



BONE CANCER RESEARCH TRUST.

Report of the Trustees and Financial Statements for the year ended 30<sup>th</sup>. June 2009.

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**BONE CANCER RESEARCH TRUST**  
Charity Reg. No. 1113276

**TRUSTEES' REPORT  
AND  
FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 30 JUNE 2009**

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## 1.0 LEGAL AND ADMINISTRATIVE INFORMATION:

Date of Trust Deed: - 15<sup>th</sup>. December 2005.

Charity Registration Details:- Registered Number 1113276, registered on 14<sup>th</sup>. March 2006 in England.

Working Names:- BCRT : bcrt : Bone Cancer Research : BCR : Team Bones.

Trustees who served during the year 1<sup>st</sup>. July 2008 to 30<sup>th</sup>. June 2009.

Nicholas Darren Bones

John Dealey (Deputy Chairman)

Fiona Marie Foley

Michael Brian Palmer Francis (Chairman)

Robert Grimer MB BS FRCS (Eng) FRCS (Edin) Orth. (did not seek re-election @ 21<sup>st</sup>. February 2009)

Patrick Michael Hardman

Sally Hurst

Ian John Lewis MB ChB FRCP FRCPCH

Roger Paul (appointed 22<sup>nd</sup>. November 2008)

Gillian Pilcher

Patricia Smith

Clerk to the Trustees : Rosalyn M. Francis MA.

**Legal and Administrative Information** *(continued)*

Scientific Advisory Panel:-

Professor I J. Lewis MB ChB FRCP FRCPCH.

*Consultant Paediatric & Adolescent Oncologist, St. James's University Hospital, Leeds.*

Mr. R. Grimer MB BS FRCS (Eng) FRCS (Edin) Orth.

*Consultant Orthopaedic Surgeon, Royal Orthopaedic Hospital, Birmingham.*

Dr. J. Whelan MD MB BS FRCP.

*Consultant Medical Oncologist and Clinical Director of Cancer Services,  
Meyerstein Institute of Oncology, University College Hospital, London.*

Registered Office:-

Children's Day Hospital, St. James's University Hospital,  
Beckett Street, Leeds, LS9 9PG.

Fundraising and Administration Office:-

Suite 7, Gledhow Mount Mansion,  
Roxholme Grove, Leeds, LS7 4JJ.

Telephone: 0113 262 1852. Fax: 0113 262 5391.

Email: [info@bonecancerresearch.org.uk](mailto:info@bonecancerresearch.org.uk) Web Address: [www.bcrct.org.uk](http://www.bcrct.org.uk)

Trustee Correspondence:-

Clerk to the Trustees,  
6, Blake Court, Wheldrake, York, YO19 6BT.  
Telephone: 01904 448696.

**Legal and Administrative Information** *(continued)*

Independent Examiner:-

C. J. Darwin ACA,  
Messrs. Thomas Coombs & Son, Chartered Accountants,  
29, Clarendon Road, Leeds, LS2 9PG.

Solicitors:-

Brooke North LLP,  
Crown House, Great George Street, Leeds, LS1 3BR.

Bankers:-

The Co-operative Bank,  
PO Box 250, Delf House, Skelmersdale, WN8 6WT.

Human Resource Consultants:-

Abacus HR Ltd.,  
Abacus House, 7 Summerlea Court, Herriard, Basingstoke, Hampshire, RG25 2PN.

BCRT Staff:-

Head of Fundraising:-

David Fisher BSc.  
Telephone : 0113 2621853. Fax: 0113 2625391.  
Email: [david@bcrt.org.uk](mailto:david@bcrt.org.uk)

Administrator:-

Kate Connor BA.  
Telephone : 0113 2621853. Fax: 0113 2625391.  
Email: [kate@bcrt.org.uk](mailto:kate@bcrt.org.uk)

The Trustees present their Annual Report and Financial Statements for the year ended 30<sup>th</sup>. June 2009.

The comparative period covers 1<sup>st</sup>. July 2007 to 30<sup>th</sup>. June 2008.

As an opening statement, the Trustees wish to record their observation that the composition of the Trust is changing in that the baseline membership of the Trust is diminishing from being a bereaved family and friends fund raising charity, into a more inclusive and coherent organisation where present and former patients of Primary Bone Cancers are playing an increasingly important part. Despite the restrictions of data protection legislation, this is being achieved through positive wishes of present and former patients to come to the Trust and be involved in its vision.

The Trustees also acknowledge the considerable support and guidance being given freely by many Medical Practitioners and Professionals, which is opening doors into many areas hitherto closed.

The Trustees are delighted to report that, as at the end of the Financial Year to 30<sup>th</sup> June 2009, over £1,150,000 has been raised since the Trust became an organisation in December 2005 and a Registered Charity in March 2006.

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.

The Trustees believe that they have complied with the duty set out in section 4 of the Charities Act 2006, and have paid due regard to public benefit guidance published by the Charity Commission.

## **2.0 HOW THE BONE CANCER RESEARCH TRUST CAME INTO BEING:**

In September 2004, Dr. Ian Lewis, Consultant Paediatric & Adolescent Oncologist at St. James's University Hospital, Leeds, invited 5 families from Lewes (Sussex), Helston (Cornwall), Liverpool, Newcastle-upon-Tyne and York to a meeting to explore areas of mutual interest. All were bereaved families having lost a teenage daughter or son as a result of having the most common form of Primary Bone Cancer – Osteosarcoma. All the families had started raising funds in memory of their child but none had been able to find a charity dedicated to funding research into this type of cancer. Dr. Lewis explained that Primary Bone Cancers (PBCs) did not, in fact, attract extensive research funding from the National Health Service or the national cancer charities and, as a result, there was little research into the causes of PBCs, or into developing new treatments.

The families learnt that around 90% of all new cases of Osteosarcoma per annum were detected in children and teenagers, the peak age being between 15 - 20 years. The survival rate for Osteosarcoma beyond 5 years was 55%.

Four of the five families resolved to continue discussions to see if, by pooling their financial resources, a viable fund could be set up to kick start much needed research. By March 2005, a theme had been developed which saw any future Charitable Trust as being:-

*“Devoted to promoting research into the causes and treatment of Primary Bone Cancer, and in particular of Osteosarcoma and Ewing's Sarcoma.”*

Further meetings took place and it became apparent that viability could be strengthened if contact was made with families of children and teenage patients of another PBC – Ewing's Sarcoma. With Ewing's Sarcoma, the age range was slightly different peaking between 10 – 20 years, with a survival rate beyond 5 years of some 60%. Together, new cases of Osteosarcoma and Ewing's Sarcoma would number around 400 young people per annum in the United Kingdom. In addition, some research into Ewing's Sarcoma had

been identified, chiefly through the Adam Dealey Foundation for Ewing's Sarcoma which had funded research projects since 1998.

Two more goals would be considered. All those participating in the discussions were from bereaved families. No consideration had been given to involving those patients undergoing treatment (and their families), or to patients who were now in remission. To address this, it was decided to seek someone from the latter category to be a Trustee, and consequently, in July 2005, Nick Bones joined the Working Party.

Further objectives were agreed. In addition to promoting research into *"causes and treatment"*, the Trust would back research into *"improving patient outcomes"*. Also, the Trust would look to *"provide information, support and, in the longer term, counselling services for those suffering from Primary Bone Cancer, and their families."* It was also realised that the appraisal and selection of suitable research projects could not be undertaken by the Founding Members as they were not appropriately qualified. It was decided that a Scientific Advisory Panel should be established, and Dr. Ian Lewis was invited to consider the scope, organisational structure and membership of the Panel. At the same time, thought was given to widening the appeal of the future Trust by inviting Medical Practitioners to participate in the Trust's activities.

The Dealeys attended the Working Party in July 2005. They were in contact with another Ewing's patient family in the Republic of Ireland (the family and friends of Krystle Smith) who came over to the Working Party's September 2005 meeting. At this meeting, 9 families decided to formalise an alliance, and to establish a Charitable Trust.

