accelerate progress in this area.

# **STRATEGIC OBJECTIVES & ACHIEVEMENTS** INFORMATION



#### In 2019 we continued to be the go-to organisation for trustworthy and accurate information for all forms of primary bone cancer and tumour.

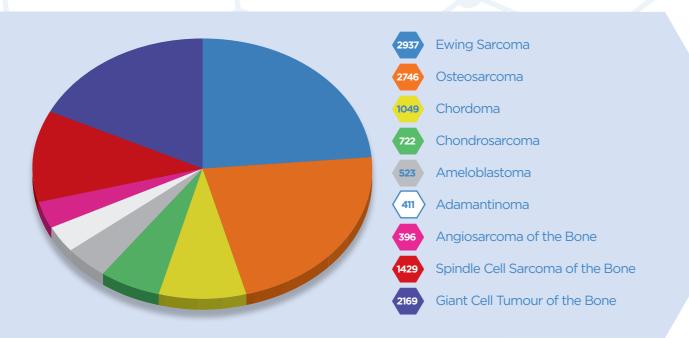
During the year we saw unprecedented demand for our information resources, driven, in part by the introduction of our new Support & Information Service. In total 25,548 resources were distributed across the UK and internationally to patients, family members and healthcare professionals. Additionally, demand continued to rise with more individuals than ever before accessing our information online from the UK and overseas.

We continued to promote information for the rarer forms of primary bone cancer to ensure patients do not face this disease ill-informed or unaware of our resources. We did this digitally and face-to-face at a variety of events across the UK. As a direct result, we saw a substantial increase in demand for information covering the less common forms of primary bone cancer. Below is a chart, demonstrating the number of primary bone cancer-specific printed materials we distributed in 2019.

We continue to be the only organisation to have developed freely available, dedicated information for all forms of primary bone cancer and primary bone tumours, therefore it is imperative that we continue to promote these materials in a way that will reach patients.

Throughout the year we continually reviewed our information and our approach to ensure we were meeting the needs of our community. To ensure we were reaching patients with information where and how they needed us, we delivered 13 Support & Information Days across the UK, below is a quote from a current patient we spoke with at one of these events.

I just wanted to make contact to say thank you for the resources. I was sent your information booklet last week and found it very informative and easy to follow. It also highlighted your website to me, and I absolutely loved the section with all the real-life stories to read highlighting that I am not alone...



## **IN 2019 WE DISTRIBUTED** A TOTAL OF 25,548





## 2017-2022

# 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.

We continued to promote and distribute our 2018-developed Step-By-Step Guide for Patients in 2019. To date, 1,457 copies have been distributed to support patients.

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

Demand for our children's resources rose by 198% in 2019. We have now distributed 1,797 copies of Harry has an Operation and Abbie has Osteosarcoma to support children and their families facing a bone cancer journey.

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

We continued to ensure our website was optimised for individuals abroad to access our information. The highest number of international vistors accessing our information came from the United States, Russia, Canada, Germany, Australia, Sweden, Netherlands, India and France. Additionally, our Polish translated guide to Ewing sarcoma was accessed 826 times online.

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

Throughout the year our online hub for healthcare professionals was accessed 1.099 times - this was broadly in line with what we saw in 2018.

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

Our Step-by-Step Guide for Patients was developed with families and carers in mind, and as a result, is an interactive resource that can be used by the whole family.

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

We understand and recognise that we cannot provide specialist information on all issues faced by primary bone cancer patients and signposting to recognised and trusted charities and organisations is the best way to ensure our patients can access a full range of information. Through our new Support & Information Service and our website we now signpost to over 70 other useful organisations for our patients and family members.

# WHAT WE'RE GOING TO DO IN 2020

- We will begin a review of our information resources and phase out the discontinued Information Standard 1
- We will gather new data and produce robust new information on signs and symptoms of primary bone cancer for the public and healthcare professionals.
- We will deliver information on a range of key themes that are currently outside our standard information 3 portfolio and we will explore new ways to deliver information for patients and their families.





## **STRATEGIC OBJECTIVES & ACHIEVEMENTS AWARENESS**

In 2019 we focused our awareness activities in two ways; raising awareness amongst the public and raising awareness amongst healthcare professionals to improve earlier diagnosis. We continued to deliver an array of initiatives centred around internationally recognised campaigns and, as always, our main awareness focus was Bone Cancer Awareness Week in October which reached over 4 million individuals.

In total our public awareness activities reached over 36.000.000 people, in addition we reached a further audience of 21,068,942 though mentions and stories in the media. Our increased reach dramatically increased digital engagement with the charity and we saw a massive increase of interaction across our social media channels. To meet this demand and to ensure we could continue providing awareness-raising content, we recruited a Digital Communications Executive into the team- an essential step which has proven invaluable at bolstering our capabilities and responsiveness.

We have ensured that all our public facing communications always tie back to our strategic aims and objectives. Throughout 2019 It was pleasing that we continued to receive praise and feedback from our community that we were, indeed, delivering on our strategic objectives and 2017 - 2022 commitments.

To aid our healthcare professional-focussed awareness activities, we appointed our first ever GP Ambassador. Dr Phillip Green. Since appointment, Dr Green's insight and knowledge have been invaluable in aiding our planning and shaping our activities.

With the assistance of Dr Green, we gathered data and started laying the foundations of a large-scale awareness campaign to specifically educate healthcare professionals on the presenting signs and symptoms of primary bone cancer across the UK - this is planned to take place during 2020.

In November and December we were delighted to host 5 third-year medical students from The University of Sheffield as part of their social accountability module. As part of this placement, the students conducted a review of our GP Training Module and developed a new learning resource aimed at medical students but applicable for all healthcare professionals to improve understanding of primary bone cancer. In 2019, 600 copies of this resource were distributed to all third-year medical students at The University of Sheffield and it is now also freely available as a training resource on the website for The Musculoskeletal Association of Chartered Physiotherapists.

WE REACHED OVER

36,000,000

**PEOPLE INTERNATIONALLY** 

## 2017-2022

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

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

During each public awareness campaign we launched in 2019, we ensured GPs were part of our focussed targeting, using video and links to our online resources. Our Symptoms Awareness Video, fronted by patients and our GP Ambassador, Dr Phillip Green was viewed 208,912 times during the year. We began groundwork for a UK wide campaign targeting GPs in 2020.

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

Our online hub for healthcare professionals was accessed 1,099 times in 2019 providing the healthcare community with dedicated and bespoke primary bone cancer information to aid correct identification of symptoms. We began groundwork for a UK wide campaign to target wider healthcare professionals in 2020.

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

We continued to fund the National Sarcoma Awareness Project in 2018, to date over 1,000 medical students and junior doctors have been educated by the project. In 2018 we funded 4 top performing students to undertake short term Clinical Fellowships at regional sarcoma treatment centres. As a direct result of participating in the project, one student went on to identify a sarcoma patient during the year, accelerating the patient's diagnosis and start of treatment.

