

## Bone Cancer Awareness Week 21 – 28 June 2008 “Growing Pains”, Sports Injury or Bone Cancer?

Our first ever Bone Cancer Awareness Week proved to be a huge success, resulting in some great coverage across all major media outlets, from local newspapers to national TV. Our message highlighting the problems of delayed diagnosis of primary bone cancer reached a very wide audience throughout the UK and Ireland. We would like to say a huge Thank You to everyone who agreed to share their experiences with TV, radio and newspapers, and for all of your efforts to make the week such a triumph.

Along with the vast coverage we received in the media, many of you also organised fundraising and awareness raising events in the lead up to and during the week. These events included a Bed Push

through Plymouth, the Anthony Pilcher Bone Cancer Trust Summer Ball, a coffee morning at the Leeds Cancer Unit, a fun day for staff at Virgin Management in London and sponsored runs in Leeds, Hamburg and Gloucester.

Here at BCRT we also made our first steps into the campaigning world by tabling an early day motion at the houses of parliament with the support of Dr Ian Gibson MP, the Chair of the All Party Parliamentary Group on Cancer. The EDM was:

“That this House supports Bone Cancer Awareness Week from 21st to 28th June 2008, coordinated by the Bone Cancer Research Trust which promotes research into the causes and treatment of primary

bone cancer; notes that primary bone cancers take longer to diagnose than any other type of cancer in young people; recognises the vital and urgent importance of raising the level of awareness of the symptoms of primary bone cancer amongst medical professionals, in particular GPs, and the general public; and congratulates the Bone Cancer Research Trust which is working to raise awareness of primary bone cancer which affects over 400 children and young people every year in the UK.”

We received 82 signatures from MPs across all parties who we will now be able to approach in our efforts to get primary bone cancer higher on the government agenda when it comes to funding and services.

## Belgium to Berlin Cycle Challenge 2009

We are recruiting teams of four people to join us on the first annual BCRT Cycle Challenge from 15th to 17th May 2009. This year, teams will cycle in relay the 540 miles from Ghent to Berlin in just three days. The route will follow mainly quiet country roads through beautiful parts of Europe that you may otherwise never see. Each team will pay an entry fee of just £1,000 (£250 per person), which will cover the costs of the channel crossings, accommodation and breakfast and evening meals over the three days. We then ask each team to pledge to raise a minimum of £1,000. Over the three days you will experience exhaustion, exhilaration and adventure.

Stamina, map reading (although the route is fully marked) and leadership will all be tested and it is a great team building exercise. Each rider will need to be able to ride their share of the 540 mile route, which will include some climbs over the three days, as you cover up to 190 miles as a team each day. If you have any questions, or would like more information about the event please contact David Fisher either by email [david@bonecancerresearch.org.uk](mailto:david@bonecancerresearch.org.uk) or use the telephone number below. Help us to make the first BCRT Cycle Challenge a huge fundraising success by signing up your team today!



## STOP PRESS!

**Our next Patients' and Supporters' Conference will take place on Saturday June 27th 2009. Full details will be available on our website in the New Year and also in our spring newsletter.**

## BONE CANCER AWARENESS WEEK 2009

Following on from the success of this year's Awareness Week, we are now working on the 2009 week which will be from 20th – 27th June. The focus for the week will be announced later in the year through our website with more details about how we would like you to get involved appearing in the spring 2009 newsletter.

## Christmas Collection 2008



Order your Christmas Cards today! Our 2008 Christmas cards are available to order using the form on the back page or online through our website.

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# RESEARCH

## REPORT FROM THE SCIENTIFIC ADVISORY PANEL

The work of the Scientific Advisory Panel (SAP) is vital for BCRT to achieve its aims. The SAP oversees research grant applications and ensures that the projects are viable and of good quality by a system of peer review. Peer review means that applications are sent out to independent doctors and scientists who let us know whether these projects are feasible and worthwhile. BCRT is very grateful to all those people who undertake this task voluntarily.

Since BCRT's first call for grant applications in 2006, we have received a number of applications from many major research groups throughout the country. Nine projects totalling £290,000 have been funded and another four projects are under active consideration.

We asked three researchers to summarise the project for which they have received funding from BCRT in 2008:-

**Professor Nicholas Athanasou and Dr Helen Knowles, University of Oxford (£27,213)**

A reduced oxygen supply, known as hypoxia, is common to many tumours and is associated with poor prognosis. We are studying effects of hypoxia on Ewing's sarcoma and osteosarcoma cells. This includes investigating which genes are activated by hypoxia and how they affect processes such as cell death, growth and migration. These experiments suggest that hypoxia contributes to the development of bone tumours and represents a potential target for novel anticancer therapies.

**Dr Richard McNally, Newcastle University (£30,601)**

Previous studies have found some evidence of a possible association between fluoride intake and risk of developing a bone tumour. To address this question we will carry out a series of geographical analyses to determine whether the incidence of bone tumours is related to fluoride levels in drinking water. It is anticipated that findings from this study will indicate the direction of further research into the possible causes of bone tumours.



