

## Another incredible year!



Secondly, we are making great strides in attracting more support from Ireland, thanks to the dedicated work of Patricia & Chris Smith, and Fiona & John Foley (See page 7).

Thirdly, BCRT has gained recognition by being invited by The National Institute for Health and Clinical Excellence (NICE) to take part in an assessment process for a possible new treatment for osteosarcoma (See page 2).

Welcome to Issue 2 of our Newsletter. As we approach the end of our 3rd year (June 2008), it's appropriate for us to reflect on what we have achieved – and what we wish for in the future.

Firstly, in just 30 months we have raised a staggering £1/2 million+, thanks to the very hard work of all our supporters. This has meant that we are now funding 5 Research Projects, with a further 3 under consideration, for which we have ring-fenced funds of some £260,000 – and we are actively investigating other new proposals. This has given us the confidence to open our own office close to St. James's University Hospital, Leeds, and appoint David Fisher as our full-time Head of Fundraising and Kate Connor as our part-time Administrator.

As for the future, we have masses of fundraising events planned including swimming the English Channel, running the London Marathon and the Edinburgh, Leeds and Manchester 10km runs plus attempting the Ben Nevis & Great Glen Way Challenges. Our 2nd Patients' & Supporters' Conference looks to build on key issues including recent medical developments in diagnosis, fertility, artificial limbs and advocacy.

So I hope you will enjoy this Newsletter – and keep spreading the word about BCRT.

Best wishes,  
Mike Francis  
Chairman, BCRT

## JOIN US IN LEICESTER FOR OUR PATIENTS' AND SUPPORTERS' CONFERENCE ON SATURDAY 28TH JUNE 2008



BCRT is holding its second Patients' and Supporters' Conference on **Saturday 28th June** at the Hilton Hotel, Leicester. The one day conference is for bone cancer patients, their families and friends. The conference will include:-

- Talks by current and former patients
- Presentations by international experts about diagnosis and treatment
- News of the latest medical research
- Plenty of opportunity to meet other patients and families and put questions to the specialists

The conference is free of charge and includes lunch and refreshments.

Please go to [www.bcrt.org.uk](http://www.bcrt.org.uk) or call 0113 262 1852 for more information and to book your place(s).

## STOP PRESS!

Very many thanks to Gill Callar and Debbie McCartney for all they have contributed to BCRT as two of its founding Trustees. We know they will keep in touch through continuing to raise both funds and awareness of the aims of the charity in their own parts of the country. We welcome Sally Hurst & Fiona Foley as new Trustees. Sally brings to us her skills as a journalist working for the BBC as well as having experienced osteosarcoma herself. Fiona is very much part of our expansion plans in Ireland and is a successful fundraiser.

Congratulations to our Trustee and Chairman of the Scientific Advisory Panel, Dr. Ian Lewis, on being made an Honorary Professor of Cancer Studies in Children and Young People at the University of Leeds – a very well deserved honour for an extremely dedicated professional.

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Look what our supporters have been up to since Autumn! Climbing up mountains and scrambling down a river with inflatables! All to raise money and awareness for bone cancer! Read more in the fundraising section, starting on page 4.

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# RESEARCH

## REPORT FROM THE SCIENTIFIC ADVISORY PANEL

Research is central to the aims and activities of BCRT.

The ambition of the BCRT Trustees was to fund research so that people developing bone cancer might have a better chance of survival and an improved quality of life.

The BCRT Trustees decided to start funding research by offering start-up grants of up to £30,000 for new areas of research in line with their aims.

The Trustees needed to have confidence that they would only fund research that might have a significant impact on bone cancers and was sensible, feasible and value for money. Giving the Trustees the information to be confident is the role of the Scientific Advisory Panel (SAP).

There are 3 full members of the SAP, Dr Jeremy Whelan, Mr Rob Grimer and Dr Ian Lewis; all doctors with enormous experience in looking after patients with bone cancers and all with a major research interest in this area. They are assisted by a number of other expert scientists and doctors with a wide range of research interests.

Each application for funding is assessed by a member of the SAP and is then sent to at least 2 other expert advisors. They tell the SAP if they think the proposed project is exciting, might lead to better outcomes in bone cancers, is achievable and value for money. This process is called 'peer review'. The SAP then collects the expert advice on all applications and makes recommendations to the Trustees.