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

We delivered various awareness raising campaigns focused around; World Cancer Day, Rare Diseases Day, Sarcoma Awareness Month, Childhood Cancer Awareness Month and Bone Cancer Awareness Week throughout the year, Each carried it's own theme to increase awareness of symptoms and diagnosis of primary bone cancer. We also showcased incredible professional individuals from the primary bone cancer community to recognise their contribution and encourage others to focus in the field of bone tumours. Throughout the year 3,200,548 webpages were accessed on our website from an international audience, driven by our public awareness activities.

# WHAT WE'RE GOING TO DO IN 2020

- We're going to launch a large scale, multi-faceted campaign to reach every GP, Radiologist, Musculoskeletal and diagnose primary bone cancer.
- We will focus Bone Cancer Awareness Week 2020 on early diagnosis and the training of healthcare
- We will continue to deliver national and international awareness campaigns focussing on the different aspects of a primary bone cancer journey.





## **STRATEGIC OBJECTIVES & ACHIEVEMENTS** SUPPORT

In 2018, we conducted a survey to understand the support needs of our patients. This revealed that they weren't currently being served by existing support services offered by other charities. It became apparent that this unmet need could not be met by any existing organisation and that our patient community looked to the Bone Cancer Research Trust to provide this specialist support service. In 2019, as part of Sarcoma Awareness Month, we launched the UK's first ever dedicated primary bone cancer Support & Information Service.

Our Support & Information Service aims to offer an extra layer of support to that provided by healthcare professionals, who we work hand-in-hand with. To lead our dedicated Information & Support Service, we recruited a registered Adult Nurse, Louise Kirby, who we welcomed to the team in February 2019.

Throughout the year, we offered direct support to 854 individuals and 26 families shared their experiences with primary bone cancer to help others going through a similar journey. Our patient stories were viewed 166,272 times as a means of support - a 16% increase on views in 2018

We know that a primary bone cancer diagnosis can be lonely, with many of our patients feeling isolated and unable to get peer support. In recognition of this, we launched 8 dedicated Digital Support Groups, which remove the geographical barriers to accessing peer-topeer support. These digital groups have attracted 457 new members since their launch and have become a safe space for patients and families to share updates and ask questions about their journey.

Building on the success of the 2018 Bone Cancer Conference, the 2019 event, which took place between 28th - 30th June in Leeds, attracted 290 registrants. including 197 past & current patients and family members. We welcomed guest presenters from St Gemma's Hospice, Henry Dancer Days and Chemo Cookery Club to deliver key seminars on palliative and end of life care, support for children with bone cancer and the importance of nutrition when diagnosed with cancer.

The rest of the event was filled with emotional and moving patient stories and updates from Bone Cancer Research Trust funded researchers. In collaboration with Henry Dancer Days, we provided interactive storytelling sessions for the younger attendees.

The Bone Cancer Conference offers a free retreat for those affected by primary bone cancer, allowing overnight accommodation and the chance to meet others. For many, the Bone Cancer Conference offers the only chance to meet others diagnosed with a primary bone cancer.

Attendees reported a 63% reduction in feelings of anxiety by attending the event and 100% of guests rated it 'Good' to 'Excellent'. 56% of guests reported a reduction in feelings of social isolation and loneliness after attending and 100% of guests said they wanted to attend again.



### **OUR SUPPORT & INFORMATION SERVICE PROVIDES:**

- A freephone Support & Information Line 0800 111 4855 (Mon Fri 9am 5pm)
- Confidential and professional support from our Support Team
- Access to reliable, accurate and award-winning primary bone cancer and tumour specific information
- Correct signposting to organisations that can also assist you
- Access to patient stories and the opportunity to be connected with others, who have had similar experiences
- An annual conference, bringing together our community in a supportive and safe environment
- Primary bone cancer & tumour support support groups across the UK
- Dedicated digital support groups

## 2017-2022

# 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.

Throughout 2019 we actively provided a listening ear service through our new Support & Information Line. We also connected a number of families going through similar journeys, to provide one another mutual support.

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

During Bone Cancer Awareness Week 2019, we launched 8 dedicated Digital Support Groups, covering all forms of primary bone cancer and tumour.

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

On the 29th June, we held our highest attended conference to date, attracting delegates from across the world.

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

Throughout the year, we actively promoted the sharing of patient stories as a way of providing peer support. In 2019, 26 new families shared their experiences with us and our patient stories now cover 8 of the 9 forms of primary bone cancer and tumour.

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

In 2019, with the introduction of our new Support & Information Service, we set out to expand our links with other support-providing organisations and we now work collaboratively with Maggie's, Henry Dancer Days and Limb Power, to name a few.

# WHAT WE'RE GOING TO DO IN 2020

- We will promote and expand our Digital Support Groups to attract new members affected by all forms of primary bone cancer and tumours
- We will hold two Bone Cancer Conferences to meet ever growing demand and ensure we cover more geographical locations to improve accessibility to our flagship event.

3

We will explore new and innovative ways to reach all patients diagnosed with primary bone cancer.





ANNUAL REPORT AND ACCOUNTS 2019

# **OUR FUNDRAISING APPROACH & RESPONSE TO** COVID-19

In 2019 we continued our increased trajectory in fundraising, raising more than ever before in our history, £1,674,565. The driving force of our success continues to be our relationship-led approach, putting our supporters in the driving seat and offering fundraising options that are tailored to them and providing an exceptional supporter experience.

In recognition of our approach, techniques and achievements, we were awarded Fundraising Team of the Year and Fundraising Campaign of the Year at the Yorkshire & Humber Institute of Fundraising Annual Awards - two accolades we were honoured to receive.

In January 2019, we set an ambitious but realistic target for our fundraising of £1,159,487. Our supporters went above and beyond supporting our work. We were astounded by the creativity and diversity our community demonstrated through their fundraising which lead to us hitting and surpassing our targets.

It was a truly inspiring year with so many of our supporters having a personal connection to primary bone cancer. Their dedication, passion and determination were awe-inspiring. In total, 1,392 individuals took on various personal sporting challenges (an increase of 132% from 2018) whilst hundreds of others fundraised in their communities, organising their own events to generate funds. Our regular-giving Research Sponsors and loyal supporters who donate to us by Direct Debit continued their support, increasing our pool of reliable income for charitable activities.

In 2019, we continued our programme of fundraising diversification with great success. Our core income now comes from three main sources: Corporate / Trusts & Foundations, Community and Challenges & Events. Since 2017 we had been testing the viability of Corporate / Trusts & Foundations fundraising by using an external consultancy firm, in 2019 we recruited a new, in-house team to deliver this area of our fundraising portfolio.

At the Bone Cancer Research Trust we continue to follow individual and community-led fundraising methods, an approach that continues to work well for us, removing the need for higher cost, and sometimes more intrusive fundraising methods such as door-to-door or telemarketing fundraising. We continually assess the costs of our fundraising and work hard to find savings to invest back into our charitable work.