The 9 Founding Members were:-

CHARITY OR GROUP	LOCATION	FAMILY
Adam Dealey Foundation for Ewing's Sarcoma	Hemel Hempstead, Hertfordshire	Adam was diagnosed with Ewing's Sarcoma, aged 9.
Anthony Pilcher Bone Cancer Trust (Reg. Charity No. 1099337)	Peacehaven, East Sussex	Anthony was diagnosed with Osteosarcoma, aged 14
Christopher Hardman Osteosarcoma Research Fund (Reg. Charity No. 1111059)	Wirral, Merseyside	Christopher was diagnosed with Osteosarcoma, aged 13
Guy Francis Bone Cancer Research Fund	York, North Yorkshire	Guy was diagnosed with Osteosarcoma, aged 17
Family & Friends of Krystle Smith	Arklow, County Wicklow, Republic of Ireland	Krystle was diagnosed with Ewing's Sarcoma, aged 17
Family & Friends of Emma Callar	Helston, Cornwall	Emma was diagnosed with Osteosarcoma, aged 14
Family & Friends of Stephanie McCartney	Keighley, West Yorkshire	Stephanie was diagnosed with Osteosarcoma, aged 13
Family & Friends of Joe Thompson	Kettering, Northamptonshire	Joe was diagnosed with Osteosarcoma, aged 11
Family & Friends of Jennifer Carvell	Liverpool, Merseyside	Jennifer was diagnosed with Osteosarcoma, aged 13



### 3.0 INITIAL STRUCTURE GOVERNANCE AND MANAGEMENT:

#### 3.1 Governing Document:

The Trust became an Unincorporated Trust, constituted under a Trust Deed dated 15<sup>th</sup>. December 2005. On the 14<sup>th</sup>. March 2006 it became a Registered Charity, Number 1113276. The Trust Deed was signed by Nicholas Darren Bones, Gillian Anne Callar, John Dealey, Michael Brian Palmer Francis, Robert Grimer, Patrick Michael Hardman, Ian John Lewis, Deborah Alice McCarthy, Gillian Pilcher, and Patricia Smith.

#### 3.2 Organisational Structure:

The Trustees must hold at least 4 Ordinary Meetings each year and agree the broad strategy and areas of activity of the Trust, including consideration of grant making, investment, reserves and risk management policies and performance.

#### 3.3 First Trustees:

The first Trustees, in accordance with the Trust Deed, hold the office of Trustee for the following number of years:-

<b>3 years</b>	<b>4 years</b>	<b>5 years</b>
N. D. Bones R. Grimer	J. Dealey D.A.McCartney G. Pilcher	G. A. Callar M. B. P. Francis P. M. Hardman I. J. Lewis P. Smith

The First Trustees elected Michael Francis and John Dealey as Chairman and Deputy Chairman of Trustees respectively.

The background to each First Trustees is as follows:-

Nicholas Darren Bones	Former Osteosarcoma Patient
Gillian Anne Callar	Mother of Emma
John Dealey	Father of Adam
Michael Brian Palmer Francis	Father of Guy
Robert Grimer	Medical Practitioner
Patrick Michael Hardman	Father of Christopher
Ian John Lewis	Medical Practitioner
Deborah Alice McCartney	Mother of Stephanie
Gillian Pilcher	Mother of Anthony
Patricia Smith	Mother of Krystle

### **3.4 Scientific Advisory Panel (SAP):**

In accordance with the wishes of the Founding Members, a Scientific Advisory Panel was established under the Chairmanship of Dr. Ian Lewis, 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.

The role of the SAP is to:-

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

The first appointed members of the Scientific Advisory Panel were:-

Dr. I J. Lewis MB ChB FRCP FRCPCH.  
*Consultant Paediatric & Adolescent Oncologist, St. James's University Hospital, Leeds.*

Mr. R. Grimer MB BS FRCS (Eng) FRCS (Edin) Orth.  
*Consultant Orthopaedic Surgeon, Royal Orthopaedic Hospital, Birmingham.*

Dr. J. Whelan MD MB BS FRCP.  
*Consultant Medical Oncologist and Clinical Director of Cancer Services,  
Meyerstein Institute of Oncology, University College Hospital, London.*

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

The Trust Deed requires the Board of Trustees to have at least 10 members. Apart from the first Trustees, every Trustee must be appointed by a resolution of the Trustees passed at a Special Meeting. On their appointment, each new Trustee is provided with at least a copy of the Trust Deed, and the Charity's latest Annual Report and Financial Statement of Accounts.

## **4.0 OBJECTIVES AND ACTIVITIES:**

The Trust Deed states that the Trustees must apply the income in furthering the relief of sickness generally and in particular, but not so as to limit the generality, the foregoing:-

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;

Providing counselling, support and information services for persons suffering from Primary Bone Cancer, and their families.

### **4.1 Grant Making Policy:**

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

The Charity is particularly interested in providing “*pump-priming*” grants that might initiate or support work that could lead to more substantial applications to national or international funders. It is intended that there will be up to two calls for grant applications each year. Applications for grants should be submitted, using the downloadable form on the Charity’s website – [info@bcrt.org.uk](mailto:info@bcrt.org.uk). This can be sent either electronically to [research@bonecancerresearch.org.uk](mailto:research@bonecancerresearch.org.uk) or six copies of the form can be posted to the Charity’s Fundraising and Administration Office (fao Mrs. Kate Connor). Applications should be expected to receive notification of the outcome of the round within 3 months of the closing date for applications.

BCRT now has National Institute for Health Research Clinical Research Network (NIHR CRN) Partner status which will ensure that studies funded by BCRT will be eligible for inclusion in the Portfolio (including other partner organisations). This will allow our research projects to have access to clinical infrastructure/NHS Service Support through the NIHR Clinical Research Networks.

Initially, the Trustees will consider bids of any sum up to £30,000.

Applications received by the Trust are forwarded to the Scientific Advisory Panel (SAP) for assessment. The Charity insists on external peer review for all funding requests of £10,000 and above. Requests for sums less than this may be granted by the SAP and Trustees without formal external review. Each application for external review will be overseen by a Specialist Advisor with particular expertise who will recommend appropriate Reviewers. External Reviewers will be asked to confirm that there is no significant conflict of interest.

Each round of applications will be considered by the SAP, who will determine which applications are of sufficient quality to be funded, and rank them accordingly. They could choose to recommend all or none. Recommendations will then be considered by the Trustees, who have the final decision on funding. This will be determined by available funds, not the quality of research.

## **5.0 STRUCTURE, GOVERNANCE AND MANAGEMENT for the year 1<sup>st</sup>. July 2008 to 30<sup>th</sup>. June 2009:**

### **5.1 Trustees:**

Details of the Trustees who have served for the year 1<sup>st</sup>. July 2008 to 30<sup>th</sup>. June 2009 are listed on page 4.

The Trustees have met on 5 occasions –

13<sup>th</sup>.September 2008; 22<sup>th</sup>.November 2008;

21<sup>st</sup>. February 2009; 2<sup>nd</sup>. May 2009; 28<sup>th</sup>. June 2009.

Michael Francis and John Dealey were re-elected as Chairman and Deputy Chairman of Trustees respectively at the Board of Trustees’ Annual General Meeting, held on 21<sup>st</sup>. February 2009.

The intended resignation of Robert Grimer was received at the meeting held on 22<sup>nd</sup> November 2008. The Board expressed their thanks to Robert for all his hard work in towards creating the Trust, and were pleased to learn that he wished to continue as a member of the Scientific Advisory Panel.

A new Trustee, bringing experience in fundraising and investment planning, was approved by resolution on 22<sup>nd</sup> November 2008. The Board welcomed Roger Paul, parent of Claudia Paul who was a primary bone cancer patient.

The Trustees will continue to seek other additional and helpful areas of expertise.

## 5.2 Scientific Advisory Panel (SAP):

Mr. Robert Grimer MB BS FRCS (Eng) FRCS (Edin) Orth., and Dr. Jeremy Whelan MD MB BS FRCP, continued as members of the SAP, under the Chairmanship of Professor Ian Lewis MB ChB FRCP FRCPCH.