*Mr. Rob Grimer, Member of the BCRT Scientific Advisory Panel*

Since starting this process in the summer of 2006, we have advertised on three occasions for researchers to apply. In total we have had 13 applications of which we have funded 7 projects and we are waiting to make a decision about an eighth. As these projects are approved, we put details onto the website and one of these, from Dr Richard McNally and colleagues in Newcastle, is described in more detail on page 3.

The fourth call for grant applications is now open with a closing date of 28th April.

We are very pleased at the level of interest that BCRT has generated and are determined to pursue our goal of improving outcomes for bone cancer patients.

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## Research Grants: How to Apply

One of the basic aims of the BCRT 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 proposed that there will be up to 2 calls for grant applications each year. Dates will be posted in advance on the website and decisions reached within 3 months of the closing date. Initially the Trustees will consider bids of any sum up to £30,000.

The Spring closing date for applications is 28th April 2008. Please check the website for the Autumn 2008 closing date which is likely to be in October.

For further information on grant requirements please go to [www.bonecancerresearch.org.uk/researchgrants.shtml](http://www.bonecancerresearch.org.uk/researchgrants.shtml) or e-mail [research@bonecancerresearch.org.uk](mailto:research@bonecancerresearch.org.uk).

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## NICE Commences Assessment of New Treatment for Osteosarcoma

The National Institute For Health And Clinical Excellence (NICE) is considering an assessment of a new treatment for osteosarcoma. The treatment is called Mifamurtide or L-MTP-PE. This treatment is thought to work by stimulating some of the body's immune cells to help control osteosarcoma. A large clinical trial was held in the USA with close to 700 patients, half of whom received Mifamurtide. The results reported by the Children's Oncology Group appear to demonstrate an improvement in survival for those patients who received Mifamurtide.

This drug is not yet available in the UK or Europe, but the company manufacturing it have applied to the European Medicines Evaluation Agency (EMA) for registration. If approved, this would enable them to make the drug available. It is expected that the EMA will make a decision later this year.

The NICE assessment, if carried out, will examine whether this treatment is cost-effective enough to be made available to patients in the UK. BCRT have been invited to take part in this process and we are keen to encourage its availability.

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## An epidemiological study of bone tumours in children and young adults



By Dr Richard McNally  
Newcastle University

Little is known about the possible causes of bone tumours in children and young adults. A recent study of national (UK) data has found that there is geographical variation for osteosarcomas diagnosed in children aged 0-14 years. This lends support to the possibility that certain environmental factors may be involved, particularly those that show geographical variation. Another recent study has found that bone sarcoma patients who were treated in specialist hospitals had better survival rates than patients who were treated in non-specialist hospitals. It is not known whether survival is related to socio-economic factors.

The main aim of the proposed study is to identify focused scientific hypotheses for further investigation. These hypotheses will be related to factors that may contribute to the development of bone tumours and factors that may be important for improved chance of survival after diagnosis of a bone tumour.

There are two parts to this study. The first part proposes carrying out a thorough review of what is currently known about the incidence, survival and causes of bone tumours in young people (aged 0-49 years). The second part proposes a set of analyses of population-based data from the North of England and the West Midlands.

Such analyses of population-based data are a cost-effective way of generating new hypotheses. This approach has been successfully used in studying childhood leukaemia and led to the development of plausible scientific hypotheses. Additionally factors that may affect survival will be studied.

The data analysis study will concentrate on the three regions from the North of England (the Northern Region, Yorkshire, the North West) and also the West Midlands. Data will be obtained from five sources: the Northern Region Young Persons' Malignant Disease Registry (NRYPMDR), the Yorkshire Specialist Registry of Cancer in Children and Young People (YSRCCYP), the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS), the West Midlands Regional Children's Tumour Registry (WMRCTR) and the Manchester Children's Tumour Registry (MCTR). All registries are population-based and are periodically cross-checked with data from regional and national cancer registries to ensure information

is as accurate and complete as possible. Data for the Yorkshire and Northern regions will be available for 0-24 year olds from the NRYPMDR (from 1968 onwards) and the YSRCCYP (0-29 year olds from 1990 onwards) and 0-14 year olds from 1974 onwards) and for 25-49 year olds from the NYCRIS (from 1975 onwards). Data for North West England and the West Midlands will be available for 0-14 year olds from the MCTR (from 1954 onwards) and the WMRCTR (from 1957 onwards). This novel piece of work aimed at children and uniquely young adults covers the entire age-incidence peaks for bone tumours.