As we moved into 2020, we were hit with the unprecedented impact of COVID-19. We responded quickly and swiftly to safeguard our supporters, staff and volunteers. We worked hard to shore up our income sources that were most vulnerable to the impact of the pandemic and we began work to move our approach to virtual-based fundraising opportunities. Despite our best efforts, in March 2020 our monthly income was 80% lower than that which we had raised in March 2019.

Where possible we have deferred costs, negotiated no-cost extensions and reductions to our outgoing expenditure. We will continue to explore all new fundraising avenues and opportunities that arise to ensure our charitable activities are supported in line with our strategic plans throughout the rest of 2020 and into 2021.

The Bone Cancer Research Trust is a member of the Fundraising Regulator. During 2019 we received no complaints from the regulator relating to our fundraising activities.

> INDRAISING REGULATOR

**128 CYCLISTS COVERED 11,387** MILES

**16 SUPPORTERS SWAM 52 MILES** 

**15 BRAVE PEOPLE DIVED THROUGH** THE SKIES

**718 WONDERFUL RUNNERS RAN 5,955 MILES** 

65 JINGLE BONES CHRISTMAS JUMPER DAYS TOOK PLACE

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72 BAKE IT FOR **BONE CANCER EVENTS TOOK** PLACE

**22 INCREDIBLE** PEOPLE TOOK ON CHALLENGES **AROUND THE** GLOBE

**45 SUPPORTERS TOOK ON OBSTACLE RUNS** 

**64 TREKKERS TREKKED 1.612 MILES** 

**379 FUNDRAISING EVENTS WERE** ORGANISED BY **SUPPORTERS** 

\*

**384 PEOPLE STEPPED UP** FOR BONE CANCER

ANNUAL REPORT AND ACCOUNTS 2019

# THANK YOU

Thank you to everyone that supported us in 2019, in the UK and overseas! We value all those that support us, fundraise for us and work collaboratively with us, helping us strive to achieve our goals.

#### **Special Funds**

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

Adam Dealey, Adam Hassall Tribute Fund, Adam Panther Tribute Fund, Al Dawson Tribute Fund, Alex Albiston, Alex Lewis Memorial Fund, Anthony Pilcher, Chloë's Fight, Chris Fairley Fund, Christopher Hardman (CHORF), Christopher Spratt Tribute Fund, Daniel Bridle Memorial Fund, Daniel Humphreys Tribute Fund, Darren Wilkinson AmeloWarrior Fund, Dila's Fund, Emily Barker Tribute Fund, Frank's Fund, Gemma Pickering Tribute Fund, Guy Francis, James Stewart Tribute Fund, Jennifer Carvell, Jessica Gower My Blue Heart Fund, Jordon Wilson Tribute Fund, Jude's Fund, Ken Davies Tribute Fund, Kenny McCabe, Krystle Smith, Laura Connolly Tribute Fund, Liberty's Legacy, Liz Clarke-Saul Fund, Lol's Legacy, Mary Collard Tribute Fund, Matt's Beacon Fund, Nick Pollard, Pushing for a Cure (Pete Lloyd), Rhodri Jones Memorial Appeal, Ruth Grace's Battle, Scott Abbruzzese Memorial Fund, Tom Stead Tribute Fund, Ximena Howell

#### **Our Active Ambassadors**

Laurence Whiteley Dr Phillip Green Peter Lloyd

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

Clive & Sylvia Richards Charity Takeda UK **QBE** Foundation Ewing Sarcoma Research Trust Children with Cancer UK Impulse Decisions RNB Group Caddick Construction Garfield Weston Foundation Balcombe Trust Thompson Family Charitable Trust Chaldon Charities Trust Tom Hunt Trust Barbour Foundation Manning Stainton Shard Media Group Murray Harcourt Friends for Dinner Caddick Construction

#### Volunteers

Adam Bowers Aimee Hunter Felicity Smith Julie Scorer Terri Bush

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

#### **Patient Information Panel**

Pete Lloyd Phillipa Vance Jane Wingrove Daisy Wingrove Dr Phil Green

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

Dr Sandra Strauss Mr Kenneth Rankin Mr Craig Gerrand Mr Paul Cool Professor Alison Gartland Professor Susan Burchill Professor Robert Falconer Professor Graham Cook

### Other people or organisations that helped or support

Sam Created Middlechild Productions Keda Consulting Henry Dancer Days Amputation Foundation Chemo Cookery Club The Crosby Family – for their support for the Bone Cancer Conference Ricky Carrington Photography Romana Carter

## REFERENCE AND ADMINISTRATIVE DETAILS FOR YEAR ENDED 31ST DECEMBER 2019

#### **Trustees**

Andrew Lewis (Chair) Roger Paul (Deputy Chair) Gillian Elizabeth Johnston Sarah Bernadette Dawson Pip Large (resigned 10th January 2020) Malcom Matthews Hannah Millington James Maffin Arlene Eves Jonathan Stevenson Bernadette Brennan Alison Gartland (appointed 25th April 2020) Damian Harper (appointed 6th February 2020) Darrell Green (appointed 6th February 2020)

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

Liz Eatock

#### Independent Scientific Advisory Panel: Professor Pam Kearns

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

#### **Mr Simon Allocca**

Lay member of Independent Scientific Advisory Panel

#### **Professor Robert Brown** (Member) Chair in Translational Oncology, Imperial

College London and The Institute of Cancer Research **Dr Richard Grose** 

(Member) BSc, PhD, Barts Cancer Institute

**Professor Andy Hall** (Member) Newcastle University

**Piers Gaunt** (Member) Senior Biostatistician, University of Birmingham

#### Co-opted members to assess fellowship

#### applications: Professor Susan Burchill

Professor of Adolescent and Paediatric Cancer Research, Leeds Institute of Molecular Medicine, University of Leeds

Dr John Anderson Reader in Paediatric Oncology, Institute of Child Health, London

Dr Andrew Peet Reader in Paediatric Oncology, University of Birmingham

#### Senior Leadership Team:

Mat Cottle-Shaw Head of Fundraising and Communications

Zoe Davison Head of Research, Information and Support

Liz Eatock Head of Finance (resigned 22nd August 2019)

Christine Taylor Head of Finance (appointed 3rd October 2019)

#### **Principal Address**

Unit 10, Feastfield 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**

HR Dept Vale of York Business Services Ltd Victoria Lodge, 8 Sands Lane Elloughton, HU15 1JH

#### **Investment Managers**

Brewin Dolphin 10 Wellington Place Leeds, LS1 4LX

ANNUAL REPORT AND ACCOUNTS 2019

# **REPORT OF THE TRUSTEES FOR YEAR ENDED 31ST DECEMBER 2019**

The trustees present their report with the financial statements of the charity for the year ended 31st December 2019. 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 2015).

#### **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

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 Christies NHS 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 an HR and Training Consultant who became a trustee after her son Al died from Osteosarcoma in November 2007. She also lectures on related topics and spreads awareness of primary bone cancer through her involvement with degree courses for Nurses and Physiotherapists at Huddersfield and Manchester Universities.