## 5.3 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 current and previous periods as detailed in Note 2 of the Financial Statements. The specific connections are:-

Trustee	Related Party
Gillian Pilcher	Anthony Pilcher Bone Cancer Trust. RCN 1099337.
John Dealey	Adam Dealey Foundation for Ewing's Sarcoma.
Fiona Foley	Blathnaid Foley Trust (Republic of Ireland)
Michael Francis	Guy Francis Bone Cancer Research Fund
Patrick Hardman	Christopher Hardman Osteosarcoma Research Fund. RCN 1111059
Patricia Smith	Family & Friends of Krystle Smith. (Republic of Ireland)

## 5.4 Risk Management:

The Trustees have examined the major strategic, business and operational risks which the Charity faces, and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to lessen these risks.

## 5.5 Trust Patron:

The Trustees would like to record their sincere thanks to their Patron, Marc Woods - Paralympics Gold Medallist and former osteosarcoma patient, for his continued interest and support in the work of the Trust.

## 5.6 Enlargement of the Trust's own office facilities:

During 2008, it became clear to the Trustees that the original office in Suite 1D of Gledhow Mount Mansion was too small to accommodate the expanding work of the Trust. Fortuitously, larger accommodation became available in the small building, and in December 2008, the Trust moved into Suite 7.

The new offices will provide office accommodation for a predicted expanding number of staff, together with a small meeting room.

## 5.8 Administrator:

In mid-May 2009 Kate Connor (Administrator) started maternity leave, and her place was taken on a temporary basis, by Lauren Heslop, BA (Hons), a graduate in Marketing.

**5.9 Voluntary Workers:**

The Trustees are very appreciative of the work carried out by numerous volunteers throughout the United Kingdom and the Republic of Ireland in organising fundraising events. There are also many people who have had a major role in the background preparing the Conferences, BCRT Newsletter, Awareness Week and Media coverage.

In particular, the Trustees would like to thank Rosalyn Francis for her work as Clerk to the Trustees, and in her preparation of minutes and other documentation for Trustees' meetings, and contact with the Charity Commission, the Trusts' legal and accounting advisors, and supporting the Chairman - with clerical work and research.

Also, the Trustees thank Alan Johnston for his work as Website Manager, particularly his vigilance in ensuring that the website is monitored, regularly refreshed, is compliant, is informative and is user friendly. The BCRT Website is highly regarded by other organizations, particularly in the way new stories and events are introduced, together with offering appropriate links to other websites.

Finally, the Trustees would like to express their thanks to Tabitha Hazeldine, a student in Public Relations at the University of Huddersfield, for her voluntary work in the office, particularly during the Bone Cancer Awareness campaign and annual conference.

**5.10 Human Resources Consultancy:**

Abacus HR Ltd. continue to be the Trust's Human Resources Consultants. The Board thanks Gillian Pilcher for her continuing hard work in liaising with the Company on the Trustees' behalf.

**5.11 Professional Advisors:**

The Trustees were pleased to re-appoint as their Independent Examiner, Mr. C. J. Darwin, ACA, of Messrs. Thomas Coombs & Son, Chartered Accountants, and thank him for his scrutiny.

The Trustees also confirmed the continuing appointment of Brooke North LLP of Leeds as their Solicitors, and The Co-operative Bank as their Bankers.

**5.12 General, Dedicated and Restricted Fund Accounts:**

As part of maximizing 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, including those from 4 of the 6 Related Parties listed above (see paragraph 5.3).

Dedicated Accounts are funds which have been opened in memory of an individual, usually by bereaved family and friends. Not only do they allow their loved one's name to be remembered within the Bone Cancer Research Trust, they also can be used for local fundraising and raising awareness.

Restricted Accounts are very similar to Dedicated Accounts in that they are in the names of a loved one, but they may be restricted for a specific purpose, for example, to be ring-fenced for a particular aspect of research.

As at 30<sup>th</sup>. June 2009, the spread over the 3 types of account was as follows:-

General Accounts	Dedicated Accounts	Restricted Accounts
Adam Dealey Foundation for Ewing's Sarcoma	Guy Francis Bone Cancer Research Fund	Family & Friends of Krystle Smith (Ewing's Sarcoma)
Anthony Pilcher Bone Cancer Trust	Family & Friends of Jennifer Carvell	The Rhodri Jones Appeal (Osteosarcoma)
Blathnaid Foley Trust	Family & Friends of Kenny McCabe	Family & Friends of Hilary Lawler (Ewing's Sarcoma)
Christopher Hardman Osteosarcoma Research Trust	Family & Friends of Joseph Wright	Family & Friends of Nicola Curran (Ewing's Sarcoma)
General donations & other income	Matt's Beacon Fund  Adam Panther Fund  Daniel Round Fund  Paul Gavin Fund  Nick Pollard Fund	

## 6.0 LINKS WITH OTHER ORGANISATIONS:

### 6.1 National Alliance of Childhood Cancer Parent Organisations (NACCPO) (RCN 1090871):

As Chairman of Trustees, Michael Francis represents the Trust on the National Executive Committee of NACCPO. This umbrella organisation has direct access to both national and international institutions who are leaders in the development and administration of research, health and support services for all cancers affecting children, teenagers and young adults.

Gillian Pilcher and Alan Johnston represented the Trust at the NACCPO Annual General Meeting (Bournemouth : 20<sup>th</sup>. June 2009). The BCRT display stand formed part of the conference exhibition.

### 6.2 British Sarcoma Group – 4th. Annual Conference (Glasgow : 18<sup>th</sup>. – 20<sup>th</sup>. March 2009):

BCRT has attended all 4 Conferences (the other 3 being in Birmingham, Manchester and Sheffield), where the Trust has taken the opportunity to mount a display of its work. This year, the Trust was represented by Michael Francis. The Conference provides a unique link to networking with Medical Professionals from Multi-Disciplinary Teams. Professor Ian Lewis spoke to the Conference, asking "What would you like BCRT to do to help you?" Preferences were captured electronically and will be analysed to develop stronger links with the centres of excellence. Dr. Gill Lawrence, Director of the West Midlands Cancer Intelligence Network also spoke, outlining the work of the National Sarcoma Register Steering Group, of which BCRT is a member.

### **6.3 Sarcoma UK:**

The Trust continues its dialogue with Sarcoma UK, and looks forward to further collaborative working on projects of mutual interest including NICE Appraisals; the National Sarcoma Register; and the British Sarcoma Group Conference in February 2010 in London

### **6.4 National Institute for Health and Clinical Excellence (NICE):**

In December 2007, NICE invited the Trust to comment on the draft remit and draft scope on a proposed Health Technology Appraisal for the drug *Liposomal muramyl tripeptide ethanolamine (Mepact) for Osteosarcoma*. Following the Trust's submission, a further invitation was made by NICE to attend a Scoping Workshop on 26<sup>th</sup>. February 2008. Three Trustees attended this, and this led to a full Technical Appraisal meeting in February 2009; Two Trustees, Sally Hurst and Michael Francis, respectively Patient and Carer Expert Witnesses gave evidence, and were joined by Professor Tim Eden, TCT Professor of Teenage Cancer at the Christie Hospital, Manchester as the Trust's as the Professional Expert. The findings of the Appraisal Committee are awaited.

### **6.5 National Sarcoma Register Steering Group (NSRSG) (West Midlands Cancer Intelligence Group - WMCIG):**

The Trust was offered 2 places on the newly formed NSRSG as Patient Representatives, and these were taken by Michael Francis and Hannah Millington (a former Osteosarcoma Patient). All cancers are to have Registers as set out in the Government's Cancer Reform Strategy. WMCIG have been made responsible for Breast and Bone & Sarcoma Cancer Registries, with the objective of improving the outcomes for patients. As Breast Cancer can develop into a secondary "Breast Cancer in the Bone", the link is very pertinent.

Four key areas have been identified in relation to the Sarcoma Register:-

The need for better information, based on collecting the right data to improve outcomes.

The need for information to inform the commissioning of sarcoma services.

Development of the Sarcoma Register needs to be joined up with other initiatives in relation to sarcoma services. such as the Map of Medicine initiative,

Through the NHS Standard Contract for Acute Services, the electronic transfer to cancer registries of the national cancer registration data set and multi-disciplinary team (MDT) meeting data will be mandatory requirements from NHS Hospital Trusts by 2011.

Robert Grimer is the Steering Group Chairman. Jeremy Whelan is also a member of the Group. There are 2 other Patient Representatives from Sarcoma UK (Guy Sidford and Terri Johnson) with whom BCRT are working closely.

