

BONE CANCER RESEARCH TRUST Charity Reg. No. 1113276

TRUSTEES' REPORT
AND
AUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31<sup>st</sup> DECEMBER 2013



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# BONE CANCER RESEARCH TRUST. Report of the Trustees and Financial Statements for the year ended 31<sup>st</sup> December 2013.



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#### 1.0 LEGAL AND ADMINISTRATIVE INFORMATION

Date of Trust Deed: - 15th. December 2005.

Charity Registration Details:-

Registered Number 1113276, registered on 14th March 2006 in England.

Working Names:-

BCRT: bcrt: Bone Cancer Research: BCR: Team Bones

Trustees who served during the year 1 January 2013 to 31 December 2013 were:-

Sarah Bernadette Dawson John Dealey Fiona Marie Foley Craig Hamilton Gerrand MB ChB FRCSED MD MBA Laura Elizabeth Horton Ian John Lewis MB ChB FRCP FRCPCH Roger Paul (Chairman) Gillian Elizabeth Pilcher Andrew James Sheppard Patricia Smith (resigned 30<sup>th</sup> June 2013) Jessica Cumming (appointed 18<sup>th</sup> May 2013)

Gill Lawrence (appointed 18<sup>th</sup> May 2013)

Andrew Lewis (appointed 18<sup>th</sup> May 2013)

Clerk to the Trustees: Jane Nattrass BA (Hons), PGCE

Chief Executive: Julie Harrington

Independent Scientific Advisory Panel:-

Professor Andy Hall, Associate Dean of Translational Research, Newcastle University. Professor Ian Lewis, Medical Director of the Alder Hey Children's NHS Foundation Trust Mr Craig Gerrand, Consultant Orthopaedic Surgeon, Freeman Hospital, Newcastle upon Tyne Mr Rob Grimer, Consultant Orthopaedic Surgeon, Royal Orthopaedic Hospital, Birmingham Professor Jeremy Whelan, Professor of Cancer Medicine and Consultant Medical Oncologist, University College Hospitals London

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

# Registered Office:-

10 Feast Field, Horsforth, Leeds, LS18 4TJ

Telephone: 0113 258 5934 Fax: 0113 258 7145 Email: info@bcrt.org.uk Website: www.bcrt.org.uk



Independent Auditor:-

Mr C J Darwin FCA Messers Thomas Coombs & Son, Chartered Accountants, 29 Clarendon Road, Leeds, LS2 9PG

Solicitors:-

Schofield Sweeney Solicitors, 76 Wellington Street, Leeds, LS1 2AY

Bankers:-

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

HR Consultants:-

Breathing Space HR,

**Investment Managers:-**

Brewin Dolphin, 34 Lisbon Street, Leeds, LS1 4LX

The Trustees present their Annual Report and Audited Financial Statements for the year ended 31 December 2013. In this report, the Trustees have sought to provide clear details about the activities undertaken by the Charity to further its charitable purposes for the public benefit.

#### 2.0 OBJECTIVES AND ACTVITIES FOR THE PUBLIC BENEFIT

BCRT is an unincorporated body, a trust that is governed by a Trust Deed, and managed by a Board of Trustees. The Trust Deed states that the Trustees must apply the income in furthering BCRT objects, as follows:

- Promoting research into the causes and treatment of Primary Bone Cancer in young people and in particular of Osteosarcoma and Ewing's Sarcoma, and publishing the useful results thereof;
- Provide counselling, support and information services for persons suffering from Primary Bone Cancer, and their families.

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

#### 2.1 Grant Making Policies:

One of the foremost aims of the Bone Cancer Research Trust is to promote research into Primary Bone Cancers (PBC) and in particular Osteosarcoma and Ewing's Sarcoma. The Charity is interested in research that can improve outcomes for patients, and so considers research applications from a variety of perspectives. These include biological, translational, clinical, epidemiological, psycho-social and health services research.

We recognise that Primary Bone Cancer is a rare condition, but the knowledge garnered from research that we fund is often transferable to other related fields, and vice versa. Therefore we are keen to encourage collaborations so that scientific knowledge can be nurtured and shared as widely as possible for maximal benefit.

Types of research grants considered:

- o **Small grants -** requests for sums less than £10,000
- Pump-priming grants exploratory proposals of up to £30,000
- o **Project grants -** for more substantial proposals of up to £75,000.



Research Fellowships - for individuals committed to a career in academic or clinically related research in bone cancers. Successful applicants would be expected to register for a higher degree (PhD or MD) at the host institution. Our fellowship scheme takes the form of a project grant of up to four years in length, providing salary support to pursue a specific, clearly described piece of research in collaboration with a recognised researcher in the field.

Applications should be submitted using a downloadable form from the website www.bcrt.org.uk

Applications received are forwarded to the Independent Scientific Advisory Panel (ISAP) for the formal assessment process. We insist on external peer review for all funding requests of £10,000 and above. Peer reviewers are international specialists selected on the basis of their expertise in the field of research relevant to the application. External reviewers are asked to confirm that there is no significant conflict of interest.

Applications are independently assessed and scored by each peer reviewer, and individual scores are collated to form an average. If an application does not reach a minimum average score then it is rejected from the process; feedback is provided to all unsuccessful applicants.

The applications scoring above the required minimum are then considered by the Independent Scientific Advisory Panel, who will determine which submissions are of sufficient quality to be funded and rank them accordingly. They could choose to recommend all or none of the applications.

Recommendations are then considered by BCRT Trustees, who have the final decision on funding.

BCRT has National Institute for Health Research (NIHR) Partner status which will ensure that studies funded by BCRT will be eligible for inclusion in the NIHR Portfolio. This allows our research projects to have access to clinical infrastructure and NHS Service Support through the NIHR Clinical Research Networks.

BCRT has applied to become a member of the Association of Medical Research Charities (AMRC), which is the national membership organisation of leading medical and health research charities.