#### **Arlene Eves**

Arlene is a pensions lawyer experienced in advising trustees of occupational pension schemes. She was diagnosed with chondrosarcoma in 2007 and 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 2018 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 iournals 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

Allie graduated with a BSc in Biomedical Technology from Sheffield Hallam University in 1995 and completed a PhD at The University of Liverpool in 2001. She undertook post-doctoral training at the Institute de Génetique Moléculaire de Montpelier, CNRS, France and in the lab of the late Sandy Marks Jnr at the University of Massachusetts Medical School, USA before returning to the University of Liverpool in 2004. Allie was appointed to lecturer in Bone Biology at The University of Sheffield in 2006, promoted to Senior Lecturer in 2011, Reader in Bone and Cancer Biology in 2014 and Professor of Bone and Cancer Biology in 2017.

#### **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 2019 were:

- Gillian Johnston (Committee Chair)
- Andy Lewis
- Roger Paul
- Pip Large (resigned 10th January 2020)
- 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
  - Minutes of trustee meetings for the current year
  - BCRT's conflict of interest policy
    BCRT's financial procedures

ANNUAL REPORT AND ACCOUNTS 2019

- "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 four 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 31st December 2019 was 18 (including 4 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. 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.

BCRT is entirely funded by 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.

Since 31 December 2019 the spread of COVID-19 has severely impacted many local economies around the globe. In many countries businesses and charities are being forced to cease or limit operations for long or indefinite periods of time. Measures taken to contain the spread of the virus, including travel bans, quarantines, social distancing and closures of non-essential services, have triggered significant disruptions to organisations worldwide, resulting in an economic slowdown. Notably fundraising operations of the charity have been impacted with most events being postponed or cancelled. The charity has taken advantage of the Government 's Job Retention Scheme by placing 8 staff (38% of the total workforce) on furlough leave.

As at 31st December 2019, BCRT had investments valued at £1.283 million. As a result of the COVID-19 pandemic the first quarter of 2020 global stock markets experienced great volatility and a significant weakening. Governments and central banks have responded with monetary and fiscal interventions to stabilise economic conditions. As at 31 May 2020 the fair value of the charity's investments was £1.186 million.

Trustees continue to monitor the ongoing situation closely. They have determined that the events are non-adjusting subsequent events, and accordingly the financial position and results of operations as of and for the year ended 31 December 2019 have not been adjusted to reflect their impact. The duration of the COVID-19 pandemic, as well as the effectiveness of government and central bank responses, remains unclear at this time. It is not possible to reliably estimate the duration and severity of these consequences, as well as their impact on the financial positions and results of the charity for future periods.

#### 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 annual income in 2019 at £1.675m, an increase of 18.5% over the previous year. Most of our income is made up of individual voluntary donations. Our supporters undertake many fundraising activities, including challenges such as the London Marathon, and events which supporters have organised themselves. We have continued to build relationships with several corporate entities who support our fundraising activities, and we have received grants and other donations from a number of Trusts and Charitable Foundations. We gratefully thank every single fundraiser

who contributed in 2019, 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 £952k on charitable activities, including awarding grants totalling £422k. Fundraising costs were £495k, 30.3% of total income. We ended the year with a surplus of £355k which will be spent in subsequent years on our charitable work.

#### **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, commercial property and alternative investments. The funds are held in two portfolios and managed by Brewin Dolphin. The first portfolio, which comprised 72% of the total fund at 31 December 2019, has an investment mandate of 'income and capital growth with moderate investment risk', whilst the mandate for the second portfolio (28% of total value at year end) is 'income and capital growth with low investment risk'.

During 2019 the moderate risk portfolio out-performed the MSCI WMA balanced index by 16.8%, whilst the higher risk fund exceeded the MCSI WMA Conservative index by 12.9%. Investment income of £37,673 was received during the year, and charges of £9,284 were levied. The market value of the investment portfolio was £1,283,057 at 31 December 2019.

The charity's investments have been impacted by the global 'lock down' and fears of recession caused by the COVID-19 pandemic, and they saw a significant decline in value during the first quarter of 2020. Since the end of March the markets have recovered somewhat despite the negative economic data, and the market value of the portfolio at 31 May was £1,185,501, a reduction of 8% from the 2019 year end value.

The Trustees hold regular review meetings with Brewin Dolphin, the charity's investment managers, 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, currently estimated to be £800,000 for 2020.

At the end of 2018 there was a designated reserve of  $\pm$ 99,803, which was released in full against the PhD awarded in 2019.

During the year the Trustees agreed to designate £120,000 towards the costs associated with infrastructure grants, travel grants and the clinical trials accelerator grant during 2020 and 2021.

Restricted reserves at 31 December 2019 were £300,102, whilst free reserves were £935,447. This exceeds the level required by the reserves policy. The Trustees regularly monitor and review the reserves held 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 and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed 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, including the income and expenditure, of the charity for that period. In preparing those 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 which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (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 26th October 2020 and signed on behalf by Andy Lewis - Trustee.

#### Independent Auditor's Report to the Trustees of Bone Cancer Research Trust Opinion

We have audited the financial statements of Bone Cancer Research Trust (the 'charity') for the year ended 31st December 2019 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 2019 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- The trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- The trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

#### **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 Act 2011 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 Responsibility 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

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.

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 Section 144 of the Charities Act 2011 and regulations made under Section 154 of that Act. 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: 26th October 2020

# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST DECEMBER 2019

	UN	IRESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL FUNDS 2019	TOTA FUNDS 201
	NOTES	£	£	£	
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	952,247	681,982	1,634,229	1,379,34
Other trading activities	3	2,663	-	2,663	3,70
Investment income	4	37,673	-	37,673	30,49
Total		992,583	681,982	1,674,565	1,413,55
EXPENDITURE ON					
Income generation	5	494,696	-	494,696	478,28
Charitable activities	6				
Research		(140,945)	721,198	580,253	606,0
Awareness		201,884	1,509	203,393	164,94
Information		41,246	-	41,246	66,97
Support		91,724	21,471	113,195	22,77
Governance		13,772	-	13,772	9,43
Total		702,377	744,178	1,446,555	1,348,44
NET INCOME/(EXPENDITURE) BEFO	RE				
INVESTMENT GAINS/(LOSSES)		290,206	(62,196)	228,010	65,10
Net gains/(losses) on investments		126,512	-	126,512	(85,68
NET MOVEMENT IN FUNDS		416,718	(62,196)	354,522	(20,57
RECONCILIATION OF FUNDS					
Total funds brought forward		655,353	362,298	1,017,651	1,038,22
TOTAL FUNDS CARRIED FORWARD		1,072,071	300,102	1,372,173	1,017,6