### **6.6 Teenage Cancer Trust (TCT) (RCN 1062559):**

So many Primary Bone Cancer patients experience at first hand the work of TCT in providing hospital ward facilities appropriate to the needs and lifestyles of teenagers and young adults. A close working relationship is developing between the 2 charities for the mutual benefit of those they both seek to support. Professor Ian Lewis is actively involved in forging contacts, and BCRT is grateful to Mrs. Sue Morgan MBE, MacMillan Clinical Nurse Specialist at St. James's University Hospital, Leeds, and Professor Tim Eden, TCT Professor of Teenage Cancer at Christie Hospital, Manchester for their advice and support.

The Trust are also grateful for the continuing support and encouragement from the TCT Chief Executive, Simon Davies.

## 7.0 ACHIEVEMENTS AND PERFORMANCE:

The Trust continues to focus on the development of fundraising opportunities, whilst widening its network base of Patients and Supporters, in support of its core object – funding medical research and improving patient outcomes.

### 7.1 Research Applications and Grants:

During the year 2006/07 the first 2 Research Grants were awarded. One of these is now published research and a synopsis appeared in the Trust's Spring 2009 Newsletter, which is reproduced on the BCRT Website. By June 2009, some 13 Research Projects had been approved for funding. Details of all the Projects are set out below:

PROJECT / CONFERENCE				
Research Grant / Conference Award				
BCRT Year	Grant Round Closing Date	Description	Recipient / Beneficiary	Value £
2006/07		International Consensus Meeting on Local Control of Ewing's Sarcoma at The Belfry, West Midlands. (26 <sup>th</sup> . & 27 <sup>th</sup> . March 2007) & Support.	67 delegates from 11 countries throughout Europe & North America.	17,406
	1 <sup>st</sup> . Round 10 <sup>th</sup> . July 2006	An Epidemiological Study of Bone Tumours in Children and Young Adults.	Dr. Richard McNally Institute of Health and Society, University of Newcastle. <i>To start on 18<sup>th</sup>. June 2007 and finish 11<sup>th</sup>. July 2008 (13 months). Target date for publication January 2009.</i>	29,985
		The Development of Clinical Protocols for Ewing's Sarcoma Treatment Using Gene Transfer of T-Cell Receptors.	Dr. John Anderson Unit of Molecular Haematology & Cancer Biology, Institute of Child Health, Great Ormond Street Children's Hospital, London. <i>To start on 1<sup>st</sup>. October 2006 and finish on 31 March 2010 (42 months).</i>	34,500
		<b>TOTAL FOR CONFIRMED GRANTS/AWARDS &amp; SUPPORT : 1<sup>st</sup>, July 2006 to 30<sup>th</sup>, June 2007</b>		<b>81,891</b>
2007/08	2 <sup>nd</sup> . Round 19 <sup>th</sup> . March 2007	Cancer stem cells in Osteosarcoma: potential for development of new prognostic markers and treatment.	Professor Adrienne Flanagan Royal National Orthopaedic Hospital, Middlesex. <i>To start on 1<sup>st</sup>. October 2007 and finish on 30<sup>th</sup>. September 2010 (36 months).</i>	28,800



Report of the Trustees and Financial Statements for the year ended 30<sup>th</sup>. June 2009.

		Identifying a novel role for deregulated Fibroblast Growth Factor Receptor Signalling in the growth control of human Osteosarcoma cells.	Dr. Agamemnon Grioriadis King's College, London. <i>To start 1<sup>st</sup>. October 2007 and finish on 30<sup>th</sup>. September 2008 (12 months).</i>	29,720
		A pilot pharmacogenomic study of the influence of cytotoxic metabolising gene polymorphisms on toxicity and outcome in respectable Osteosarcoma.	Dr. Rachael Windsor, University College Hospital, London. <i>To start on 4<sup>th</sup>. November 2007 and finish on 31<sup>st</sup>. October 2008 (12 months).</i>	30,000
	3 <sup>rd</sup> . Round 20 <sup>th</sup> . October 2007	Effects of hypoxia on growth, apoptosis and angiogenic capacity of Osteosarcoma and Ewing's Sarcoma cells; regulation by Hypxia-inducible Factor.	Professor Nicholas Athanasou and Dr. Helen Knowles, University of Oxford. <i>To start on 1<sup>st</sup>. April 2008 and finish on 31<sup>st</sup>. March 2010 (24 months).</i>	27,213
		Molecular mechanisms of organ-specific Ewing's Sarcoma metastasis.	Professor Josef Vormoor, Northern Institute for Cancer Research, University of Newcastle. <i>To start on 1<sup>st</sup>. August 2008 and finish on 31<sup>st</sup>. July 2009 (12 months).</i>	31,772
		Environmental contributions to the aetiology of bone tumours in young people: small area analyses.	Dr. Richard McNally Institute of Health and Society, University of Newcastle. <i>To start on 1<sup>st</sup>. October 2008 and finish on 30<sup>th</sup>. September 2009 (12 months).</i>	30,601
		1 <sup>st</sup> . Patients' and Supporters' Conference at the Leicester Hilton Hotel. (14 <sup>th</sup> . July 2007); and 2 <sup>nd</sup> . Patients' and Supporters' Conference at the Leicester Hilton Hotel. (28 <sup>th</sup> . June 2008).	1 <sup>st</sup> . Conference : 99 attendees  2 <sup>nd</sup> . Conference : 93 attendees	3,394  3,468
		1st. Newsletter (Autumn 2007) 2 <sup>nd</sup> . Newsletter (Spring 2008) 1st. Bone Cancer Awareness Week (June 2008) & Support		16,787
		<b>TOTAL FOR CONFIRMED GRANTS/AWARDS &amp; SUPPORT : 1<sup>st</sup>, July 2007 to 30<sup>th</sup>, June 2008</b>		<b>201,755</b>
	4 <sup>th</sup> . Round 13 <sup>th</sup> . September 2008	A Pilot Study of the aetiology and genetics of bone tumours in children, teenagers and young adults	Professor Jillian Birch Royal Manchester Children's Hospital, University of Manchester <i>To start on 1<sup>st</sup>. January 2010 and finish on 30<sup>th</sup>. June 2011 (18 months)</i>	47,555
		The role of tumour-associated macrophages in the anti-osteosarcoma effects of bisphosphonates	Dr. Anke Jozefien Roelofs and Professor Michael John Rogers. University of Aberdeen. <i>To start 1st. February 2009 and finish on 31 January 2010 (11 months)</i>	30,829

		Investigating the combination of fenretinide and TRAIL receptor agonists in ESFT	Professor Susan Burchill Candlelighter's Children's Cancer Research Laboratory, Leeds Institute of Molecular Medicine, St. James's University Hospital, University of Leeds. <i>To start on 1<sup>st</sup>. April 2009 and finish on 31<sup>st</sup>. March 2010 (12 months)</i>	49,591
		Targeting FGF receptor signalling for the treatment of osteosarcoma	Dr. Agamemnon Grigoriadis Kings College, London <i>To start on 1<sup>st</sup>. June 2009 and finish on 31<sup>st</sup>. December 2009 (7 months)</i>	29,720
		A Pilot pharmacogenomic study of the influence of cytotoxic metabolising gene polymorphisms on toxicity and outcome in resectable osteosarcoma. PROJECT 2	Dr. Rachel Windsor University College Hospital, London <i>To start on 1<sup>st</sup>. December 2008 and finish on 30<sup>th</sup>. November 2009 (12 months)</i>	41,956
		3 <sup>rd</sup> . Patients' and Supporters' Conference at Sopwell House, St. Albans, Herts., (27 <sup>th</sup> . June 2009).	117 attendees	6,291
		3 <sup>rd</sup> . Newsletter (Autumn 2008) 4 <sup>th</sup> . Newsletter (Spring 2009) 2nd. Bone Cancer Awareness Week (June 2008) & Support		9,837
		<b>TOTAL FOR CONFIRMED GRANTS/AWARDS &amp; SUPPORT : 1<sup>st</sup>, July 2008 to 30<sup>th</sup>, June 2009</b>		215,779
		<b>3 YEAR TOTAL 1<sup>st</sup>. July 2006 to 30<sup>th</sup>. June 2009</b>		<b>499,425</b>

Applications for the 5<sup>th</sup>. Round of Research Grants closed on 6<sup>th</sup>. April 2009 with 5 further projects, totalling £161,821, under consideration.