*Dr Jeremy Whelan, Member of the BCRT Scientific Advisory Panel*

**Professor Jillian Birch, University of Manchester (£47,555)**

Osteosarcoma and Ewing's sarcoma show marked peaks in incidence which coincide with the adolescent growth spurt. Causes of these bone cancers may be linked to growth. Myself and Professor Patricia McKinney will carry out a two-centre pilot study in Manchester and Leeds to investigate this link. The study involves interviewing patients and their parents, collecting biological samples and abstracting medical records. The pilot is an essential forerunner to a major international study.

**The next closing date for grant applications is 6th April 2009.**

We are very pleased with the growing recognition amongst the scientific community of the role that BCRT has to play in establishing research in this area. We will keep you updated through the website and this newsletter.

## Development of the National Sarcoma Register



**by Berni Lee, Trainee in Public Health at the West Midlands Cancer Intelligence Unit**

A national register of all patients with a bone cancer or Soft Tissue Sarcoma (STS) is being developed by the West Midlands Cancer Intelligence Unit (WMCIU),

which is one of the national Cancer Registries. Over time the Sarcoma Register is expected to improve management of the disease and improve outcomes, such as survival rates and complication rates.

The National Sarcoma Register will allow us to better understand:

- The pattern of disease among the population, for example how many people are affected by different types of tumours and where they live.
- How patients are treated, for example how many have surgery and/or chemotherapy
- Factors that influence survival, for example the stage of disease at diagnosis

Information from the register should also guide future research into bone cancer and STS and the services that are provided to treat it.

Data that is available in different data sets on patients with bone cancer and STS is currently being brought together into a single record. Discussions are underway with the clinicians who manage the disease in the UK so that there can be agreement about the precise information that should be collected on the Sarcoma Register in future and what reports should be produced from it. Through their representation on the Steering Group Committee, The Bone Cancer Research Trust and Sarcoma UK have been influential in ensuring that the perspective of patients and carers are reflected in the content of the Register.

It will take some time before the register is fully developed but the West Midlands Cancer Intelligence Unit would be interested in the views of patients, their families and carers about use of the register and the type of information they would like to see produced from it.

**What information would you like to be held in the National Sarcoma Register? How do you envisage the Register being used to improve outcomes for bone cancer patients? Email [kate@bonecancerresearch.org.uk](mailto:kate@bonecancerresearch.org.uk) with your views and these will be presented by the BCRT representatives at the next National Sarcoma Register Steering Group meeting.**

# Life After Treatment

**So you've left hospital after your final chemo: you can sleep in your own bed, eat home-cooked food, indulge in a drink or two without having to record the fluid levels on a chart - but what happens next? You may feel that life will never be the same again, but there comes a time when daily life has to return to some kind of normality. Here three former bone cancer patients share their experiences of returning to school, university and work.**

**Adam Gill, 17, from Guernsey, was diagnosed with Ewing's sarcoma in May 2007 and returned to school this September.**

As the third week of school draws to a close, a few questions inevitably run through my mind. What homework do I have for Monday? What's for dinner? But, one that's been bugging me for a while: where can I hire a good bodyguard?



No, really. I'm not concerned about my personal safety (though having a bodyguard for safety reasons would be pretty cool), but returning to school after recovering from Ewing's sarcoma isn't as straightforward as it normally would be.

I join the year below, year 12, taking the classes I would have done last year. However, this is more significant than merely a new year group and 18-month-old chemistry knowledge that has more than a few moles of iron oxide. And this is where my bodyguard comes into the equation.

In the sixth form at my school, we combine with a nearby girls' school for lessons. As there's only a ten-minute window between lessons to walk between the two schools (which is actually a push if you're fit and walk quickly), the school have somehow managed to get free taxi transport for me.

Though I know it won't last forever and I will have to go back to relying on good old ambulatory transport eventually, there is a certain satisfaction in being the first to a lesson and looking at all the

"How did you get here so fast?" faces.

So, ticking off the list, I have a chauffeur service, have had a dietician, personal trainer, physio, have covered two pages in my local newspaper, have had a private plane, have been on opiates and many other drugs, have spent a significant amount of time without hair...the only thing missing from making me a full blown celebrity is a bodyguard.

In all seriousness though, my return to school has been as smooth as it could have been. The school has been immensely supportive and flexible, asking how they can help me (though, I must add that the taxis were not my idea - not that I'm complaining).

So, as I return to the 'daily grind', resolving vectors and memorising eukaryotic cell structure, while I may not have been able to 'hit the ground running', I've definitely been able to hit the ground, find my feet, and, when I need it, a taxi as well.

Read more from Adam at [www.gillspatch.co.uk](http://www.gillspatch.co.uk).

**Marnie Fraser, 27, from Aberdeen, was diagnosed with osteosarcoma in November 2004 and went back to university two years later.**

I was diagnosed with osteosarcoma in November 2004, two weeks after my 24th birthday. I was in my third year at university, where I was studying for a degree in Publishing with Journalism.