## STATEMENT OF FINANCIAL POSITION AT 31ST DECEMBER 2019

	UNRESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL FUNDS 2019	TOTAL FUNDS 2018
NOTES	£	£	£	£
FIXED ASSETS				
ntangible assets 13	5.048	-	5.048	14.595
Tangible assets 14	11,576	-	11,576	390
nvestments 15		-	1,283,057	1,030,137
	1,299,681	-	1,299,681	1,045,122
CURRENT ASSETS				
Stocks 16	52,404	-	52,404	66,121
Debtors 17	219,289	-	219,289	252,923
Cash at bank and in hand	253,075	300,102	553,177	347,749
	524,768	300,102	824,870	666,793
CREDITORS				
Amounts falling due within one year 18	(627,623)	-	(627,623)	(560,778)
NET CURRENT ASSETS/(LIABILITIES)	(102,855)	300,102	197,247	106,015
TOTAL ASSETS LESS CURRENT LIABILITIES	1,196,826	300,102	1,496,928	1,151,137
CREDITORS Amounts falling due after more than one year 19	(124,755)	_	(124,755)	(133,486)
				(100) 100)
NET ASSETS	1,072,071	300,102	1,372,173	1,017,651
FUNDS				
Jnrestricted funds				
- Free reserves			935,447	540,565
- Fixed asset reserve	_		16,624	14,985
- Designated reserves 23			120,000	99,803
Restricted funds 22	2		300,102	362,298
TOTAL FUNDS 21			1,372,173	1,017,651

The financial statements were approved by the Board of Trustees on 26th October 2020 and were signed on its behalf by:

**Andy Lewis - Trustee** 

# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST DECEMBER 2019

		2019	201
	NOTES	£	
Cash flows from operating activities:			
Cash generated from operations	1	344,454	178,50
Net cash provided by (used in) operating activities		344,454	178,50
Sach flows from investing activities			
Cash flows from investing activities: Purchase of tangible fixed assets		(12,618)	
Purchase of fixed asset investments		(296,664)	(411,01
Sale of fixed asset investments		170,256	369,8
Net cash provided by (used in) investing activities		(139,026)	(41,20
Net cash provided by (used in) investing activities		(139,026) 205,428	(41,20
	1		

## **NOTES TO THE STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31ST DECEMBER 2019**

	2019	2018
	£	£
let income/(expenditure) for the reporting period (as per he statement of financial activities)	354,522	(20,577)
Adjustments for: Depreciation charges Mortisation charges oss/(gain) on investments oss on disposal of fixed assets Inrealised loss/(gain) on investments Increase)/decrease in stocks Increase)/decrease in debtors Increase in creditors	1,432 9,547 2,970 - (129,482) 13,717 33,634 58,114	2,367 9,547 (1,333) 227 87,014 (54,528) (68,284) 224,129

Net cash provided by (used in) operating activities

344,454 178,562

# **NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31ST DECEMBER 2019**

#### **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 2015)', 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 financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

#### 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.

#### 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

- expenditure incurred in order to raise funds for charitable purposes.
- grant funding research into finding a cure for primary bone cancer.
- Research Awareness

Support

- increasing survival rates through raising awareness of primary bone cancer.
- Information
- providing accurate and reliable information across all forms of primary bone cancer.
- 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	34% (2018: 35%)
Research	41% (2018: 46%)
Awareness	14% (2018: 12%)

)

Information Support



#### 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

#### Stocks

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

#### Taxation

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.

#### **2. DONATIONS AND LEGACIES**



#### **3. OTHER TRADING ACTIVITIES**

Other trading income

Total

#### Computer equipment - 33% on cost and 25% on cost

2019	2018
£	£
700,020 934,209	531,733 847,614
1,634,229	1,379,347

2019	2018
£	£
2,663	3,705
2,663	3,705

#### **4. INVESTMENT INCOME**

	2019	2018
	£	£
Investment income	37,673	30,498
Total	37,673	30,498

#### **5. INCOME GENERATION**

2019	2018
£	£
185,576	168,971
134,953	177,763
4,161	2,833
88,026	70,746
81,980	57,968
494,696	478,281
	<b>£</b> 185,576 134,953 4,161 88,026 81,980

#### 6. CHARITABLE ACTIVITIES COSTS

DIRECT COSTS	GRANT FUNDING OF ACTIVITIES (SEE NOTE 7)	ADMINISTRATION COSTS (SEE NOTE 8)	TOTALS
£	£	£	£
73,965	419,388	86,900	580,253
172,930	-	30,463	203,393
35,069	-	6,177	41,246
96,242	-	16,953	113,195
-		13,772	13,772
378,206	419,388	154,265	951,859
278,148	494,061	97,956	870,165
	£ 73,965 172,930 35,069 96,242 - <b>378,206</b>	DIRECT COSTS         ACTIVITIES (SEE NOTE 7)           £         £           73,965         419,388           172,930         -           35,069         -           96,242         -           378,206         419,388	DIRECT COSTS         ACTIVITIES (SEE NOTE 7)         COSTS (SEE NOTE 8)           É         É         É           73,965         419,388         86,900           172,930         -         30,463           35,069         -         6,177           96,242         -         16,953           -         13,772         378,206

#### 7. GRANTS PAYABLE

			2019	2018
			£	£
Research			419,388	494,061
The total grants paid to institutions during the year was as follows:	2019 Unrestricted	2019 Restricted	2019 Total	2018
Dr Roberts, UCL Institute of Orthopaedics and Musculoskeletal Science, Royal National Orthopaedic Hospital, University College London "Mimicking the bone microenvironment to create a chimeric osteosarcoma model (COM)"	(2,274)	-	(2,274)	-
Mr Kenneth Rankin, Sample collection support - Newcastle	-	16,000	16,000	15,000
Mr Paul Cool, Sample collection support - Oswestry	-	-	-	11,000
Professor Adrienne Flanagan, Royal National Orthopaedic Hospital, Sample collection support - Stanmore	-	19,873	19,873	19,873

#### Continued...

#### The total grants paid to institutions during the year was as fol

Dr Graham Caine, The Royal Orthopaedic Hospital, Sample collection support - Birmingham

Mr Thomas Cosker, University of Oxford, Sample collection support - Oxford

Professor Sue Birchill, University of Leeds, Modelling Ewing sard heterogeneity and tumour microenvironment to improve outcom

Dr Sandra Strauss, University College London, ICONIC - Improvi Outcomes through Collaboration In Osteosarcoma

Professor Graham Cook, University of Leeds, Oncolytic virus the for Ewing sarcoma

Dr Robert Falconer, University of Bradford, Development of a targeted methotrexate prodrug with enhanced therapeutic inde for osteosarcoma

Dr Helen Knowles, Botnar Research Centre, Nuffield Orthopaed Centre, A Potential New Therapeutic Target in Osteosarcoma

Mr Adam Cribbs, University of Oxford, Therapeutic targeting an understanding of oncogenic driver networks in chordoma

Professor Agamemnon Grigoriadis, Kings College London, Haem oxygenase-1 a novel druggable target for prevention of osteosarcoma growth and metastasis

Dr Iben Lyskjaer, University College London, validation of DNA methylation- specific markers for circulating tumour DNA analy sarcoma patients

Professor Sue Birchill, Identification of the lead candidate NRXN isoform as a prognostic biomarker and a novel target for therap

### Restricted funding allocated to payments of existing grants meeting the specific restrictions

Total

During the year there was a change in the manner in which restricted funding was allocated to those specific charitable causes. Previously the restricted funding covered payments of existing grants, however during the year this was changed such that entire grant awards and associated liabilities were allocated directly to the relevant restricted fund.