Incidence patterns, trends and survival will all be described. Statistical modelling will be used to investigate the potential effect of socio-economic deprivation. Data on 0-24 year olds from the NRYPMDR will allow both the place of residence at birth and at diagnosis to be analysed. This will allow a distinction to be made between the possible effect of earlier and later exposures to environmental agents. Survival patterns will be analysed to determine whether there are differences in the survival between patients of different ages, gender and social class.

We are currently thoroughly reviewing the literature on the descriptive epidemiology and aetiology of bone tumours. This work will be written up and submitted for publication in a peer-reviewed journal. We have completed an initial analysis of incidence and survival for paediatric cases of bone tumours. We are preparing an abstract, based on this analysis, for submission to the forthcoming International Society for Paediatric Oncology conference to be held in Berlin (October 2008). We hope to continue our research by examining possible links between water fluoridation and risk of bone tumours.

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## Bone Cancer Awareness Week

### 21-28 June 2008

Help us to raise awareness of Primary Bone Cancer during the inaugural **Bone Cancer Awareness Week** from **Saturday 21st to Saturday 28th June 2008**

#### Events already planned:

##### Sunday 22 June

###### Leeds 10K - Jane Tomlinson's Run For All

Join over 150 runners on Team Bones and help us to raise over £30,000 at one event!  
See page 5 for full details.

##### Saturday 28 June

###### BCRT Patients' and Supporters' Conference 2008

BCRT's 2nd annual conference for patients and supporters. A great day with speakers including current and past patients and professionals.

#### How you can help:

- Hold a fundraising event of your own such as a sponsored walk, a coffee morning or a car boot sale
- Arrange a collection at your local supermarket
- Ask your company to hold an event for BCRT, have a raffle or a dress down day
- Ask for some of our posters to put up in your local shops, library, workplace or anywhere else

**We need your help to make this event a huge success!**  
**Please contact us now for your 'Bone Cancer Awareness Week Pack'**

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# How far would

## Fundraising Opportunities in 2008

Walk, Trek, climb or cycle for BCRT in the UK or Overseas

**285 miles  
on a bike?**



### Cycle London to Paris

On the 11th June Harriet Webb, Jenny Reid, Milly Bell and Rachel Holloway (Team Bones!) will be departing on a four day cycle ride from London to Paris in support of BCRT. They are doing the challenge to raise money for BCRT and to raise awareness of bone cancer after Peter Franklin, a good friend of the team and Harriet's boyfriend was diagnosed with Ewing's sarcoma in September last year.

Team Bones will be cycling a total of 285 miles (450km), between sixty and ninety miles a day, leaving from Greenwich and arriving four days later in Paris, finishing at the Eiffel Tower.

Harriet said "This is going to be a huge challenge for all four of us, but we are confident that we can complete the cycle ride and raise significant amounts of money for BCRT!"

Many thanks to the team for having raised over £12,000 and they are still raising more!!

**5895 metres  
up a mountain?**



### Climb Kilimanjaro

Two groups of intrepid explorers took on the highest free standing mountain in the world to raise money for BCRT.

Mike, Andrew and Richard Fletcher, Matthew Doughty, Lindsey Agar, Steve Justice and Corinne White all took on this challenge of a lifetime and raised just over £4000 in memory of their friend Guy Francis, who died, following a six year battle with osteosarcoma, in 2002, aged 23.

Robbie Jones and Martin Wells took on the challenge and raised over £1000 in memory of their friend Rhodri Jones, who died in 2006, aged 20 having been diagnosed with osteosarcoma just eight months before.

**42 kilometres  
across a mountain range?**



### Trek Machu Picchu

On Friday 4th October Katie Emmett and I (Emma Upton) set off on our trek to Machu Picchu in Peru. The trek itself was challenging, especially having to acclimatise to the high altitude and coping with the extremely cold weather conditions. Our team of guides, sherpas, cooks and horses that helped us along the way were very knowledgeable about the history of the Incas and the area that we trekked. We stayed in villages and met the local people who were very friendly and pleased to see us. The route we took was relatively new and westerners had only been seen in the area a few times. The scenery was breathtaking and you could see for miles. Once we got to Machu Picchu itself, it was the most amazing feeling knowing that we had achieved a huge challenge for ourselves and raised over £8,000 for BCRT, which made it all the more rewarding!

### Overseas Challenges

Take on the challenge of a lifetime and raise funds for BCRT at the same time. From trekking in Peru to cycling in Cuba, the range of overseas challenges you can take part in to raise money towards our vital work is huge and there really is something for everyone. All of the participants who have taken part in these events so far have had a great time both raising money and on the challenges, and have raised huge

amounts of money towards our work.