#### 3.0 STRUCTURE, GOVERNANCE AND MANAGEMENT

#### 3.1 Governing Document

The Trust became an Unincorporated Trust under a deed dated 15<sup>th</sup> December 2005. On 14 March 2006 it became a Registered Charity in England & Wales, Number 1113276.

#### 3.2 Trustees

Details of Trustees that have served within the period of 1 January 2013 to 31 December 2013 are listed on page 4 of this report. Trustees have a primary fiduciary responsibility, complying with Charity Law, exercising prudence and a duty of care. They also have responsibility for strategy and its ultimate implementation by the CEO and staff team.

The trustees have met on 4 occasions during the last year:

2<sup>nd</sup> February 2013 18<sup>th</sup> May 2013 11<sup>th</sup> August 2013



16<sup>th</sup> November 2013

Fiona Foley was duly re-elected as a Trustee in February 2013, and one trustee, Patricia Smith, resigned in June 2013.

Three new Trustees were appointed in 2013; Jessica Cumming, Gill Lawrence and Andy Lewis were all appointed on 18<sup>th</sup> May 2013.

#### 3.3 Recruitment and Appointment of Trustees

The Trust Deed requires the Board of Trustees to have at least 10 members. On their appointment, new Trustees are provided with:

- Copy of latest audited "Report and Accounts"
- o Management accounts for current year
- BCRT Contacts List
- o Minutes of Trustees meetings
- o Trust Deed
- o "Hallmarks of an Effective Charity", published by the Charity Commission
- "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.

#### 3.4 Sub-committees

In addition to the Trustees, there are a series of sub-committees that focus on particular aspects of BCRT's work. Sub-committees are made up of at least two trustees, appropriate members of staff, and volunteers. Sub-committee proposals are recommended to Trustees for decision, prior to implementation. Current sub-committees include: Finance, Ireland, Management, Marketing, Research & Information and Support.

#### 3.5 Independent Scientific Advisory Panel (ISAP)

The Scientific Advisory Panel was established under the Chairmanship of Prof. Andy Hall, to assist the Trustees in the award of Research Grants. The SAP consists of eminent Medical Practitioners, who are supported by a number of invited Specialist Advisors drawn from respected research centres throughout the United Kingdom and Ireland.

The role of the ISAP is to:-

- o arrange and agree timescales for calls for research applications
- o decide which Special Advisors (SA) should receive individual applications
- o agree external peer reviewers with the SAs
- o receive external peer review and recommendations from SAs
- meet to determine ranking and funding priority of applications, and make recommendations to Trustees

The members of the Scientific Advisory Panel are listed on page 4 of this report.



#### 3.6 Related Parties

Reflecting the formation of the Trust by a number of Founding Groups, some of the Trustees are connected to the income received by the Charity during the period 1 January 2013 to 31 December 2013 as detailed in Note 2 of the Financial Statements. The specific connections are:

Trustee Related Party

John Dealey Adam Dealey Foundation for Ewing's Sarcoma.

Fíona Foley Blathnaid Foley Trust

Gill Pilcher Anthony Pilcher Bone Cancer Trust. Charity No: 1099337.

Patricia Smith Family & Friends of Krystle Smith

#### 3.7 Risk Management

The Trustees have examined the major strategic, business and operational risks which the Charity faces, and confirm that systems and procedures are in place which enables the Trustees to manage the Charity and mitigate any risk. The CEO has a day to day responsibility to highlight any major risks, that they become aware of in the course of their duties.

Trustees recognise that the organisation is in financial good health, and they receive regular monthly operational and financial reports that enable them to maintain an overview of the organisation's activities. Investments are monitored on a quarterly basis, and additionally there is a minimum of two meetings with investment managers per annum.

BCRT also has a Finance Committee in place, which reviews the financial performance in greater detail, looking at future cash flows, as well as the budget.

#### 3.8 Staff

During 2013, Harriet Unsworth, Information and Research Officer, left to join Cancer Research UK in a similar role.

BCRT was able to recruit Jennifer Houniet into the same role quite rapidly, so there was good continuity in relation to Information and Research.

BCRT also added two further headcount as part of the planned development of the Organisation; those were, Jamie Strachan, Corporate Fundraiser and Chantal Spittles, PR Officer.

# 3.9 Voluntary Workers

The Trustees are very appreciative of the work carried out by numerous volunteers throughout the United Kingdom and Republic of Ireland for their tireless work in organising fundraising activities. There are also many people that have played a major role in other BCRT activities such as office administration, conferences, newsletter, Bone Cancer Awareness Week, and media coverage.

The Trustees also thank Alan Johnston for his ongoing work as IT Advisor, particularly for his work in preparing an IT strategy to modernise our IT infrastructure, and supporting the implementation of the "cloud" into BCRT's IT systems.



#### 3.10 General, Dedicated and Restricted Fund Accounts:

As part of maximising the opportunities presented by different types of fundraising, the Trustees continue to offer 3 different types of accounts:

- General Accounts are where the bulk of donations are placed, which then can be used to support all aspects of the Charity
- Dedicated Accounts are funds which have been opened in memory of an individual, usually by bereaved family and friends. Not only do they allow a loved one's name to be remembered within BCRT, they can also be used for local fundraising and raising awareness.
- Restricted Accounts are very similar to dedicated accounts, but are restricted so that the funds may only be used for a particular purpose, for example ring-fenced for a specific area of research.

#### 4.0 LINKS WITH OTHER ORGANISATIONS

During 2013, BCRT extended its external links and worked with numerous organisations, including the following:

- Association of European Cancer Leagues
- Bone Cancer Awareness Trust
- British Sarcoma Group
- o Cancer 52
- o Cancer Campaigning Group
- Cancer Patient Information Pathway Stakeholder Group
- o Cancer Research UK
- Childhood Cancer Parents Alliance (formerly NACCPO)
- European Society for Paediatric Oncology
- Ewings Sarcoma Trust
- o International Alliance of Patients' Organisations
- Irish Cancer Society
- Irish Platform for Patients' Organisations, Science and Industry
- Medical Research Charities Group (Ireland)
- National Cancer Intelligence Network
- o NCIN Sarcoma Site Specific Clinical Reference Group
- Rarer Cancers Foundation
- o Rare Disease UK
- Sarcoma UK
- Sarcoma Patients EuroNet Association (SPAEN)
- Teenage Cancer Trust
- UK CTYA Cancer Information Steering Group
- Public Health England, Knowledge and Intelligence Team (KIT) West Midlands.