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, latterly, the fund raising 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.

First Round : 1998.

- *Basic fibroblast growth factor (bFGF) – induced apoptosis and fibroblast growth factor receptor (FGFr) expression in Ewing's Sarcoma.* Dr. Sue Burchill, University of Leeds. (£20,992).

- *Assessment of chromosomal abnormalities / Ewing's / PNET tumours by 24 colour FISH, colour banding and comparative genomic hybridisation.* Dr. Nick Coleman, University of Cambridge. (£10,000).

Second Round : 2000.

- *The role of novel FGFR3 variant in the development and behaviour of Ewing's Sarcoma.* Dr. Sue Burchill, University of Leeds. (£33,377).

Third Round : 2002.

- *RNA interference as a novel therapeutic tool against Ewing's Sarcoma / Primitive Neuroectodermal Tumours.* Professor Chris Boshoff and Dr. Richard Frow, The Wolfson Institute for Biomedical Research, University College, London. (£20,000)

Fourth Round : 2004.

- *Developing a methodology to investigate international differences in presentation and outcome in patients with Ewing's Sarcoma.* Dr. Ian Lewis, St. James's University Hospital, Leeds. (£25,000).

Fifth Round : 2005. In conjunction with the Family and Friends Of Krystle Smith.

- *Exploiting hypoxia and angiogenesis for therapeutic advantage in Ewing's Sarcoma family of tumours.* Dr. Sue Burchill, University of Leeds. (£24,516).
- *Two clinical trials of treosulfan in relapsed and advanced Ewing's Sarcoma.* Dr. Jeremy Whelan, University College London Hospitals. (£25,000).

These 7 Research Projects total £158,885.

## **7.2 Promotional Activity:**

The Trustees are pleased to report a continuing and expanding level of activity across the whole spectrum of promotional activity, resulting in accelerated income growth and active participation by Patients and Supporters alike.

## **7.3 2<sup>nd</sup>. Bone Cancer Awareness Week ( 20<sup>th</sup>. June – 27<sup>th</sup>. June 2009):**

The theme of the Awareness Week was “*Survival rates in Primary Bone Cancer show no improvement for over 20 years*”. This theme was based on the findings of the Trust's first published research by Dr. Richard McNally of the Institute of Health & Society, University of Newcastle, entitled “*An Epidemiological Study of Bone Tumours in Children and Young Adults*”.

Local, regional and national media coverage was sought, based on case studies contributed by patients and supporters. Two specialist posters were published with wide distribution including bulk mailings to the centres of excellence. In preparation for the Awareness Week, presentations were made to several Members of Parliament who have an interest in paediatric and oncological issues.

#### 7.4 3<sup>rd</sup>. BCRT Patients' and Supporters' Conference:

The 3<sup>rd</sup>. Conference (27<sup>th</sup> June 2009) was attended by over 100 delegates and provided a chance for people to meet together with others in similar positions and find out what research and developments have occurred.

The event was also attended by a number of researchers who brought along large, informative and fascinating posters about the BCRT funded research work they are currently carrying out. Also on display were photos of some of the fantastic fundraising that supporters have been doing as well as information and support for future ideas. The day began with an exciting message from the chairman Mike Francis who was thrilled to be able to announce that the Trust had reached the £1million mark in its fundraising. The theme of the conference was the fact that there has been no change to survival in 20 years and the key note speech was given by Professor Sir Alan Craft of the Northern Institute for Cancer Research (Department of Child Health), University of Newcastle. A Past President of the Royal College of Paediatrics and Child Health, a former Chairman of the Academy of Medical Royal Colleges, and member of the General Medical Council, his distinguished career has made him one of the leading authorities on paediatric oncology and child health. His plain speaking on the impact of treatment for cancer on young people, and how procedures and practices need to be improved in the future, found agreement from a very appreciative audience with comments such as "*inspirational*" and "*motivating*".

The Trustees would like to express their thanks to all of the speakers who included:

Personal Experiences:-

- Paul Gavin
- Marnie Fraser
- Ffion Miles
- Hannah Millington
- Zack Hagan
- Jordan Penney

Expert speakers included:

- Lucie Talbot – Physiotherapist from The Royal Orthopaedic Hospital, Birmingham on "*Quality of Survival – talk on physiotherapy / rehabilitation following surgery*".
- Dr. Jeremy Whelan – Consultant Medical Oncologist & Clinical Director of Cancer Services, Meyerstein Institute of Oncology, University College Hospital, London on "*Improving bone cancer survival in the next 10 years*".
- Dr. Bob Grant – a GP from St. Brycesdale Surgery, Fife on "*How can the speed of diagnosis be improved?*"
- Professor Chris Boshoff – Professor of Cancer Research in Sarcomas, University College Hospital, London on "*Improving survival through laboratory research*".

The main group split off into five smaller discussion groups to allow people to discuss issues they were closer to. These included

- Two Life after Treatment groups; one for patients and one for relatives and supporters
- Ewing's Sarcoma
- Osteosarcoma
- Coping with Loss

To find out more about the discussion groups please refer to the Trust's website for "*Conference 2009*".

The day concluded with a lively and inspiring talk by Giles Long MBE and a question and answer session.

The conference was the perfect opportunity for a number of cheques to be presented with funds raised by supporters at various events in recent weeks particularly the "Bake a Cake" events which took place in Awareness Week. This year's Conference was supported by Mr. Kipling who sponsored the event and kindly donated cakes as refreshments for the delegates.

The overall experience for many was described as excellent, calling it a positive and inspiring experience, informative and enjoyable, educational and inspirational. A patient said "I've learnt a lot and feel a positive outcome from it" while a parent said "it was good to catch up with people I've met before and also to meet others." For more feedback information please refer to the BCRT website. A researcher said "It was a good opportunity to hear patients' and families concerns about research and funding, and where they think we should focus".

The Trustees would also like to express their thanks to *Mr. Kipling* and the management of Sopwell House for their generous assistance in planning this 3<sup>rd</sup>. Conference.

Next year's conference will again be at Sopwell House, St. Albans, Hertfordshire.

#### **7.5 Autumn 2008 and Spring 2009 BCRT Newsletters:**

The Trustees realise that good communications is paramount to attaining and maintaining contact with all those interested in the work of the Trust. But different customer groups – patients, former patients, families, friends, medical practitioners – will have different interests. In an attempt to cover all these interests, a pilot Newsletter was published in the Autumn 2007. It highlighted the success of the 1<sup>st</sup>. Patients' and Supporters' Conference with articles about the Speakers and the Discussion Groups; gave a full report on the International Consensus Meeting for medical practitioners; outlined the research being undertaken at University College Hospital, London (one of the Trust's first research grant awards); and reported on recent fundraising events, together with news of events being planned. The circulation included personal mail shots, as well as bulk mailings into hospitals and clinics.

It was received with warm approval giving the Trustees the confidence to launch a second Newsletter in the Spring 2008.

The 3<sup>rd</sup>. Newsletter (Autumn 2008) reported on the June 2008 conference and the development of the National Sarcoma Register, plus an update on research projects and patients' personal experiences. The wide range of fundraising activities were also reported on.

The 4<sup>th</sup>. Newsletter concentrated on "*Getting active after treatment*" with contributions from BCRT Patron & Paralympic gold medallist Marc Woods; BCRT Trustee and England parafootballer Nick Bones, plus Paralympic swimming hopeful Laurence Whiteley. The Trust's first published research paper from Dr. Richard McNally of the University of Newcastle was featured, as was the NICE Appraisal Committee meeting on the breakthrough drug *MEPACT*.