If you want to cycle from London to Paris, like Team Bones, Climb up Kilimanjaro like our intrepid explorers, or Trek to Machu Picchu like Emma and Katie, then please contact the fundraising office or visit the website [www.bcart.org.uk](http://www.bcart.org.uk) to find out more about all of our challenges.



### UK Challenges



Join Team Bones on one of our UK challenges, from a weekend scaling the heights of the highest Mountain in the UK, Ben Nevis, to a five day walk through some of the best scenery Scotland has on the Great Glen Way Challenge.

Our UK Challenge events are a great way to enjoy the beautiful countryside that the UK has to offer at the same time as raising vital funds for BCRT.

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

# you go for BCRT?

## Fundraising Opportunities in 2008

### Running Events for BCRT

#### 10 kilometres in Leeds City Centre



**22 June 2008**

The Leeds 10km Jane Tomlinson's Run for All will again see 12,000 people take to the streets of Leeds either running, walking, wheeling or hopping the 10km route. This is the second year of the event and the route takes in all the iconic City Centre landmarks including City Square, Corn Exchange, Town Hall, Library, Vicar Lane and the Headrow. The city will come alive with a carnival atmosphere so why not bring the family along to enjoy a great day out.

Following the success of last years event in which 56 runners joined our team and raised over £10,000, we have again secured places for this great run. Team Bones will have over 150 runners this year and we are hoping to raise £30,000 - enough to fund one of our research projects. You can join Team Bones on this fantastic day! All we ask is for your registration fee of £20, and that you pledge to try and raise a minimum of £200 so that we can reach our target to fund one of our vital research projects.

#### 10 miles along the South Coast



**22 October 2008**

The BUPA Great South Run takes place in Portsmouth and is Britain's leading 10-mile running event. A fast, flat route in Southsea, Portsmouth is the ideal course to record a personal best and is regarded as one of the most popular road races in the United Kingdom.

We have a limited number of places available to join Team Bones on this run. We are asking each participant to pay their registration fee of £32 and then pledge to raise a minimum sponsorship of just £200. If you are interested in joining Team Bones then please contact us to guarantee your place before they run out.

#### Half Marathon in London's Parks



**12 October 2008**

This is the first ever Royal Parks Half Marathon, starting and finishing in Hyde Park. The route winds through Hyde Park, Kensington Gardens, Green Park, St James's Park and along the River Thames amongst avenues of beautiful autumnal trees, taking in superb views of Buckingham Palace, the Houses of Parliament, Marble Arch, the London Eye and the Royal Albert Hall. With 12,500 runners expected to take part, this half marathon is sure to become an exceptional annual event.

The Bone Cancer Research Trust will have at least 50 runners on Team Bones for this event and participants and spectators will be able to enjoy a fantastic variety of activities on the day, including a food and fitness festival. BCRT will have a stand in the charity village to meet all of our runners at the end of the race. We are asking all Team Bones participants to pay their registration fee of £40 and the pledge to raise a minimum of £275 for what is sure to be a great half marathon event.

### Congratulations!

Well done to Jamie Evans, who took part in the 2007 Great North Run, raising a fantastic £1,116 in memory of Rhodri Jones (pictured right); and to Amy and Beth Gallagher who have recently completed the Bath Half Marathon, also in memory of Rhodri Jones, and raising over £700 towards our work. THANK YOU!



### Good Luck

Good luck to all of our runners in 2008, whether you are running 5 or 10k, 10 miles, or even half and full marathons, we wish you the best of luck in your efforts and thank you very much for your support.

As we go to print, Ceris Crow and Andy Ball are taking part in the London Marathon and Gwyneth and Richard Parry in the Rotterdam Marathon - all on April 13th! Good luck to you all!

Would you like  
the chance to win  
**£10,000**  
four times a week?



By taking part in The Weather Lottery you can help us to fund vital research into Primary Bone Cancer.

For just £1 a week, you will be helping us to raise much-needed funds to improve the outcomes for children and young people with bone cancer.

The lottery is really fun and simple to play. Just select six single lucky numbers (between 0 and 9) to play our daily game (four days a week, Monday to Thursday).

Every day we will take the last digit of the recorded temperature

(in Fahrenheit) as reported in the Daily Telegraph for six locations and scan all the entries to see who has won. You can check your numbers daily through The Daily Telegraph or on-line at [www.theweatherlottery.com](http://www.theweatherlottery.com).