The BCRT approach aims to foster collaboration, and we believe that by working together with complementary organisations, it enables us to enhance our impact and achieve more for people affected by Primary Bone Cancer.



#### 5.0 ACHIEVEMENTS AND PERFORMANCE

BCRT is dedicated to improve outcomes for people affected by Primary Bone Cancer. We aim to achieve this through 4 main areas of activity: research, information, awareness and support.

#### 5.1 Research Applications and Grants

In 2013, BCRT received 16 applications for research grants, of which 6 were funded and 4 applications for Research Fellowships, of which one was agreed, but funded in 2014.

#### **Grants**

BCRT 36/13 Professor Sue Birchill - £74,345 – Genotype and Phenotype of Self-renewing Cancer-initiating Ewing Sarcoma Cells.

BCRT 33/13 Dr Sandra Strauss - £74,797 – Investigation of CL67 as a first-in-class novel inhibitor of the HIF1a pathway in osteosarcoma.

BCRT 34/13 Dr Neil Cross - £29,419 - Enhancement of Death Receptor sensitivity in osteosarcoma using nuclear export inhibitors.

BCRT 37/13 Dr Kenneth Rankin - £9,993 – The feasibility of Detection and Characterisation of Circulating Tumour Cells in osteosarcoma.

BCRT 35/13 Mr Lee Jays - £30,000 – Can we reliably detect viable, dying or dead Ewing's sarcoma cells in pre-tumoural tissues following induction chemotherapy?

BCRT 32/13 Professor Adrienne Flanagan - £13,601 – Generating osteosarcoma cell lines which will be analysed as part of the International Cancer Genome Consortium (ICGC).

#### **Fellowships**

BCRT 38/14 Professor Donald Salter - £114,018 - NG2/CSPG4 in osteosarcoma: functional roles and novel therapeutic target.

(Please note that although this Fellowship was awarded in December 2013, the recipient was informed in January 2014 and so the £114,018 cost will be in the 2014 accounts)

In addition to the normal Research grants, BCRT have funded the Royal College of General Practitioners (RCGP) to produce an e-learning module for all of their members, which focuses entirely on Primary Bone Cancer. BCRT has worked closely with RCGP to ensure that all the information contained in the module is consistent with that published by BCRT. The module will be available in summer 2014. Thanks to Val Mathews for her sterling work with RCGP, which will result in an exceptional training module for GP's, and improve GP knowledge and improve the time to diagnosis.

BCRT is delighted to report that grants awarded in 2013 have taken the total expenditure on research to over £1.7million.



#### 5.2 Information Provision

During 2013, we continued to produce high quality information to meet the needs both of people affected by Primary Bone Cancers, and of professionals that need to know more about the facts of the condition. Our Information Standard certification denotes that the information we produce is based on the best possible current evidence and clinical practice, with input from doctors, surgeons and patients. Compliance with this quality mark requires our systems and processes to be thoroughly audited on an annual basis; we are pleased to report that BCRT remains compliant following the audit.

During 2013, significant work went into producing information on chondrosarcoma, the most common Primary Bone Cancer to affect adults. This information is currently under review, as per BCRT processes, prior to being released.

#### 5.3 Awareness

BCRT continued to produce regular newsletters giving an update on BCRT's activities, the personal experiences of our patients and their families, fundraising achievements, awareness campaigns and updates from researchers on their progress with funded projects. Despite the proliferation of online communications, we remain committed to producing hard copies of the newsletter for circulation to our supporters, clinics and waiting rooms where we know paper copies are particularly helpful. We also began to work on developing a monthly e-bulletin to enhance communication with supporters across all areas of BCRT and will be launching this in 2014.

Bone Cancer Awareness Week (BCAW) is a key fixture in BCRT's calendar to raise awareness about primary bone cancer among the media and public in the UK and Ireland.

The main purpose of the week is not fundraising but to make people more aware of primary bone cancer, as it is a rare condition which can be difficult to diagnose.

The theme for the BCAW 2013 (5-12 October) was 'early diagnosis', underpinned by the National Cancer Intelligence Network's 2013 report, showing survival rates haven't improved in 25 years.

We are delighted to report that the campaign saw media cuttings more than triple on the previous year's coverage, with a total of 344 pieces:

- o 53 print articles (four national newspapers and one specialist magazine)
- o 30 radio mentions
- 5 pieces of TV coverage
- o 256 internet articles

Campaign reach was excellent during the week – we reached more than 43 million people, which is 63% of the population of the UK & Ireland:

- o Print coverage reached more than **4.7m** of the population
- o Radio coverage **14.1** million potential listeners
- TV coverage over 5.1 million viewers
- o Digital audience of more than **15 million** readers
- Social media coverage was also a big success reaching 74,998 people on Facebook and gaining around 90 new Twitter followers alone.

We also strive to maintain awareness and engage with our supporters through social media, and our 2013 achievements are summarised below:

- 3,859 Twitter followers (an increase of 30% compared to 2012)
- 2,612 Facebook likes (an increase of 50% compared to 2012)



7,469 website hits on average per month, with 11,230 views in October (an increase of 134% compared to 2012)

Other awareness achievements include writing press releases about our fundraisers and supporters, uploading a variety of content to social media and continuously publishing compelling personal stories across a range of media outlets.

#### 5.4 Support

Our Support Committee connects people affected by Primary Bone Cancer with others who have had the condition, or share a similar experience. We work with patients and families to provide support during their journey, but we do not provide medical advice, nor connect patients with medical professionals.