Again, the wide range of fundraising activities were reported including the announcement of a "*Bake A Cake For Bone Cancer*" with the enthusiastic support of *Gavin and Stacey* star James Corden and his *Smithy's Cake* recipe, and the event was sponsored by *Mr. Kipling*. Other contributions from personalities included:

- Diane-Louise Jordan's Organic Victoria Sponge (*BBCTV Blue Peter* Presenter)

- Ben Shephard's Carrot Cupcakes with Orange Zest (*The Krypton Factor Presenter*)
- Andy Abraham's Roasted Banana Cheesecake (*Eurovision Song Contest & The X Factor finalist*)
- Nick Owen's Marshmallow & Chocolate Swiss Roll (*Journalist & TV Presenter*)
- Aled Jones' Welsh Cakes (*Singer and Broadcaster*)
- Austin Healey's Gluten-free Chocolate Cake (*England & British Lions Rugby Union Footballer*)

The Trustees thank all those who have made this event such a success.

#### **7.6 BCRT in Ireland:**

Plans for a major expansion of the Trust's activities in the Republic of Ireland are advancing well under the leadership of Trustees Patricia Smith and Fiona Foley. The Trustees thank them and their supporters for the major fundraising and awareness initiatives which they are driving forward.

#### **7.7 Fundraising Events by Schools and Colleges:**

As Primary Bone Cancer is a childhood, teenage and young adult disease, it is not surprising that schools get involved in fundraising. Here are some of the schools, colleges and junior sports clubs that have supported BCRT through the year:-

Burleigh Community College, Loughborough `George Spencer School Wigton Moor Football Club Ist. Bracebridge Heath Rainbow Guides St. John's Primary School Cherry Trees Preparatory School Winstanley Tennis Club Sherborne School Katy Cairns School of Dance The Sally Prout School of Dancing 7<sup>th</sup>. Feltham Sea Scout Group Falinge Park High School William Borlase's Grammer School St. Cecilia's RC Technology College, Longridge University of Teesside.

Many thanks to you all.

#### **7.8 Some of the many Fundraising Events in 2008/08:**

The Trustees have been overwhelmed by the number and variety of events organised by the Trust's supporters. These are some of the events – and apologies for any that have not been included here:-

Belgium to Berlin Cycle Challenge Jane Tomlinson's 10Km Run For All in both Leeds and York Coast-to-Coast Cycle Across the USA G-Fete York London to Paris Cycle Ride UK Three Peaks Challenge Guinness World Record Field Target Shooting Cuba Cycle Challenge British Military Fitness Kinabalu Challenge Great Manchester Run London Marathon Great North Run Royal Parks Half Marathon Tromso Midnight Sun Marathon London Triathlon Asics British 10Km Rotterdam Marathon Ravelympics Plymouth Bed Push Wigs and Hats Day (during a visit by HM The Queen) Sky Diving Scottish Police College Quiz Night Brathy Windermere Marathon James Bond Casino Night Lands End to John O'Groats Cycle Ride Bangers & Mash Night Posh Flocks & Black Ties Night and numerous Coffee Mornings, Party Nights, Discos .....Many, many thanks.

#### **7.9 BCRT Merchandising:**

The Trust now offers a range of promotional merchandise including Christmas cards; sweatshirts and T-shirts, both with the BCRT logo; enamelled badges; car stickers; and several books written by BCRT supporters.

### **7.10 Development of the Website and other electronic forms of communication:**

The World Wide Web offers unbounded opportunities for information sourcing and communication. The continuing development and maintenance of the Trust's website is regarded as a vital tool in staying in touch with other organisations; with the Trust's supporters; together with providing information for all those wishing to find out about Primary Bone Cancer or to seek the Trust's support.

As Primary Bone Cancer is predominantly a young person's cancer, creating the opportunities to embrace electronic technology which, they in particular, are used to is seen as an high priority. The Trustees have therefore encouraged new and innovative ideas including:

[www.justgiving.com](http://www.justgiving.com) (linking to all fundraising events by individual supporters : also generates Gift Aid).  
[www.everyclick.com](http://www.everyclick.com) (providing a home page which generates income every time a site is sought).  
[www.theweatherlottery.com](http://www.theweatherlottery.com) (a fun lottery for supporters).  
[www.nochex.com](http://www.nochex.com) ((for BCRT online merchandise shopping).  
[www.health.groups.yahoo.com](http://www.health.groups.yahoo.com) (providing 2 online Forums – one specifically for patients).  
[www.bonecancerresearch.org.uk/links\\_blog.shtml](http://www.bonecancerresearch.org.uk/links_blog.shtml) ( a patients' blog crèche).  
[www.bonecancerresearch.org.uk/links\\_org.shtml](http://www.bonecancerresearch.org.uk/links_org.shtml) (reciprocal links to other organisations).  
[www.facebook.com](http://www.facebook.com) (social networking).  
[www.twitter.com](http://www.twitter.com) (cyber tracking)

### **7.11 Looking to the Future:**

The Trustees look forward to the expansion of the Trust's activities in the next year. Several BCRT inspired events are planned, as well as continuing support for local groups and individuals in their fundraising ideas.

The Trustees will look to continue their funding of quality research projects, and will consider carefully any increase in the baseline level of funding of £30,000 per project.

Consideration will also be given to attracting further expertise to the Board, especially in the areas of financial investment and management, and medical practice.

## **8.0 FINANCIAL REVIEW:**

The Financial Statements comply with the Statement of Recommended Practice "Accounting and Reporting by Charities" (SORP 2005) issued in March 2005, and the Trust Deed.

The financial results of the Charity are shown in the annexed Financial Statements. The net assets of the Charity are £458,932 (2008: £309,141) 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 2008/09 of £223,231 (2008: £225,404), of which £196,300 has been committed to the award of approved Research Grants (2008: £178,106).

Gross receipts for the financial year are £477,653 (2008: £330,550). Since the foundation of the Trust on 15<sup>th</sup>. December 2005, £1,150,612 has been raised of which £449,425 has been spent or is committed to charitable activities.

### **8.1 Principle Funding Sources:**

In 2006/07, the principal funding of the Charity continued to originate from the Founding Groups. Whilst these Groups still continue to be an important funding source, new sources are now making a major contribution to the financial strength and stability of the Charity.

### **8.2 Charity Reserves:**

The Charity maintains sufficient reserves in order to enable the Charity to meet its objectives as stated above. The reserves of the Charity are continually monitored and reviewed within the context of the funds required to fulfil the objectives of the Charity.

### **8.3 Investment Policy:**

There are no restrictions on the Charity's power to invest. At present, the funds of the Charity are held in current and deposit bank accounts. The Trustees consider this is the most appropriate form of investment at this time, given the nature of the Trust involving awarding grants and funding each year. Accordingly, the Trustees have no formal ethical policy on investments held by the Charity.

### **8.4 Donations:**

Any donations, large or small, will help to fund research into Primary Bone Cancer and, hopefully, save young lives in the future. Anyone wishing to make one-off donations or set-up a regular donation to the Charity should contact the Head of Fundraising at the Trust's Fundraising & Administration Office. Cheques should be made payable to "Bone Cancer Research Trust". Donations can also be made via [www.justgiving.com](http://www.justgiving.com), and some events can be sponsored in the same way. Further information regarding donations can be obtained by e-mailing [donations@bonecancerresearch.org.uk](mailto:donations@bonecancerresearch.org.uk).

### **9.0 PLANS FOR FUTURE PERIODS:**

The Trustees plan to continue the activities of the Charity in a similar manner as those of the previous year, through the Fundraising and Administration Office in Leeds.

Approved by the Board of Trustees on 6<sup>th</sup>. March 2010 and signed on its behalf by:-

**Michael Brian Palmer Francis**  
Chairman of Trustees

**Roger Paul**  
Trustee and Treasurer



## **10.0 FINANCIAL STATEMENT:**

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

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 Charity's financial activities during the year, and of its financial position at the end of the year. 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 UK accounting standards and statements of recommended practice 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 accounting records that disclose with reasonable accuracy the financial position of the Charity, and which enable them to ensure that the financial statements comply with the Charities Act 1993, the Charity (Accounts Reports) Regulations 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.

**Michael Brian Palmer Francis**

**Chairman of Trustees**

**Roger Paul**

**Trustee and Treasurer**

Date: 6<sup>th</sup>. March 2010

## **11.0 INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE BONE CANCER RESEARCH TRUST:**

I report on the Financial Statements of the Charity for the year ended 30th June 2009, which are set out on pages 27 to 38.