If you match three or more numbers in sequence you win a cash prize. This will be paid automatically to you; there is no need to claim. Match six numbers and you could win £10,000!

Contact us now for more information

**Fundraising Office: 0113 2621852**

# Done your own thing? Thank You!

It is with great regret that there is insufficient space to thank everyone who has supported us over the past six months on these pages. However, we hope you enjoy reading about a selection of the fundraising and challenge events that have been taking place on BCRT's behalf throughout the country and that you are inspired to do your own thing!

## CHORF Fashion Show



The CHORF fashion show which was organised by Roz Tranfield and took place on the 8th of November was a huge success! The event was attended by Nicola Roberts from Girls Aloud and made all the local papers i.e. Liverpool Echo, Wirral News, Daily Post, Wirral Globe! The event raised approximately £11,000! FANTASTIC!!!

## Adam Panther Memorial Auction

An auction and raffle event was held at The Fiveways in Ormskirk on Thursday 13th December for the Adam Panther Memorial Bone Cancer Fund and has raised approximately £2,000 so far. Thanks to everyone involved who made donations, supported by buying raffle tickets and attended on the night itself.

In addition, following the success of the August 2007 gig in Ormskirk in memory of Adam Panther, Adam's friends Ben Beetham and Dave Michael have decided to set up a full time promotions company in aid of BCRT - fantastic! Read all about it at [www.myspace.com/apmbcf](http://www.myspace.com/apmbcf). The second gig in Adam's memory was held on Saturday 15th March at Roadkill in Liverpool and was another great success.

## 12th Adam Dealey Foundation Golf Day



22 Teams attended the 12th Adam Dealey Golf Day on October 12 2007 at the Verulum Golf Club in St Albans. The golf was followed in the evening by a Gala Dinner in the evening at Sopwell House Hotel attended by over 200 people.

As always the day was an outstanding success with over £18,500 being raised. This year's Golf Day is taking place on October 10th, please get in touch if you would like to attend.

It is now 12 years since Adam sadly passed away and over £240,000 has now been raised in his memory and his parents John and Marian and brother Justin would like to put on record their appreciation for the support from family and friends without whom this would not have been possible. Thank you very much for your continued support!

## Gibson Les Paul Custom 68 Special

The star lot in the Adam Panther auction did not reach its reserve, so we are looking at other avenues so that the maximum amount can be raised through its sale, as we know it will be a highly sought after item of memorabilia. It is a Gibson Les Paul Custom 68 Special, 1 of only 10 in the world and digitally signed by Justin Hawkins of The Darkness. He himself has 2 of them so we have 1 of the 8 in circulation. It comes with a C.O.A. and is valued at £7500. It was very kindly donated by Adam's friend, Jonny Appleton who won it in a competition in N.M.E. If anyone knows of any potential buyers, or knows of any relevant outlets to advertise the guitar for sale that would help us get the maximum benefit from its sale please contact the BCRT fundraising office - Sue Newsome (Adam's Mum)



## Colnburry Club River Scramble



On the 2nd February 2008, a particularly crisp and sunny day, 20 intrepid young men and women braved the cold of the river Coln in order to raise over £1000 for the BCRT. Their harrowing journey took them 4 miles down the river, over weirs and under bridges from The Fossebridge Inn to the Bibury Court in Gloucestershire. The temperature was close to zero degrees. The 'Colnburry Club' successfully navigated the treacherous scramble through ice covered water. They all sported well needed wetsuits and the only aid they had was one inflatable item each. These inflatable's ranged from surf boards to bottles of whisky (I don't blame them - although I am not sure if they float). There was great support from family and friends who provided hot soup on route, as well as passers by who supported the cause generously. Huge thanks go to James Russell who is the co founding member of the infamous Colnburry Club. Let's hope that next year's event is equally as sunny but perhaps a touch warmer.

## Valentine's Ball - Cornwall



A Valentine's Ball was organised in memory of Gary Scott and Emma Callar. The night was a complete success and everyone had

a wonderful time. They had a raffle with many prizes ranging from a teddy to a signed book by Rick Stein. Roses were also sold to go with the theme of the night. Gwealdues Hotel was fantastic in helping to organise and they put on a splendid buffet for everyone. A big thank you to them and everyone who attended the evening! The event raised £612. Thank You!