From our own personal experiences we know it helps to share that journey and here at BCRT we can help do that in number of ways. We have a dedicated email address which is staffed by volunteers who consistently respond promptly to each enquiry, and every contact is dealt with in the strictest confidence. We can't change the diagnosis but we can let you know you are not alone. Together we can make a difference.

One of our main support focussed charitable activities is our annual Patients' and Supporters' conference, which aims to reach out to people affected by bone cancer. It is our policy for these conferences to be accessible by anyone wanting to participate, so we don't charge for attendance. We know that this unity and support is very much appreciated by attendees, with feedback comments from 2013 including 'excellent organisation', 'really god mix of speakers', 'great to have a say in what BCRT does' and 'brilliantly well planned day with fantastic research sessions'.

In 2013 we took a slightly different approach to previous years. We had two conferences – a two day conference in June and a one day conference in October. The reason for this was to give more of our supporters a greater opportunity to attend. The first conference took place from Saturday 22<sup>nd</sup> June to Sunday 23<sup>rd</sup> June at Weetwood Hall in Leeds and was attended by 105 delegates. Our second conference took place on Saturday 12<sup>th</sup> October at The Marriott Hotel in Bristol and was attended by 90 delegates. Delegates at both conferences were a mix of former and current patients, family members, medical professionals and supporters. June saw a greater number of younger, current patients which was most likely because this conference was over two days and attracted a greater percentage of families with current primary bone cancer patients. As well as hearing from medical professionals about developments into primary bone cancer, last year's conferences provided an opportunity for delegates to have some input our future priorities, learn about the research we are funding, take part in interactive workshops and most importantly speak to others who are going through similar experiences.

We would like to take this opportunity to thank all of the contributors who helped to make last year's conference a great experience for our delegates:

#### Speakers:

- o Gill Pilcher, BCRT Trustee
- Marie Dixon, English Federation of Disability Sport
- Dr Paul Unwin, Stanmore International Ltd
- Mr Craig Gerrand, Orthopaedic Surgeon and Chair, BCRT Research and Information Committee
- Andy Hall, Chair of BCRT's Scientific Advisory Panel
- o Dr Michal Capra, Our Lady's Hospital for Sick Children, Dublin
- Professor Jeremy Whelan, Consultant Oncologist, University College London Hospitals
- o James Dwyer, Irish Paralympian, 2012 Olympics Equestrian Team
- Jamie Strachan, Partnerships Manager, BCRT

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- o Edward Hookway, University of Oxford
- o Brad Bradwell, Bone Cancer Awareness Trust
- Marc Wood, BCRT Patron and former osteosarcoma patient

#### Personal experiences:

- o Elwin Underwood
- Milan Patel
- James Wigg
- o Laura Horton, BCRT Trustee and former Ewing's sarcoma patient
- Tony Sutton
- Sonal Anand
- Ailbhe Foley

#### Researchers:

- o Professor Sue Burchill, Leeds University
- Karen Blakey, Research Assistant at University of Newcastle
- Dr Sandra Strauss, Senior Clinical Research Associate, University College Hospitals
- o Dr Franel le Grange, Clinical Research Fellow at University College London Hospitals

#### Workshop facilitators:

- o Dr Lorna Fern and Rebecca Birch, Leeds University
- Craig Gerrand
- o Andrew Sheppard, BCRT Trustee and former Ewing's sarcoma patient
- o Sherron Furtado, Newcastle Upon Tyne Hospitals NHS Foundation Trust
- o Amy Simpson, Marcus Longley and Marina McDonald, Welsh Institute for Health and Social Care

#### 5.5 Ireland

BCRT prides itself on being an organisation without National boundaries. During 2013 activities and fundraising events continued to take place in the Republic of Ireland and Northern Ireland as well as across the remainder of the United Kingdom. Our campaign to build awareness across all 32 counties of Ireland resulted in a steady increase in the number of enquiries received from Irish patients and their families. We have continued to focus on the importance of raising the profile of Primary Bone Cancer in Ireland to ensure improved outcomes for all those affected in these islands.

#### 5.6 Fundraising achievements

In 2013 we set ourselves an ambitious target to achieve £820,000 income, however we fell short of this target by approximately £18,000. During 2013, our incredible fundraisers have undertaken many different activities to raise money for us, including our biggest ever Team Bones event with 250 supporters running the Royal Parks Half Marathon, raising a total of £113,000. We are extremely grateful to every one of you that took part in this monumental event.

We are very pleased that 2013 also saw our second London Marathon Team Bones, another great milestone for BCRT. This event significantly increased our fundraising income compared to the year prior, plus the prestige and additional awareness generated has maximised return on the additional costs incurred. The number of BCRT places in London Marathon, increased from 24 in 2012 to 40 in 2013, however the event generated an income of £123,272.



There were many fundraising challenges taking place in support of BCRT during 2013, and we thank everyone that ran, walked, cycled, swam and trekked further than they thought possible. In addition, many people organised their own events involving baking, singing, zumba-ing, raffling, dancing, shaving, raft-building, and almost every other possible sport!

#### 6.0 FINANCIAL REVIEW

The Financial Statements comply with the Statement of Recommended Practice on Accounting by Charities, and the Trust Deed.

The financial results of the Charity are shown in Sections 10 to 12 of this report. The net assets of the Charity are £980,143 (2012: £843,345) and the Trustees consider that, at the date of this Report, the financial position of the Charity is sound.

The Trustees are pleased to report commitment to charitable activities, including support costs, for 2012/13 of £463,166 (2011/12: £640,417), of which £232,155 has been committed to the award of approved Research Grants (2011/12: £433,048). A further Research Fellowship expenditure of £114,018 was approved in December 2013, however the accounting rules mean that it will be shown in BCRT's January 2014 accounts.

Gross receipts for the financial year are £801,616 (2011/12: £764,833). Since the foundation of the Trust on 15<sup>th</sup> December 2005, £4,137,989 has been raised of which £2,094,461 has been spent or is committed to charitable activities. The Trustees have reserved the additional funds for future use in specific research opportunities.