			2019	2018
			£	£
llows:	2019 Unrestricted	2019 Restricted	2019 Total	2018
	-	24,579	24,579	24,579
	-	9,000	9,000	11,000
rcoma omes	-	-	-	67,414
ving	-	-	-	275,000
nerapy	-	120,500	120,500	42,500
lex	-	72,303	72,303	27,697
dic	-	-	-	(2)
nd	40,381	19,316	59,697	-
	-	70,000	70,000	-
ysis in	-	15,000	15,000	-
N1 py	-	14,710	14,710	-
	(333,860)	333,860	-	-
	(295,753)	715,141	419,388	494,061

#### **8. ADMINISTRATION COSTS**

	MANAGEMENT	INVESTMENT MANAGEMENT COSTS	GOVERNANCE COSTS	TOTALS
	£	£	£	£
Research	86,900	-	-	86,900
Awareness	30,463	-	-	30,463
Information	6,177	-	-	6,177
Support	16,953	-	-	16,953
ncome generation	72,696	9,284	-	81,980
Governance	-	-	13,772	13,772
Total	213,189	9,284	13,772	236,245
Total 2018	136,704	9,783	9,437	155,924

Administration costs, included in the above, are as follows:

	RESEARCH	AWARENESS	INFORMATION	SUPPOR1
	£	£	£	f
Wages	35,502	12,444	2,524	6,926
Social security	2,493	874	177	486
Pensions	561	197	40	110
ent, rates and water	13,212	4,631	939	2,577
elephone	3,305	1,159	235	645
ostage and stationery	4,411	1,547	314	86
undries	1,334	468	95	260
ravel and subsistence	1,221	428	87	238
oftware licences	10,388	3,642	739	2,026
ecruitment and human resources costs	5,508	1,931	393	1,074
tock management	3,748	1,314	266	73
ank charges	329	115	23	64
egal fees	412	144	27	82
mortisation of intangible fixed assets	3,892	1,364	276	760
epreciation of tangible fixed assets	584	205	42	113
oss on sale of tangible fixed assets	-	-	-	
Portfolio management	-	-	-	
rustees' expenses and meeting costs	-	-	-	
Auditors' remuneration	-	-	-	
Accountancy and legal fees	-	-	-	

Total	86,900	30,463	6,177	16,953
Total 2018	63,323	16,966	6,887	2,343
	INCOME GENERATION	GOVERNANCE	2019 TOTAL ACTIVITIES	2018 TOTAL ACTIVITIES
	£	£	£	£
Wages	29,699	-	87,095	52,059
Social security	2,085	-	6,115	3,228
Pensions	470	-	1,378	536
Rent, rates and water	11,052	-	32,411	29,079
Telephone	2,766	-	8,110	4,542
Postage and stationery	3,691	-	10,824	9,574
Sundries	1,117	-	3,274	1,278
Travel and subsistence	1,021	-	2,995	2,036
Software licences	8,691	-	25,486	9,360
Recruitment and human resources costs	4,607	-	13,513	8,850
Stock management	3,136	-	9,195	-

Continued on next page...

Continued	INCOME GENERATION	GOVERNANCE	2019 TOTAL ACTIVITIES	2018 TOTAL ACTIVITIES
	£	£	£	£
Bank charges	275	-	806	877
Legal fees	343	-	1,008	3,144
Amortisation of intangible fixed assets	3,255	-	9,547	9,547
Depreciation of tangible fixed assets	488	-	1,432	2,367
Loss on sale of tangible fixed assets	-	-	-	227
Portfolio management	9,284	-	9,284	9,783
Trustees' expenses and meeting costs	-	6,065	6,065	3,423
Auditors' remuneration	-	5,425	5,425	5,400
Accountancy and legal fees	-	2,282	2,282	614
Total	81,980	13,772	236,245	155,924
Total 2018	57,968	9,437	155,924	

9. AUDITORS' REMUNERATION

Fees payable to the charity's auditors for the audit of the cha

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

The average number of trustees in the year was 11 (2018: 10).

There were no trustee's remuneration or other benefits for the year ended 31st December 2019 nor for the year ended 31st December 2018.

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 £1,335 (2018: £265). 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 £3,611 (2018: £2,919) were reimbursed to six trustees (2018: five trustees).

#### **11. STAFF COSTS**

	2019	2018
	£	£
Wages and salaries	410,799	300,93
Social security costs	33,206	22,705
Other pension costs	7,408	3,526
Total	451,413	327,162
The average monthly number of employees during the year was as	follows:	
	2019	2018
	16	1.
Permanent staff		

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 £130,093 (2018: £102,218).

	2019	2018
	£	£
harity's financial statements	5,425	5,400

35

#### **12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST DECEMBER 2018**

	UNRESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL FUNDS
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations and legacies	828,039	551,308	1,379,347
Other trading activities	3,705	-	3,705
Investment income	30,498	-	30,498
Total	862,242	551,308	1,413,550
EXPENDITURE ON			
Income generation	478,281	-	478,281
Charitable activities			
Research	337,988	268,053	606,041
Awareness	164,944	-	164,944
Information	66,973	-	66,973
Support	22,770	-	22,770
Governance	9,437	-	9,437
Total	1,080,393	268,053	1,348,446
Net gains/(losses) on investments	(85,681)	-	(85,681)
NET INCOME/(EXPENDITURE	(303,832)	283,255	(20,577)
RECONCILIATION OF FUNDS			
Total funds brought forward	959,185	79,043	1,038,228
TOTAL FUNDS CARRIED FORWARD	655,353	362,298	1,017,651

#### **13. INTANGIBLE ASSETS**

	WEBSITE COSTS
	£
Cost	
At 1st January 2019	38,187
AMORTISATION	
At 1st January 2019	23,592
Charge for year	9,547
At 31st December 2019	33,139
NET BOOK VALUE	
At 31st December 2019	5,048
At 31st December 2018	14,595