## Sherborne School Inter House Cross Country Run

When they heard that Peter Franklin was suffering from Ewing's sarcoma his old school, Sherborne School, were determined to show their support for him by running the Inter House cross country race wearing t-shirts promoting The Bone Cancer Research Trust and getting sponsorship for their efforts. On Tuesday February 12th 70 boys from Harper House, five of the tutors and the matron and housekeeper put on their specially designed t-shirts bearing the BCRT logo and competed in the race through the Sherborne Castle grounds. They raised over £1,800 - well done!

On Sunday 16th March the House also undertook a sponsored abseil at Portland. A number of old boys of the House and some of Peter's contemporaries were present at the event. Their support is very much appreciated, thank you!



# Doing your own thing? Good Luck!

## Cycle Across America

In May 2008 friends Joseph Millington and Daniel Poole will set off for East Coast USA from where they will cycle across a continent to raise money for the Bone Cancer Research Trust. After peddling over three and a half thousand miles, the pair expect to hit San Francisco on the West Coast by early August: tired, hungry, thin, but with panniers stuffed with cash for charity.



In February 2007 Hannah Millington, Joseph's sister, was diagnosed with osteosarcoma. After 8 months of intensive chemotherapy and limb salvage surgery she is thankfully in remission. Joseph told us "We hope to raise £20,000 for the BCRT, as we fully appreciate the vital work that it performs for young people throughout the UK."

## 4th Annual CHORF Golf Day



The 4th annual CHORF Golf Day will take place on Friday 6th June at the Wallasey Golf Club. The 22 (four man) teams will tee off at 1.30pm and will include the chance to win a Honda S2000 Sports convertible on the 12th hole 'Hole in One' competition, sponsored by Two Mills Honda. Other prizes on the course include golf irons and golfing holidays in France and Portugal.

The Golf will be followed by an evening dinner and prize giving hosted by TV and Radio comedian, Sean Styles, and will finish with an auction and raffle.

Tickets are available at £345 per team or £35 per person for the evening dinner only. For more information go to [www.chorf.co.uk](http://www.chorf.co.uk)

## Anthony Pilcher Bone Cancer Trust Summer Ball 2008

The Anthony Pilcher Bone Cancer Trust Ball is being held on Saturday 14 June and will be raising money towards the work of BCRT. The event, in Alfriston, East Sussex will hope to raise both funds and awareness with a three course dinner, dancing and a raffle and auction. The event will also be one of our Bone Cancer Awareness Week events which is taking place the following week. Go to [www.apbonecancertrust.org.uk](http://www.apbonecancertrust.org.uk) for more information.

## NEWS IN BRIEF

£300 was donated in memory of Hayley Harris. Dawn Coulthard ran the Great North Run and raised £600.

Falinge Park School raised £775 in memory of Danny Round.

Roy & Mary Starkey donated £500.

£292.41 was donated in memory of Phyllis Joan Tabiner.

Anne Gray raised £180 by taking part in the Chess Valley Walk.

£5,373.30 has been donated in memory of Alex Dawson.

Pete Franklin, family and friends raised £520 by putting on a nativity play for the residents of Holberton, Devon.



Family & Friends of Krystle Smith raised £5,509.93.

£25 was donated in memory of Adam Panther.

Gillian Beecher-Bryant, teacher at St Tomas More Catholic Comprehensive, sold marmalade and raised £20.

Andy Moran ran the Liverpool 10k in memory of Jennifer Carvell and raised £450.

£330 was donated in memory of Robert Fowler.

Thames Water held a raffle and home clothes day and raised £672.

£50 was donated in memory of Martin Matthews.

£310 was raised when a group of 10 friends organised a pub quiz in Battersea.

Wigton Moor Junior Football Club raised £1,000 in memory of Luke Tunstall at their annual charity gala.



Johnathan Fenton donated £600 in memory of Joe Wright.

Jacob Coates and Jenny Reid ran the Reading Half Marathon in support of the Team Bones London to Paris cycle team (see page 4).

Littlewoods held a Reunion Fundraiser and raised £1,475 in memory of Jennifer Carvell.

£150 was donated in support of Hannah Millington.

Geoff Owen ran the Nick Beer 10k road race and raised £240 in memory of Jennifer Carvell.

€300 was donated in memory of Krystle Smith. Verney Avenue Day Centre had a Christmas collection and raised £30.

£1,000 was donated in memory of Oliver Curd.

Amanda Disley has raised £350 at KGV College in Southport in memory of her boyfriend Adam Panther.