**11.1 Respective responsibilities of Trustees and Examiner:** The Charity's Trustees consider that an audit is not required for this year under section 43(2) of the Charities Act 1993 (the Act), and that an Independent Examination is needed. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Institute of Chartered Accountants in England & Wales. It is my responsibility to:

- examine the Accounts (under section 43 of The Act);
- follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the Act);
- state whether particular matters have come to my attention.

**11.2 Basis of Independent Examiner's Report:** My examination was carried out in accordance with General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the Charity and a comparison of the Accounts presented with those records. It also includes consideration of any unusual items or disclosures in the Accounts, and the seeking of explanations from you as Trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and, consequently, I do not express an audit opinion on the view given by the Accounts.

**11.3 Independent Examiner's Statement:** In connection with my Examination, no matter has come to my attention:

- 1) which gives me reasonable cause to believe that, in any material respect, the Trustees have not met the requirement to ensure that:
  - proper accounting records are kept in accordance with section 41 of the Act; and
  - Accounts are prepared which agree with the accounting records and comply with the accounting requirements of the Act
- 2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the Financial Statements to be reached.

**Mr C.J. Darwin ACA**

**Thomas Coombs & Son**

Chartered Accountants

Century House

29 Clarendon Road

Leeds LS2 9PG

Date: 6<sup>th</sup>. March 2010

**12.0 STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 30<sup>TH</sup>. JUNE 2009:**

	Notes	Unrestricted 2009 £	Restricted 2009 £	Total 2009 £	Total 2008 £
<b>INCOME &amp; EXPENDITURE:</b>					
<b>Income Resources from generated funds</b>					
<i>Voluntary income:</i>					
Grants and donations	2	183,133	8,365	<b>191,498</b>	286,440
Investment income		13,660	-	<b>13,660</b>	8,875
<i>Activities for generating funds:</i>					
Event Income		268,270	-	<b>268,270</b>	33,424
Other trading income		4,225	-	<b>4,225</b>	1,811
<b>Total Income Resources</b>		<b>469,288</b>	<b>8,365</b>	<b>477,653</b>	<b>330,550</b>
<b>Resources Expended</b>					
Costs of generating funds	3	97,871	-	<b>97,871</b>	41,054
Charitable activities					
Grants awarded and direct costs	4	132,333	66,073	<b>198,406</b>	201,755
Support costs	4	24,825	-	<b>24,825</b>	23,649
Governance costs	5	6,760	-	<b>6,760</b>	2,110
<b>Total Resources Expended</b>		<b>261,789</b>	<b>66,073</b>	<b>327,862</b>	<b>268,568</b>
<b>NET INCOME (OUTGOING) RESOURCES</b>		<b>207,499</b>	<b>(57,708)</b>	<b>149,791</b>	<b>61,982</b>
Balances brought forward at 1 <sup>st</sup> July 2008		240,248	68,893	<b>309,141</b>	247,159
<b>BALANCES CARRIED FORWARD AT 30<sup>TH</sup> JUNE 2009</b>		<b>447,747</b>	<b>11,185</b>	<b>458,932</b>	<b>309,141</b>

All amounts relate to continuing activities.

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

The notes on pages 29 to 38 form part of these Financial Statements.

**13.0 BALANCE SHEET AT 30<sup>th</sup>. JUNE 2009:**

	Notes	Unrestricted 2009 £	Restricted 2009 £	Total 2009 £	Total 2008 £
<b>Fixed Assets</b>	7	3,440	-	<b>3,440</b>	4,587
<b>Current Assets</b>					
<b>Debtors:</b>					
Gift aid recoverable		7,897	-	<b>7,897</b>	4,375
Accrued income		11,224	-	<b>11,224</b>	-
Prepayments		3,392	-	<b>3,392</b>	-
<b>Cash at Bank</b>		690,846	11,185	<b>702,031</b>	491,447
		<hr/>	<hr/>	<hr/>	<hr/>
		713,359	11,185	<b>724,544</b>	495,822
<b>Liabilities: amounts falling due within one year</b>	8	(259,252)	-	<b>(259,252)</b>	(138,721)
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Net Current Assets</b>		454,107	11,185	<b>465,292</b>	357,101
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Total Assets less Current Liabilities</b>		457,547	11,185	<b>468,732</b>	361,688
<b>Liabilities: amounts falling due after one year</b>	9	(9,800)	-	<b>(9,800)</b>	(52,547)
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Net Assets</b>		447,747	11,185	<b>458,932</b>	309,141
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Funds</b>					
Unrestricted		447,747	-	<b>447,747</b>	240,248
Restricted	11	-	11,185	<b>11,185</b>	68,893
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Total Funds</b>		447,747	11,185	<b>458,932</b>	309,141
		<hr/>	<hr/>	<hr/>	<hr/>

Approved by the Board of Trustees on 6<sup>th</sup>. March 2010 and signed on its behalf by:

M. Francis  
Chairman of Trustees

R. Paul  
Trustee and Treasurer

The notes on pages 29 to 38 form part of these Financial Statements.

## 14.0 NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30<sup>TH</sup>. JUNE 2009:

### 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 1993.

#### **Income:**

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient reliability.

- (i) Grants receivable:  
Grants receivable are credited to the income and expenditure account on an accruals basis with grants received for specific purposes treated as restricted income.
- (ii) Donations and Gifts:  
All monetary donations and gifts are credited to the income and expenditure account in the year of receipt. No value is attributed to donations in kind and these are not included in the income and expenditure account.
- (iii) Covenanted income:  
Donations under deed of covenant together with the associated income tax recoveries are credited to the income and expenditure account when the covenant payments are receivable. Covenant payments which are due but have not been paid at the Balance Sheet date are shown as debtors.

#### **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) 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.

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing of the grant or the amount of grant payable.

(b) Irrecoverable VAT

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

(c) Charitable activities

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

(d) 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.

**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 reducing balance basis.

**2. Grants and Donations:**

	<b>Unrestricted 2009 £</b>	<b>Restricted 2009 £</b>	<b>Total 2009 £</b>	<b>Total 2008 £</b>
Adam Dealey Foundation for Ewing's Sarcoma	22,000	-	<b>22,000</b>	18,000
Adam Panther	7,000	-	<b>7,000</b>	-
Antony Pilcher Bone Cancer Trust	-	-	-	10,000
Blathnaid Foley Trust	22,515	-	<b>22,515</b>	55,573
Christopher Hardman Osteosarcoma Research Fund (CHORF)	-	-	-	20,000
Daniel Round Fund	1,141	-	<b>1,141</b>	850
Family & Friends of Jennifer Carvell	5,636	-	<b>5,636</b>	3,833
Family & Friends of Joseph Wright	958	-	<b>958</b>	2,039
Family & Friends of Kenny McCabe	978	-	<b>978</b>	80
Guy Francis	12,058	-	<b>12,058</b>	11,513
Matt's Beacon Fund	-	-	-	43,000
Nick Pollard	6,404	-	<b>6,404</b>	-
Paul Gavin	9,406	-	<b>9,406</b>	-
Stephanie McCartney	215	-	<b>215</b>	-
Other general donations	94,822	-	<b>94,822</b>	81,659
<b>Restricted Accounts:</b>				
Hilary Lawler Donation	-	-	-	1,000
The Rhodri Jones Appeal	-	-	-	25,000
Family & Friends of Krystle Smith	-	6,942	<b>6,942</b>	13,893
Family & Friends of Nicola Curran	-	1,423	<b>1,423</b>	-
	<u>183,133</u>	<u>8,365</u>	<u><b>191,498</b></u>	<u>286,440</u>

As detailed in the Report of the Trustees a number of Trustees are connected with the Supporting Groups.