#### **14. TANGIBLE FIXED ASSETS**

	FIXTURES FITT	AND INGS	COMPUTER EQUIPMENT	TOTAL
		£	£	:
COST				
At 1st January 2019		1,372	17,255	18,62
Additions	Ç	9,798	2,820	12,61
At 31st December 2019	1	1,170	20,075	31,24
DEPRECIATION				
At 1st January 2019		1,372	16,865	18,23
Charge for year		567	865	1,43
At 31st December 2019	1	1,939	17,730	19,66
At 31st December 2019	9	9,231	2,345	11,57
At 31st December 2018		-	390	39
15. FIXED ASSET INVESTMENTS				
15. FIXED ASSET INVESTMENTS	LISTED INVESTMENTS SE	TTLEME	CASH AND ENTS PENDING	TOTAL
15. FIXED ASSET INVESTMENTS	LISTED INVESTMENTS SE £	TTLEME	CASH AND ENTS PENDING £	
IS. FIXED ASSET INVESTMENTS	INVESTMENTS SE	TTLEME	ENTS PENDING	
	INVESTMENTS SE £ 995,281	TTLEME	ENTS PENDING	1,030,13
MARKET VALUE At 1st January 2019 Additions	INVESTMENTS SE £ 995,281 313,476	TTLEME	ENTS PENDING £ 34,856 -	<b>TOTAL</b> 1,030,13 313,47
MARKET VALUE At 1st January 2019 Additions Disposals	INVESTMENTS SE £ 995,281 313,476 (173,226)	TTLEME	ENTS PENDING £ 34,856	1,030,13 313,47 (190,038
MARKET VALUE At 1st January 2019 Additions	INVESTMENTS SE £ 995,281 313,476	TTLEME	ENTS PENDING £ 34,856 -	1,030,13

#### **NET BOOK VALUE** At 31st December 2019 At 31st December 2018

At 31st December 2019 no individual investment represented more than 5% of the total investment portfolio valuation.

The historical cost at 31st December 2019 is £1,114,887 (2018: £957,411).

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.

1,265,013	18,044	1,283,057
995,281	34,856	1,030,137



#### **16. STOCKS**

	2019	2018
	£	£
Stocks of fund-raising items	52,404	66,121

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

	2019	2018
	£	£
Prepaid event costs Other Debtors	194,501 24,788	174,920 78,003
Total	219,289	252,923

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

	2019	2018
	£	£
Trade creditors	31,467	21,671
Taxation and social security	12,629	7,418
Grants payable	545,474	493,357
Deferred event income	24,928	26,821
Other creditors	13,125	11,511
Total	627,623	560,778

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

	2019	2018
	£	£
Grants payable	124,755	133,486
Reconciliation of Grants Awarded		
Opening liability obligation	626,843	417,636
Research grants awarded in the year	421,662	494,063
Provisions no longer required	(2,274)	(2)
Paid during the year	(376,002)	(284,854)
Closing liability obligation	670,229	626,843
Split as:		
Due within one year	545,474	493,357
Due after more than one year	124,755	133,486

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

The following operating lease payments are committed to be paid:

	Land and Buildings		Other operating leases	
	2019	2018	2019	2018
	£	£	£	£
Expiring:				
Within one year	16,797	16,797	7,585	6,045
Between one and five years	51,918	68,715	7,555	9,970
Total	68,715	85,512	15,140	16,015

#### **21. Movement in funds**

**Unrestricted funds** General fund

#### **Restricted funds**

Ewing sarcoma Ewing Sarcoma Research Trust Liberty Schurer Frank's Fund Jordon Wilson Other funds restricted to research into Ewing Sarcoma

#### Osteoscarcoma

In support of Mary Collard Tom Stead Tom Hunt Clive and Sylvia Richards Daniel Bridle Other funds restricted to research into osteosarcoma

#### Infrastructure grant

QBE Foundation PF Charitable Trust Barbour Foundation Other funds restricted to infrastructure grants

#### Methotrexate prodrug

Three Ells Trust Balcombe Trust Funds restricted to Methotrexate PhD awarded by BCRT in 20

#### **Other research**

Christopher Spratt The Liz Clarke-Saul Fund Other funds restricted to research

#### Non research

Takeda Other funds restricted to non-research charitable activities

#### **TOTAL FUNDS**

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

	INCOMING RESOURCES	RESOURCES EXPENDED	GAINS AND LOSSES	MOVEMENT IN FUNDS
	£	£	£	£
Unrestricted funds General fund	992,583	(702,377)	126,512	416,718

	AT 1/1/19	NET MOVEMENT IN FUNDS	AT 31/12/19
	£	£	£
	655,353	416,718	1,072,071
	86,541	(84,343)	2,198
	125,499	(15,701) 81,934	109,798 81,934
	-	5,102	5,102
	10,713	7,518	18,231
	28,798	(28,073)	725
	16,536	(15,750) 13,149	786 13,149
	-		-
	14 1697	(9)	5
	1,683	445	2,128
	24,579	(11,552)	13,027
	10,000 5,000	(9,000) (5,000)	1,000
	6,000	-	6,000
	10,000	(10,000)	-
	10,000	(10,000)	-
2018	7,132	(7,132)	-
	16,476	(16,172)	304
	- 7 / 7	22,498	22,498
	347	2,145	2,492
	1,980	18,745	20,725
	1,000	(1,000)	_
	362,298	(62,196)	300,102
	1,017,651	354,522	1,372,173

Continued	INCOMING RESOURCES	RESOURCES EXPENDED	GAINS AND LOSSES	MOVEMENT IN FUNDS	
	£	£	£	£	
Restricted funds					
Ewing sarcoma					
Ewing 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	
Osteoscarcoma					
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	85,000	(85,000)		-	
Daniel Bridle	19,209	(19,218)		(9)	
Other funds restricted to research into osteosarcoma	19,209	(13,210)	-	(9)	
Other funds restricted to research into osteosarconia	10 5 0 0	(10.004)			
In first shows have a second	19,509	(19,064)	-	445	
Infrastructure grant		(70.000)			
QBE Foundation	25,317	(36,869)	-	(11,552)	
PF Charitable Trust	-	(9,000)	-	(9,000)	
Barbour Foundation	5,000	(10,000)	-	(5,000)	
Other funds restricted to infrastructure grants	3,000	(3,000)	-	-	
Mathetrevate predrug					
Methotrexate prodrug Three Ells Trust		(10,000)		(10,000)	
	-	(10,000)	-	(10,000)	
Balcombe Trust	10,000	(20,000)	-	(10,000)	
Funds restricted to Methotrexate PhD awarded by	-	(7,132)	-	(7,132)	
BCRT in 2018					
Other research					
Christopher Spratt	3,274	(19,446)	-	(16,172)	
The Liz Clarke-Saul Fund	22,498	-	-	22,498	
Other funds restricted to research	30,265	(28,120)	-	2,145	
Non research					
Takeda	40,725	(21,980)	-	18,745	
Other funds restricted to non-research charitable	-	(1,000)	_	(1,000)	
activities					
	681,982	(744,178)	-	(62,196)	
TOTAL FUNDS	1,674,565	(1,446,555)	126,512	354,522	

Comparatives for movement in funds

	AT 01/01/18	NET MOVEMENT IN FUNDS	AT 31/12/18
	£	£	£
Unrestricted Funds			
General fund	959,185	(303,832)	655,353
Restricted funds			
Ewing sarcoma			
Ewing Sarcoma Research Trust	13,324	73,217	86,541
Liberty Schurer	-	125,499	125,499
Other funds restricted to research into Ewing Sarcoma	26,520	(15,807)	10,713
Osteosarcoma			
In support of Mary Collard	3,635	25,163	28,798
Tom Stead	-	16,536	16,536