Year 11 at St Tomas More Catholic Comprehensive organised a sweet sale and raised £110.

Subs Sandwich Bar in Liverpool have raised £91.68 in memory of Jennifer Carvell.

The University of Teesside held a book sale and raised £220 in memory of Guy Francis.

Littlewoods Change Mgt & Production Support Team held a Christmas collection and raised £110 in memory of Jennifer Carvell.

Job Centre Plus in Glasgow held a 'Dress for Scotland Day' and raised £80 in memory of Kenny McCabe.

£3,000 was donated in memory of Matthew Arrowsmith.

£750 was donated in memory of Joe Wright.

£6000 was given in legacies from family members in memory of Guy Francis.

# BCRT in Ireland

BCRT is delighted to have two trustees who live in Ireland and who are working hard to raise the profile of the charity and to raise funds for research into bone cancers.

## Patricia Smith

Following the loss of their daughter Krystle to Ewing's sarcoma in 2002, Patricia and Chris Smith from Ireland, resolved to raise funds for research. Initially they knew of the Adam Dealey Foundation, set up by John and Marian Dealey in memory of their son Adam, and joined them in contributing funds raised to research into Ewing's sarcoma. In 2004 BCRT was established and both Patricia Smith and John Dealey joined other parents and supporters in becoming founding trustees of this national charity.



Patrick Hardman, Roz Tranfield and Patricia Smith

Patricia and Chris faithfully fly over to Leicester for BCRT's regular Trustees' Meetings and continue their fundraising, working incredibly hard in and around their home town of Arklow in Ireland.

Patricia raises all the money using collecting boxes. Supported by Chris, she walks and drives many miles encouraging local shops and businesses to fill the boxes over and over again. At the recent Bláthnaid Foley Trust Ball, Patricia presented BCRT with a further €2,500 bringing the total she has raised to more than £25,000. Very many thanks Patricia.



Fiona and John Foley

## Fiona Foley

Whilst in hospital with her daughter Bláthnaid, who sadly lost her fight against Ewing's sarcoma in 2006, Fiona picked up a leaflet and discovered the Bone Cancer Research Trust. It was an ambition of Bláthnaid's to raise funds for research but unfortunately she was never well enough to do so. Fiona and her husband John formed the Bláthnaid Foley Trust to carry out her wishes and a Ball was held in their home town of Sligo in Ireland on the 24th March 2007 on the eve of Bláthnaid's 14th birthday. Later in the year Fiona attended BCRT's first conference. She was able to meet the Trustees and generously presented a cheque for £16,500 raised in memory of Bláthnaid.

This year's Ball in Sligo was every bit as successful as the first and this time included Dr. Ian Lewis, BCRT's Chairman of the Scientific Advisory Panel and a Trustee, as the guest speaker. Fellow trustees Patrick Hardman and Patricia Smith also attended. Ian talked about the importance of research into this rare but devastating disease and the support that BCRT could give to improve the outcome for future sufferers. He congratulated the people of Sligo on their tremendous support and gratefully received a cheque on behalf of the charity from Fiona for £39,600.

We are delighted that Fiona herself has now agreed to become a Trustee of BCRT and with all the enthusiasm and skills that both she and Patricia bring to the role, we look forward to BCRT in Ireland growing from strength to strength.



**justgiving™**

Fundraising Made Easy!

Whether you're running a marathon, climbing a mountain, having your head shaved or collecting donations in lieu of birthday presents, go online and fundraise the easy way at [www.justgiving.com/bcrt/raisemoney](http://www.justgiving.com/bcrt/raisemoney).

In the last 12 months our supporters have raised over £27,500 through justgiving. Fantastic!

## BCRT Volunteer Box Collectors Needed

We need people to find and then 'look after' a number of collecting box sites in their locality. By swapping the boxes on a regular basis, counting and banking the money, you will also be raising awareness of our work and establishing a relationship with the box holder. They may consider supporting us in other ways.

Please email [fundraising@bonecancerresearch.org.uk](mailto:fundraising@bonecancerresearch.org.uk) or call 0113 262 1852 for further information.



## SHOP ONLINE!

Visit the BCRT online shop on our website and choose from a fantastic selection of BCRT clothing, Christmas cards and other merchandise – raise funds and awareness for BCRT!