The Trustees are aware that the return on fundraising expenditure (ratio of costs to income), has changed from 23.3% in 2012 to 33.5% in 2013. The change is largely due to the costs of increasing the places in the London Marathon, investing in an additional fundraiser targeting the Corporate Sector, and the proportional allocation of the CEO's costs to fundraising.

#### 6.1 Principle Funding Sources

The majority of our income is made up of voluntary donations and supporters undertaking some of the many fundraising activities outlined in section 5.6 above. During 2013 we received the following amounts:

Grants and donations (unrestricted):	£167,551
Grants and donations (restricted):	£134,028
Event income & sponsorship:	£469,281
Investment income:	£28,209
Other trading/miscellaneous:	£2,547
Total:	£801,616

We gratefully thank every single individual fundraiser that has contributed towards this amazing year, no matter how large or small, your donation makes such a difference and enables us to fulfill our charitable objectives.

#### 6.2 Charity Reserves

The Charity has a policy of maintaining sufficient reserves to enable the Charity to meet, as a minimum, its operational costs for the next year, estimated to be £358,816. The Charity currently has free reserves of £794,355. The Trustees have set aside the additional funds for use in specific future research activities, which will include maintaining and enhancing the Research Fellowship program, and being able to respond to the recommendations from the Research Strategy review in May 2014. The reserves of the Charity are continually monitored and reviewed within the context of the funds required to fulfil the objectives of the Charity.



#### 6.3 Investment Policy

Brewin Dolphin are BCRT's appointed Investment Managers with an investment mandate of "Income and Growth Return with Diversified Risk", and from an ethical perspective the Charity has directed that there be no investment in tobacco.

The portfolio has a benchmark of the WMA Private Investors Balanced Index (Total Return). This is a change from 2012, because in May 2013, the Trustees decided to change the risk profile of the investment from "cautious with risk" to "diversified risk", looking for capital growth as well as income return.

During 2013, the investments performed well. The total return, including realised and unrealised gains, was 16.58% against the APCIMS index of 14.12%, an outperformance of 2.46%. NB. The APCIMS figure takes into account the change from Income Index to Balanced Index in May 2013.

As at 31 December 2013, the capital value of funds invested was £852,699.

#### 6.4 Donations

Any donations, large or small, will help to fund research into Primary Bone Cancer and enable better outcomes for those affected by this devastating condition. Hopefully lives will be saved in the future as a result of donations enabling much needed research to be funded. Anyone wishing to make a donation, set up an online giving page, or for support turning your fundraising idea into reality, please contact our fundraising team on <a href="mailto:fundraising@bcrt.org.uk">fundraising@bcrt.org.uk</a>

#### 7.0 PLANS FOR FUTURE PERIODS

The Office relocation was completed successfully, however the IT Infrastructure has taken longer to resolve than first anticipated. This was due to various issues, including broadband performance, relocation to "cloud computing" and the need to upgrade the PC's to achieve significant speed improvements, and remove the Windows XP operating system, which was no longer supported by Microsoft. As a result the planned implementation of the new database/Customer Relationship Management System, was delayed along with the upgrade to the website. These two systems will now be implemented in 2014.

BCRT will complete a Strategy Review in 2014, starting with the Research Strategy; there will be a two day Research Strategy meeting in May 2014, which will include scientists and researchers from a wide range of fields. The title of the session will be "Breaking the deadlock in Primary Bone Cancer Research", and will be led by Professor Andy Hall, Chairman of the BCRT Independent Scientific Advisory Panel.

The Patients' and Supporters' Conference will revert to a single event in 2014, but will be again spread over two days. The event will be at Chesford Grange Hotel, Learnington Spa, on 28<sup>th</sup> and 29<sup>th</sup> June 2014.

BCRT's application to become a member of the Association of Medical Research Charities (AMRC) has been submitted and we expect to become members within the first quarter of 2014.

The Fundraising Events, which are promoted by BCRT, will be London Marathon, Royal Parks Half Marathon, Ride London (cycling) and a Charity Ball in the autumn.

#### BONE CANCER RESEARCH TRUST.





Bone Cancer Awareness Week will be 13<sup>th</sup>-19<sup>th</sup> October 2014. We will develop the theme for Awareness Week during the first quarter of 2014.

The Trustees have decided to change the structure of BCRT to become a Charitable Incorporated Organisation (CIO) by January 2015. This decision will have no effect on the work of Charity or on its aims and objectives; the key reasons for the change are to allow the charity to enter into contracts in its own right and the Trustees will then have limited liability for any debts of the Charity.

Approved by the Board of Trustees on 2<sup>nd</sup> August 2014 and signed on its behalf by:-

Roger Paul Chairman of Trustees **Andrew Sheppard** Trustee



#### 8.0 STATEMENT OF TRUSTEES' RESPONSIBILITIES:

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

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- · select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities 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 operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts Reports) Regulation 2008, and 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.

Roger Paul Chairman of Trustees

**Andrew Sheppard Trustee** 

Date: 2<sup>nd</sup> August 2014



# 9.0 INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES OF THE BONE CANCER RESEARCH TRUST:

We have audited the financial statements of The Bone Cancer Research Trust for the year ended 31<sup>st</sup> December 2013 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes. 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).

This report is made solely to the charity's trustees, as a body, in accordance with regulations made under Section 154 of the Charities Act 2011. 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 auditor's 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.

#### 9.1 Respective responsibilities of Trustees and Auditor:

As explained more fully in the Trustees' Responsibilities Statement set out on page 17, the trustees are responsible for the preparation of financial statements which give a true and fair view.

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's [(APB's)] Ethical Standards for Auditors.

#### 9.2 Scope of the Audit of the Financial Statements:

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charity's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Trustees' Annual Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

#### 9.3 Opinion on Financial Statements:

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31<sup>st</sup> December 2013, 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:
- have been prepared in accordance with the requirements of the Charities Act 2011.