Daniel Bridle Other funds restricted to research into osteosarcoma

#### Infrastructure grant

QBE Foundation PF Charitable Trust Barbour Foundation Other funds restricted to infrastructure grants

#### Methotrexate prodrug

Three Ells Trust Balcombe Trust Funds restricted to Methotrexate PhD awarded by BCRT in 2018

#### **Other research**

Christopher Spratt Other funds restricted to research

#### Non research

Takeda Other funds restricted to non-research charitable activities

#### TOTAL FUNDS

Comparative net movement in funds, included in the above are as follows:

RE

Unrestricted funds General fund

#### **Restricted funds**

**Ewing sarcoma** Ewing Sarcoma Research Trust Liberty Schurer Other funds restricted to research into Ewing Sarcoma

#### Osteosarcoma

In support of Mary Collard Tom Stead Daniel Bridle Other funds restricted to research into osteosarcoma

#### Infrastructure grant

QBE Foundation PF Charitable Trust Barbour Foundation Other funds restricted to infrastructure grants

#### Methotrexate prodrug

Three Ells Trust Balcombe Trust Funds restricted to Methotrexate PhD awarded by BCRT in 2018

0

AT 01/01/18	NET MOVEMENT IN FUNDS	AT 31/12/18
£	£	£
- 1,973	14 (290)	14 1,683
- - -	24,579 10,000 5,000 6,000	24,579 10,000 5,000 6,000
-	10,000 10,000 7,132	10,000 10,000 7,132
31,461 1,130	(14,985) (783)	16,476 347
- 1,000	1,980	1,980 1,000
79,043	283,255	362,298
1,038,228	(20,577)	1,017,651

	RESOURCES EXPENDED	GAINS AND LOSSES	MOVEMENT IN FUNDS
£	£	£	£
862,242	(1,080,393)	(85,681)	(303,832)
87,414 125,499 2,698	(14,197) - (18,505)	- -	73,217 125,499 (15,807)
88,923 70,203 1,959 31,575	(63,760) (53,667) (1,945) (31,865)	- - -	25,163 16,536 14 (290)
24,579 10,000 5,000 26,000	- - (20,000)	- - -	24,579 10,000 5,000 6,000
10,000 10,000 7,132	- -	- -	10,000 10,000 7,132

41

Continued	INCOMING RESOURCES	RESOURCES EXPENDED	GAINS AND LOSSES	MOVEMENT IN FUNDS
	£	£	£	£
Other research				
Christopher Spratt	8,336	(23,321)	-	(14,985)
Other funds restricted to research	6,499	(7,282)	-	(783)
Non research				
Takeda	29,277	(27,297)	-	1,980
Other funds restricted to non-research charitable	6,214	(6,214)	-	-
activities				
	551,308	(268,053)	-	283,255
TOTAL FUNDS	1,413,550	(1,348,446)	(85,681)	354,522

#### **22. RESTRICTED FUNDS**

#### **Ewing Sarcoma**

The Ewing 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.

Frank's fund represent monies restricted for research into Ewing Sarcoma.

The Jordon Wilson Restricted fund represent 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 Restricted Fund represents monies restricted for research into Osteosarcoma.

The Daniel Bridle 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.

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.

#### 22. RESTRICTED FUNDS - continued

#### **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.

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.

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

#### **23. DESIGNATED FUNDS**

# PhD grant

Multiyear grants

Total Funds

#### 24. RELATED PARTY DISCLOSURES

Trustees are required to disclose all relevant interests and register them with the Clerk to the Trustees 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 2019, consultancy services of £1,080 (2018: £nil) were provided by one of the trustees to the charity.

The Anthony Pilcher Bone Cancer Trust, of which Gill Johnston, a trustee is connected donated £Nil (2018: £11,000) to Bone Cancer Research Trust during the year.

#### **25. COMMITMENTS**

As at 31 December 2019 the charity has committed to funding further research grants of £365,495. 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.

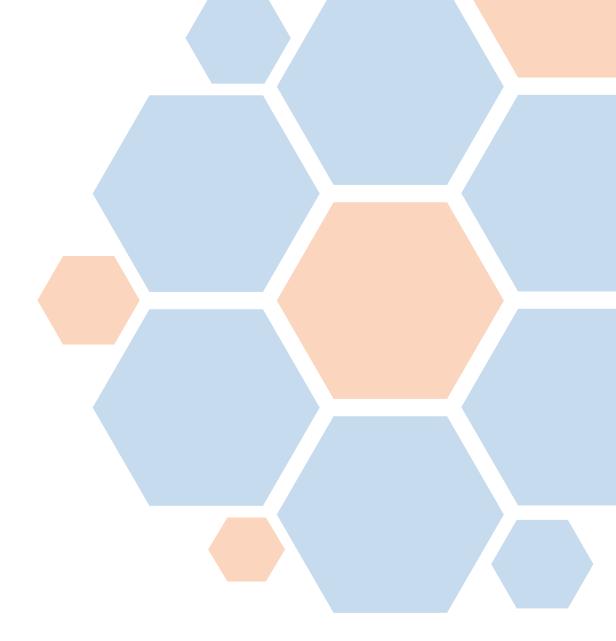
#### **26. POST BALANCE SHEET EVENTS - COVID-19**

Since 31 December 2019 the spread of COVID-19 has severely impacted many local economies around the globe. In many countries businesses and charities are being forced to cease or limit operations for long or indefinite periods of time. Measures taken to contain the spread of the virus, including travel bans, quarantines, social distancing and closures of non-essential services, have triggered significant disruptions to organisations worldwide, resulting in an economic slowdown. Notably fundraising operations of the charity have been impacted with most events being postponed or cancelled. The charity has taken advantage of the Government 's Job Retention Scheme by placing 8 staff (38% of the total workforce) on furlough leave.

As at 31st December 2019, BCRT had investments valued at £1.283 million. As a result of the COVID-19 pandemic the first quarter of 2020 global stock markets experienced great volatility and a significant weakening. Governments and central banks have responded with monetary and fiscal interventions to stabilise economic conditions. As at 31 May 2020 the fair value of the charity's investments was £1.186 million.

Trustees continue to monitor the ongoing situation closely. They have determined that the events are non-adjusting subsequent events, and accordingly the financial position and results of operations as of and for the year ended 31 December 2019 have not been adjusted to reflect their impact. The duration of the COVID-19 pandemic, as well as the effectiveness of government and central bank responses, remains unclear at this time. It is not possible to reliably estimate the duration and severity of these consequences, as well as their impact on the financial positions and results of the charity for future periods.

AT 1/1/19	PAID	DESIGNATED	31/12/19
£	£	£	£
99,803 -	(99,803)	- 120,000	- 120,000
99,803	(99,803)	120,000	120,000





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www.bcrt.org.uk
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 0113 258 5934

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