## How it all began

In September 2004, Dr. Ian Lewis, Consultant Paediatrician and Adolescent Oncologist at St. James's University Hospital, Leeds brought together 5 families. He knew they had all lost teenage children to osteosarcoma and all shared the desire to see research carried out into this cancer in order to improve the outcome for future sufferers. The decision was quickly made to expand the group to include families whose children had battled against Ewing's Sarcoma, thus uniting skills and enthusiasm as well as funds already raised, in working towards making a difference for everyone involved with Primary Bone Cancer.

This was then essentially a parents' group needing the backing and expertise of professionals. With his belief in the determination of the families, Dr. Ian Lewis worked to attract eminent medical practitioners in Oncology, Orthopaedics and Primary Bone Cancer, to form a Scientific Advisory Panel.

The Bone Cancer Research Trust became a registered charity in March 2006 and by September the first two successful applications for research grants had been accepted.

Through the website and much work on publicising the aims of the Trust, both former and current patients and their families have also become involved. The next aim is to be able to provide information and support and in the longer term, counselling services.

In just two years, the meeting of a small group of bereaved parents, has grown into a significant and credible charity which is driving forward to promote research into the causes and treatment of Primary Bone Cancer, and in particular of osteosarcoma and Ewing's Sarcoma.

## Focus On...

### The Adam Dealey Foundation

Adam was a very brave and courageous 10 year old who battled to survive a rare children's bone Cancer, Ewing's Sarcoma.

He was diagnosed with Ewing's in September 1994 and then received treatment over a ten-month period consisting of eight intensive chemotherapy courses, major surgery removing his 7th rib and part of his vertebra plus 25 radiotherapy sessions.

While still undergoing treatment it was discovered that 2 tumours had developed in his spinal canal causing him to lose the use of his legs and we were informed that no further treatment could be given.

Adam was a bright, cheerful, energetic and caring boy, and an extremely talented sports person, especially at football. In fact Adam was the youngest boy ever to be picked to play for his school team South Hill and went then went on to play tennis for Hertfordshire

It was as if Adam knew he was only to be with us for a short period and did everything at 100 miles an hour cramming as much into his short life as possible

After Adam died it was decided that donations be made in Adam's memory instead of flowers to fund the research and treatment of this terrible disease. After several phone calls it was discovered that no specific fund or charity dealt specifically with Ewing's sarcoma and the Adam Dealey Foundation was set up.



Funding was originally administered through The United Kingdom Children's Cancer Study Group now CCLG who distributed grants on behalf of the Foundation and to date £240,000 has been raised in Adam's memory in many events ranging from annual golf days to football tournaments

In 2004 I was contacted by Ian Lewis and delighted to join forces with other families who had suffered losses through both Ewing's and osteosarcoma to help form BCRT – it is something that Adam would have been proud to be associated with and hopefully we can collectively make a real difference

JOHN DEALEY

## BCRT Moves into New Offices

The BCRT has moved into its new Fundraising and Administration Office in Leeds. This is a great step forward for us and is testament to how rapidly we are expanding thanks to the generosity and hard work of all our supporters. The office is a base for our Administrator: Kate Connor, and our Head of Fundraising: Dave Fisher.



## HOW YOU CAN HELP

BCRT relies on donations, volunteers and fundraising activities to support its work. If you would like to help we would be delighted to hear from you. Please complete your personal details and indicate the information you require.



### DONATIONS

I enclose a cheque/postal order for £ / € \_\_\_\_\_

(Please make cheques payable to Bone Cancer Research Trust)

I would like this donation and all donations I make in the future, to be treated as Gift Aid until I notify you otherwise. I pay income tax and/or capital gains tax equal to the tax you reclaim on my donations.

Signed \_\_\_\_\_ Date \_\_\_\_\_

### OTHER WAYS TO HELP

- I would like to be an active supporter and help the fundraising campaign
- Please add my name to your database and send me your newsletter
- I would like to set up a standing order
- I would like to set up a Dedication Fund Account in memory of a loved one
- I would like to set up an Appeal Fund Account in my own name
- Please send me more information on volunteering opportunities

Please complete the personal details section to enable us to reclaim Gift Aid. Using Gift Aid means that, for every pound you give BCRT receives an extra 28 pence from the Inland Revenue, enhancing your donation.

### PERSONAL DETAILS

Title \_\_\_\_\_

First Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Please return your completed form to:

**Bone Cancer Research Trust, Suite 1d, Gledhow Mount Mansion,  
Roxholme Grove, Leeds, LS7 4JJ.**

**Registered Charity Number: 1113276**