Date: 2<sup>nd</sup> August 2014

# 9.4 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 Trustees' Annual Report 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.

#### **Thomas Coombs & Son**

Chartered Accountants & Statutory Auditor Century House 29 Clarendon Road Leeds West Yorkshire LS2 9PG



# 10.0 STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31st DECEMBER 2013:

	Notes	Unrestricted 2013	Restricted 2013	2013 £	2012 £
INCOME & EXPENDITURE: Income Resources from generated funds Voluntary income:		2	2	2	2
Grants and donations Investment income	2	167,551 28,209	134,028 -	301,579 28,209	300,748 22,766
Activities for generating funds: Event income and sponsorship Other trading and miscellaneous income		469,281 2,547	- - -	469,281 2,547	438,732 2,587
Total Income Resources		667,588	134,028	801,616	764,833
Resources Expended					
Costs of generating funds	3	268,613	-	268,613	178,652
Charitable activities Grants awarded and direct costs	4 4	321,211 76,760	65,195	386,406 76,760	552,332 88,085
Support costs Governance costs	5	13,443	<u>-</u>	13,443	13,900
Total Resources Expended		680,027	65,195	745,222	832,969
NET (OUTGOING) INCOMING RESOURCES FOR THE YEAR		(12,439)	68,833	56,394	(68,136)
OTHER RECOGNISED GAINS AND LOSSES Gains / (losses) on investments					
Realised Unrealised	8	8,342 72,062	-	8,342 72,062	1,822 36,971
NET MOVEMENT IN FUNDS		67,965	68,833	136,798	(29,343)
Reconciliation of funds Balances brought forward at					
1 <sup>st</sup> January 2013		733,247	110,098	843,345	872,688
BALANCES CARRIED FORWARD AT 31 <sup>st</sup> DECEMBER 2013		801,212	178,931	980,143	843,345

All amounts relate to continuing activities.

All recognised gains and losses are included in the Statement of Financial Activities.

The notes on pages 22 to 33 form part of these Financial Statements.



# 11.0 BALANCE SHEET AT 31<sup>st</sup> DECEMBER 2013:

	Notes	Unrestricted	Restricted		
		2013 £	2013 £	2013 £	2012 £
Fixed Assets					
Tangible	7	6,857	-	6,857	1,325
Investments	8	850,780		850,780	554,085
Current Assets		857,637	-	857,637	555,410
Stock Debtors:		3,894	-	3,894	6,899
Gift aid recoverable		4,231	_	4,231	5,404
Other debtors		9,307	_	9,307	9,080
Prepayment events and other costs		145,854	-	145,854	144,825
Cash at Bank		480,955	178,931	659,886	764,558
Liabilities: amounts falling due		644,241	178,931	823,172	930,766
within one year	9	(491,249)	_	(491,249)	(310,321)
Net Current Assets		152,992	178,931	331,923	620,445
Total Assets less Current Liabilities		1,010,629	178,931	1,189,560	1,175,855
Liabilities: amounts falling due after one year	10	(209,417)		(209,417)	(332,510)
Net Assets		801,212	178,931	980,143	843,345
Funds					
Unrestricted		801,212	-	801,212	733,247
Restricted	12		178,931 ———	178,931 ———	110,098
Total Funds		801,212	178,931	980,143	843,345

Approved by the Board of Trustees on 2nd August 2014 and signed on its behalf by:

R. Paul A. Sheppard Chairman of Trustees Trustee

The notes on pages 22 to 33 form part of these Financial Statements.



# 12.0 NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31st DECEMBER 2013:

# 1 Accounting Policies:

#### **Accounting Convention:**

The Accounts are prepared under the historical cost convention. They have been drawn up to comply with the Statement of Recommended Practice on "Accounting and Reporting by Charities" (SORP 2005) issued in March 2005 and applicable UK Accounting Standards and the Charities Act 2011.

### Voluntary income, including donations, event income and other 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

#### Volunteers and donated services and facilities:

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.

#### Resources expended:

Liabilities are recognised as resources expended as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

#### (a) Irrecoverable VAT

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

#### (b) Costs of generating funds

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

#### (c) Charitable activities

Costs of charitable activities include grants made and an apportionment of overhead and support costs.

#### (d) Grants payable:

Grants payable are payments made to third parties in the furtherance of the charitable objectives of the Trust. Single or multi-year grants are accounted for when 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 Trust.

### (e) Governance costs

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 and legal fees together with an apportionment of overhead and support costs.

#### BONE CANCER RESEARCH TRUST.

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#### Fund accounting:

(i) Restricted Funds:

The restricted funds (if any) are funds which have been raised for, and their use restricted to, a specific purpose, or donations subject to donor imposed conditions.

#### (ii) Dedicated Funds:

Designated funds (if any) are funds set aside out of general funds and designated for specific purposes by the Trustees.

#### (iii) Unrestricted Funds:

The unrestricted funds consist of those funds which the Charity may use in furtherance of its charitable objectives at the discretion of the Trustees.

#### Taxation:

The Trust is a Registered Charity and therefore is not liable for income tax or corporation tax on income derived from its charitable activities, as it falls within the various exemptions available to Registered Charities.

#### Fixed assets and depreciation:

Fixed assets are capitalised at their cost value. Depreciation is provided on all tangible fixed assets at rates calculated to write off the cost, less estimated residual value, of the assets over their expected useful lives. Depreciation is currently provided on the fixtures, fittings and office equipment at the principal rate of 25% per annum on a straight line basis.

#### Fixed assets investments:

Quoted investments are stated at mid market value. All losses and gains are taken direct to the Statement of Financial Activities as they arise.

Realised gains and losses on investments are calculated as the difference between sales proceeds and opening market value (purchase date if later). Unrealised gains and losses are calculated as the difference between the market value at the year end and opening market value (or purchase date if later).

#### Stocks:

Stocks are valued at the lower of cost and net realisable value. Cost is based on the cost of purchase on a first in, first out basis. Net realisable value is based on estimated selling price less additional costs to disposal.