<b>3 Cost of Generating Funds:</b>	<b>2009</b>	<b>2008</b>
	<b>£</b>	<b>£</b>
Events costs	41,232	16,065
Other trading costs	4,936	4,319
Staff costs	39,050	16,579
Other fundraising costs	12,653	4,091
	<hr/>	<hr/>
	<b>97,871</b>	<b>41,054</b>
	<hr/> <hr/>	<hr/> <hr/>
 <b>4. Charitable Activities:</b>		
	<b>2009</b>	<b>2008</b>
	<b>£</b>	<b>£</b>
<b>Grants awarded:</b>		
 <b>Professor Jillian Birch, Paediatric &amp; Familial Cancer Research Group Royal Manchester Children's Hospital</b>	 <b>47,555</b>	 <b>-</b>
<i>"A Pilot study of the aetiology and genetics of bone tumours in Children, teenagers and young adults"</i>		
 <b>Dr. Roelofs &amp; Professor Rogers, The University of Aberdeen</b>	 <b>30,829</b>	 <b>-</b>
<i>"The role of tumour-associated macrophages in the anti-osteosarcoma effects of bisphosphonates"</i>		
 <b>Professor Susan Burchill, Candlelighter's Children's Cancer Research Lab St James's University Hospital</b>	 <b>49,591</b>	 <b>-</b>
<i>"Investigating the combination of fenretinide and TRAIL receptor agonists in ESFT"</i>		
 <b>Dr. Richard McNally Institute of Health &amp; Society, University of Newcastle</b>	 <b>(3,351)</b>	 <b>30,601</b>
<i>"Environmental contributions to the aetiology of bone tumours in Young People: small area analyses"</i>		
 <b>Dr. Agamemnon Grigoriadis, Kings College, London</b>	 <b>-</b>	 <b>29,720</b>
<i>"Identifying a novel role for deregulated fibroblast growth Factor receptor signalling in the growth control of human Osteosarcoma cells"</i>		



<b>Dr. Agamemnon Grigoriadis, Kings College, London</b>	<b>29,720</b>	-
<i>"Targeting FGF receptor signalling for the treatment of osteosarcoma"</i>		
<b>Professor Andrienne Flanagan, Royal National Orthopaedic Hospital</b>	-	28,800
<i>"Cancer stem cells in Osteosarcoma: potential for development of new Prognostic markers and treatment"</i>		
<b>Dr. Rachel Windsor, University College Hospital, London</b>	<b>41,956</b>	30,000
<i>"A pilot pharmacogenomic study of the influence of cytotoxic target and metabolising gene polymorphisms on toxicity and outcome in resectable osteosarcoma"</i>		
<b>Professor Nicholas Athanasou &amp; Dr. Helen Knowles, University of Oxford</b>	-	27,213
<i>"Effect of hypoxia on growth, apoptosis and angiogenic capacity of Osteosarcoma and Ewing's Sarcoma cells: regulation by Hypoxia-Inducible Factor"</i>		
<b>Professor Josef Vormoor, Northern Institute for Cancer Research, University of Newcastle</b>	-	31,772
<i>"Molecular mechanisms of organ-specific Ewing's Sarcoma metastasis"</i>		
	<u><b>196,300</b></u>	<u>178,106</u>
Conferences	<b>6,291</b>	6,862
Newsletters	<b>(10,777)</b>	16,787
Staff costs	<b>6,592</b>	-
	<u><b>198,406</b></u>	<u>201,755</u>

**4. Charitable Activities (continued)**

	<b>2009</b>	<b>2008</b>
	£	£
<b>Support Costs:</b>		
Premises costs	7,104	1,918
Telephone	2,213	1,426
Postage	3,165	1,426
Stationery	1,071	1,091
Sundries	444	257
Depreciation	1,147	1,529
Staff costs	5,858	14,536
Recruitment and human resources costs	1,655	1,544
Travel and subsistence	2,168	399
	<u>24,825</u>	<u>23,649</u>

**5. Governance Costs:**

	<b>2009</b>	<b>2008</b>
	£	£
Meeting expenses	1,095	641
Independent examiners remuneration	3,260	1,225
Legal and professional costs	2,039	244
Staff costs	366	-
	<u>6,760</u>	<u>2,110</u>

**6. Trustees and Staff Costs:**

Staff costs:	<b>2009</b>	<b>2008</b>
	<b>£</b>	<b>£</b>
Wages and salaries	<b>47,223</b>	28,049
Employer's National Insurance	<b>4,643</b>	3,066
	<hr/>	<hr/>
Total	<b>51,866</b>	31,115
	<hr/> <hr/>	<hr/> <hr/>

The Trustees received no remuneration. No employee earned more than £60,000 per annum.

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

	<b>2009</b>	<b>2008</b>
	<b>No.</b>	<b>No.</b>
Permanent staff	<b>2</b>	2
Trustees	<b>11</b>	10
	<hr/>	<hr/>
Total	<b>13</b>	12
	<hr/> <hr/>	<hr/> <hr/>

Report of the Trustees and Financial Statements for the year ended 30<sup>th</sup>. June 2009.
 

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**7. Fixed Assets:**

	<b>Office Equipment</b>	<b>Computer Equipment</b>	<b>Total</b>
<b>Cost:</b>			
As at 1 <sup>st</sup> July 2008	476	5,640	<b>6,116</b>
Additions	-	-	-
Disposals	-	-	-
As at 30 <sup>th</sup> June 2009	<u>476</u>	<u>5,640</u>	<u><b>6,116</b></u>
<b>Depreciation:</b>			
As at 1 <sup>st</sup> July 2008	119	1,410	<b>1,529</b>
Charged during the year	89	1,058	<b>1,147</b>
Eliminated on disposal	-	-	-
As at 30 <sup>th</sup> June 2009	<u>208</u>	<u>2,468</u>	<u><b>2,676</b></u>
<b>Net Book Value:</b>			
30 <sup>th</sup> June 2009	<u><b>268</b></u>	<u><b>3,172</b></u>	<u><b>3,440</b></u>
30 <sup>th</sup> June 2008	<u>357</u>	<u>4,230</u>	<u>4,587</u>

**8. Liabilities: Amounts falling due within One Year:**

	<b>2009 £</b>	<b>2008 £</b>
Grants awarded and related creditors	<b>242,629</b>	134,767
Accruals	<b>3,452</b>	1,225
Taxation & social security	<b>236</b>	2,657
Other creditors	<b>12,935</b>	72
	<u><b>259,252</b></u>	<u>138,721</u>

<b>9. Liabilities: Amounts falling due after One Year:</b>	<b>2009</b>	<b>2008</b>
	£	£
Grants awarded	<b>9,800</b>	<b>52,547</b>

**10. Dedicated Funds:**

Designated bank accounts have existed to enable individuals to raise funds for the Charity in an individual's name. For example families and friends are able to raise money with regard to a person who has suffered from Bone Cancer.

The funds are not subject to restrictions and were previously classified as Dedicated Funds.

The Trustees are now recording these balances as part of the general fund but record the cumulative value of these contributions as at 30 June 2009 as follows:

Guy Francis Fund	120,897
Jennifer Carvell Fund	18,134
Kenny McCabe Fund	7,116
Joseph Wright Fund	15,190
Daniel Round Fund	1,991
Matt's Beacon Fund	43,000
Adam Panther Fund	7,000
Nick Pollard Fund	6,404
Stephanie McCartney Fund	215
Paul Gavin Fund	9,406
Hilary Lawler Donation	1,000

<b>11. Restricted Funds:</b>	<b>Krystle Smith</b>	<b>Nicola Curran</b>	<b>The Rhodri Jones Appeal</b>
	£	£	£
Opening balance	<b>13,893</b>	-	<b>55,000</b>
Voluntary income:			
Grants and donations	6,942	1,423	-
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<b>Total Incoming Resources For The Year</b>	<b>6,942</b>	<b>1,423</b>	<b>55,000</b>

**Expenditure:**

*Settlement of obligations for the following grants*

Dr John Anderson, Institute of Child Health (Awarded 2007)	16,826	-	-
Prof. Josef Vormoor, Northern Institute for Cancer Research (Awarded 2008)	1,085	1,423	-
Dr Rachael Windsor, University College Hospital (Awarded 2009)	-	-	15,000
Professor Adrienne Flanagan, Royal National Orthopaedic Hospital (Awarded 2008)	-	-	12,000
Dr Agamemnon Grigoriadis, Kings College (Awarded 2009)	-	-	8,398
Dr Anke Roelofs & Professor Michael Rogers, The University of Aberdeen (Awarded 2009)	-	-	11,341
	<hr/>	<hr/>	<hr/>
<b>Closing balance</b>	2,924	-	8,261
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

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

The Nicola Curran 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 Hilary Lawler Donation represents monies restricted to research into Ewing's Sarcoma.