# 2. Grants and Donations:

	2013 £	2013 £	2013 £	2012 £
Donations from connected bodies				
Adam Dealey Foundation for Ewing's Sarcoma	12,314	-	12,314	32,634
Anthony Pilcher Bone Cancer Trust	-	-	-	10,081
CHORF – The Christopher Hardman Osteosarcoma Research Fund	-	-	-	5,000
Family & Friends of Krystle Smith	-	238	238	2,121
Other general donations	155,237	-	155,237	190,567
Other restricted funds				
W S Training In Memory of Ella Redman Tom Hunt Trust C Malone Ewings Sarcoma Research Trust Three Ells Trust Rhodri Jones In Support of Mary Collard In Memory of Jim Rennie	- - - - - - -	750 1,120 10,000 1,817 37,500 25,000 225 57,378	750 1,120 10,000 1,817 37,500 25,000 225 57,378	25,000 20,000 14,673 672
	167,551	134,028	301,579	300,748
Donations from individual trustees are not disclosed				
3. Cost of Generating Funds:				
			2013 £	2012 £
Events costs			142,726	97,261
Other trading costs			498	5,550
Staff costs			88,358	46,503
Other fundraising costs			30,153	24,543
Investment management costs			6,878	4,795
			268,613	178,652
				24

Unrestricted

Restricted



# 4. Charitable Activities:

4. Charitable Activities:	2013 £	2012 £
Grants awarded:	~	~
Professor Sue Burchill, Children's Cancer Research Group, Leeds Institute of Molecular Medicine St James's University Hospital		
"Genotype and Phenotype of Self-renewing Cancer-initiating Ewing's Sarcoma Cells"	74,345	-
Dr Sandra Strauss, Department of Oncology UCL Cancer Institute, London		
"Investigation of CL67 as a first-in-class novel inhibitor of the HIF1a pathway in osteosarcoma"	74,797	-
Professor Latif, University of Birmingham, Birmingham		
"Chordoma Epigenetics"	-	9,900
Dr Neil Cross, Biomedical Research Centre Sheffield Hallam University		
"Enhancement of Death Receptor sensitivity in osteosarcoma using nuclear export inhibitors"	29,419	-
Dr Kenneth Rankin, Institute of Cellular Medicine and Northern Institute for Cancer Research University of Newcastle upon Tyne		
"The Feasibility of Detection and Characterisation of Circulating Tumour Cells in Osteosarcoma"	9,993	-
Mr Lee Jeys, Oncology Service Royal Orthopaedic Hospital, Birmingham		
"Can we reliably detect viable, dying or dead Ewing's sarcoma cells in per-tumoural tissues following induction chemotherapy?"	30,000	-
Professor Adrienne Flanagan, Department of Histopathology, Institute of Orthapedics Royal National Orthopaedic Hospital, Stanmore		
"Generating osteosarcoma cell lines which will be analysed as pasrt of the International Cancer Genome Consortium (ICGC)	13,601	-



– Bone Tumour Project"		
Prof F Gibson, Great Ormand Street Hospital for Children		
"Improving diagnosis of cancer in children and young people"	-	10,000
Professor N Athanasou, Department of Pathology, Nuffield Orthopeadic Centre, Oxford		
"Analysis of Osteolysis in Ewing's Sarcoma and Osteosarcoma and the Effect of Resorption Inhibitors on Tumor Growth"	-	70,100
Dr Harriet Holme, Department of Child Health, Royal Free Hospital, London		
"Identifying Biological Dependencies in Osteosarcoma to Develop Novel Therapeutics"	-	225,000
Dr Franél le Grange, Oncology, ULCH NHS Foundation Trust, London		
"How Outcomes for Patients with Bone Sarcomas can be Improved by Intensity Modulated Radiotherapy and Proton Radiotherapy: Optimising Delivery, Efficacy and Toxicity Profiles"	-	128,048
Grants previously awarded, now no longer required	(411)	(25)
	231,744	443,023
Analysis of grants awarded		
- Grants awarded in the period	232,155	443,048
- Grants no longer required	(411)	(25)
Research Fellowship set up costs	-	1,653
Newsletters, dissemination of information, awareness, website and conferences	54,974	36,970
The Royal College of General Practitioners (RCGP) – E Learning Module	10,328	-
Staff costs	87,756	70,065
Trustee expenses – project activities	1,604	621
	386,406	552,332
	<del></del>	



	2013 £	2012 £
Support Costs: Premises costs	17,569	10,201
Telephone	2,072	1,726
Postage	4,384	3,799
Stationery and printing	4,759	4,893
Relocation costs	3,016	7,271
Sundries	4,461	4,518
Professional memberships	1,040	-
Staff costs	29,228	22,731
Depreciation	1,561	602
Recruitment and human resources costs	4,226	25,737
Travel and subsistence	3,371	4,348
Trustee expenses – operational support	1,073	2,259
	76,760	88,085
5. Governance Costs:		
	2013 £	2012 £
Trustee meeting costs and expenses	5,119	4,657
Auditors remuneration	4,199	3,843
Legal and professional costs	4,125	5,400
	13,443	13,900



#### 6. Trustees and Staff Costs:

. Trustees and Stain Sester.	2013 £	2012
Staff costs:	£	£
Wages and salaries	187,339	128,259
Employer's National Insurance	18,003	11,040
Total	205,342	139,299

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. The Trustees received no remuneration. During the period, travel and subsistence expenses of £2,677 (2012: £2,880) were reimbursed to six trustees (2012: four trustees). No employee earned more than £60,000 per annum.

The average number of employees (full and part time):

	2013 No.	2012 No.
Permanent staff Trustees	8 11	6 11
Total	19 ——	17



# 7. Tangible Assets:

	Office Equipment	Computer Equipment	Total
Cost:			
As at 1 <sup>st</sup> January 2013	476	7,247	7,723
Additions	2,322	4,771	7,093
Disposals	(476)	-	(476)
As at 31 <sup>st</sup> December 2013	2,322	12,018	14,340
Depreciation:			
As at 1 <sup>st</sup> January 2013	476	5,922	6,398
Charged during the period	229	1,332	1,561
Eliminated on disposal	(476)		(476)
As at 31 <sup>st</sup> December 2013	229	7,254	7,483
Net Book Value:			
31 <sup>st</sup> December 2013	2,093	4,764	6,857
31 <sup>st</sup> December 2012	-	1,325	1,325



8.	Investments:		Market Value 2013 £	Market Value 2012 £
		Listed investments Cash on deposit held for reinvestment	842,943 7,837	545,061 9,024
		Total Investments	850,780	554,085
			Listed Investment Total £	
		Market value at 1 <sup>st</sup> January 2013 Additions Disposals Surplus on revaluation	545,061 273,324 (47,504) 72,062	
		Market value at 31 <sup>st</sup> December 2013	842,943	
		Historical cost at 31 <sup>st</sup> December 2013	732,336	
		At 31 <sup>st</sup> December 2013 no individual investment represer investment portfolio valuation	nted more than 5%	of the total
9.	Liabilities:	Amounts falling due within One Year:	2013 £	2012 £
		Grants awarded and related creditors Accruals Taxation & social security Other creditors Deferred income	422,289 4,742 5,663 16,213 42,342	255,160 7,255 4,720 34,177 9,009
			491,249	310,321
10.	Liabilities:	Amounts falling due after One Year:	2013 £	2012 £
		Grants awarded	209,417	332,510





# 11. Reconciliation of Grants Awarded

	2013 £	2012 £
Opening liability obligation Research grants awarded in the year Provisions no longer required Paid during the year	587,670 232,155 (411) (187,708)	314,229 433,048 (25) (159,582)
Closing liability obligation	631,706	587,670



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12. Restricted Funds:	Krystle Smith £	The Rhodri Jones Appeal £	W S Training £	Three Ells Trust	Anthony Pilcher £	In Memory Of Ella Redman £	Tom Hunt Trust £	C Malone	In support of Mary Collard £	Ewings Sarcoma Research Trust £
						-				
Opening balance		37,500		27,050	20,081				24,720	
Voluntary income:										
Grants and donations	238	225	750	25,000	-	1,120	10,000	1,817	57,377	37,500
Activities for generating funds: Event income	-	-	-	-	-	-	-	-	-	-
Total Incoming Resources For The Year	238	225	750	25,000	-	1,120	10,000	1,817	57,377	37,500
<b>Expenditure:</b> Settlement of obligations for the following grants										
Prof S Burchill	618	-	-	-	-	-	-	-	-	-
L Jeys	-	14,100	-	2,050	10,000	-	-	-	11,350	-
Prof A M Flanagan	-	10,500	-	-	-	-	-	-	3,400	-
Dr N Cross	-	10,034	-	-	-	-	-	-	-	-
H Unsworth	-	-	-	-	-	-	-	1,817	-	-
Dr Rankin	-	-	-	-	-	-	-	-	1,326	-
Total Expenditure For The Year	618	34,634	-	2,050	10,000	-	-	1,817	16,076	-
Closing balance	367	3,091	750	50,000	10,081	1,120	10,000	-	66,021	37,500

# BONE CANCER RESEARCH TRUST.



Report of the Trustees and Financial Statements for the year ended 31<sup>st</sup> December 2013.

The Krystle Smith Restricted Fund represents monies restricted for research into Ewing's sarcoma.

The Rhodri Jones Appeal represents funds raised by the Jones family for research into osteosarcoma.

The W S Training Restricted Fund represents monies restricted for research into Ewing's sarcoma.

The Three Ells Trust Restricted Fund represents monies restricted for research into osteosarcoma.

The Anthony Pilcher Bone Cancer Trust Restricted Fund represents monies restricted for research into osteosarcoma.

The In Memory of Ella Redman Restricted Fund represents monies restricted for research into osteosarcoma.

The Tom Hunt Trust Restricted Fund represents monies restricted for research into osteosarcoma.

The C Malone Restricted Fund represents monies restricted for research into Ewing's sarcoma.

The In Support of Mary Collard Restricted Fund represents monies restricted for research into osteosarcoma.

The Ewing's Sarcoma Research Trust Restricted Fund represents monies restricted for research into Genotype and Phenotype of Self-renewing cancer-initiating Ewing's sarcoma.



# **Appendix A: Formation of BCRT**

The Trustees are very aware of the important and considerable contribution to the advancement of research into Ewing's Sarcoma made some 7 years before the foundation of the Bone Cancer Research Trust by John and Marian Dealey, through the Adam Dealey Foundation for Ewing's Sarcoma, in memory of their son; and, the fundraising by Patricia and Christopher Smith in the Republic of Ireland, in memory of their daughter Krystle, who was also diagnosed with Ewing's Sarcoma.

Whilst their fundraising awards prior to 15<sup>th</sup> December 2005 play no part in the records of the Trust, nonetheless the impartial Trustees wish to place on public record an account of the fundraising activities made by the Dealey and Smith families as a grateful acknowledgement of their considerable contribution to medical research into Ewing's Sarcoma. The families funded 7 research projects, totalling £158,885.

The Dealey and Smith families were instrumental setting up BCRT in 2005, along with a number of other established groups of families and friends of Primary Bone Cancer patients. The founding groups were:

Adam Dealey Foundation for Ewing's Sarcoma
Anthony Pilcher Bone Cancer Trust
Christopher Hardman Osteosarcoma Research Fund (CHORF)
Guy Francis Bone Cancer Research Fund
Family & Friends of Emma Callar
Family & Friends of Jennifer Carvell
Family & Friends of Joe Thompson
Family & Friends of Krystle Smith
Family & Friends of Stephanie McCartney

Since the formation of BCRT, a further £1.7m has been spent on funding essential research, spanning37 different projects, each aiming to improve outcomes for people affected by Primary Bone Cancer.