After having been told I had cancer, I went into university on crutches to hand back all my library books. My classmates hugged me and were upset about me having to take time out for treatment. At this point it all felt very surreal and I couldn't imagine going back to university after something like this happening. I wasn't sure if I would ever return to finish my degree. I felt that my future was uncertain and just wanted to take one day at a time.

However, in 2006, two years after diagnosis, I returned to university to pick up where I had left off. It was very strange going back to the same place I had left two years previously. I was nervous about going back as I would have new classmates and I was older than they were. I made friends quickly and within a couple of weeks, felt like part of the class.

I didn't tell anyone about my illness, other than one girl who was curious as to why I had taken two years out. I told her about it and she was really shocked. I wasn't ashamed of my illness, in fact I will talk freely about it if people ask questions, but I didn't want to be treated any differently or for people to feel sorry for me.

I was encouraged to finish my degree by my friends and family and also by my subject leader at university who kept in touch when I was undergoing

treatment. She made it feel possible for me to return to my studies.

I was determined to do well at university and graduated this year with first class honours. I wanted to prove to myself that I was capable of getting through cancer and then returning to the life I had before. I'm now working as a Researcher for a television production company and feel that my life is back on track.



*Marnie and her parents at graduation in summer 2008*



**Sally Hurst, 29, from Leeds, was diagnosed with osteosarcoma in April 2005 and returned to work after an 18-month absence.**

It pays the mortgage, gives a focus to the day and - if you're lucky - provides mental stimulation, social interaction and fun: going to work is a fact of life for most of us, but I never really understood how important my job was to me until, suddenly, I couldn't work any more.

I was out of the workplace for 18 months, following my diagnosis with osteosarcoma in 2005. Commuting in rush hour, doing live radio broadcasts and meeting hourly deadlines were a thing of the past. My days were filled instead with the painful numbness of chemo sessions. Then there was the operation (an unexpected amputation), the rehabilitation, and the physical and mental exhaustion... By the time it was all over I felt as if I could barely remember how to switch on my computer, let alone go back to the newsroom as a fully-functioning broadcast journalist.

But my return to work was eased by negotiating part-time hours, something to which my

employers were receptive. After all, it's in their interests, as well as yours, to make sure you don't have a nervous breakdown in the first couple of weeks! So I started doing a couple of mornings a week, building back up to full-time.

I did, however, find the first few weeks very difficult. I couldn't do live reporting anymore, as I was unable to drive the radiocar so I started doing more office-bound production work. My confidence was pretty much at rock bottom and I felt like the work experience girl again. Although my colleagues were hugely supportive, I didn't feel I was pulling my weight as much as I used to. There were a couple of occasions in that first month that I found myself sobbing in the ladies' loos.

But gradually things got easier and my confidence returned. I accepted that I wouldn't be able to do all the things I used to do in the same way, and stopped comparing my old job with my new job.

I now look forward to going into work in the morning as a sign that life is back to normal. And normal - as any former cancer patient knows - is good.

Read more from Sally at [www.sallyyoung.blogspot.com](http://www.sallyyoung.blogspot.com)

*Photo courtesy of Jill Jennings Photography*

# BCRT Conference 2008

***"BCRT has demonstrated what many other charities lack or lose and that is respect and recognition of those affected by cancer, and provides a voice and a chance to make a real difference."***

That's what one visitor thought about this year's BCRT Conference. It's just one of the positive feedback comments we received following a well-attended and vibrant event.



Gaynor & Nigel Jones present BCRT with a cheque for £25,000 raised in memory of their son Rhodri

One of the themes of this year's conference was delayed diagnosis, something which many young bone cancer patients experience. It was extremely interesting, therefore, to hear from GP Dr Bob Grant about the research being done in this area. (Read on for a full report from Dr Grant.)

There was also a presentation from prosthetist Carl Elliott on amputee rehabilitation; a talk about fertility issues for cancer patients undergoing chemotherapy and radiotherapy by expert Dr Allan Pacey; and updates about medical developments into the treatment of primary bone cancers, as

well as information about research being funded by the BCRT.

The conference is a great opportunity for patients and their families to meet other people in similar situations. As well as break-out sessions, when parents, patients and medical professionals divided into smaller groups to discuss topics such as 'Coping with Loss', 'Life after treatment' and 'Ewing's Sarcoma – current issues', there was also chance to chat to speakers and delegates over lunch and coffee breaks. As one patient told us, coming to the conference gave them "the realisation that I am not alone."

We were delighted that patients also accepted our invitation to speak, including former osteosarcoma patient Hannah Millington. Hannah came to our 2007 conference while she was still undergoing treatment, so it was fantastic to see her looking so well as she took to the floor to tell her moving story.



Hannah Millington



Holly Hurst makes her conference debut

Also making her conference debut was little Holly Hurst – who at just eight months old – accompanied her mum, Sally Hurst. Sally, who was diagnosed with osteosarcoma in 2005, was told she was infertile following cancer treatment, but she gave birth to Holly in October 2007 against the odds.

There's no doubt that this year's conference was a great success – both in highlighting the fundraising and research activities of the BCRT, and in enabling patients and families to share experiences. As one delegate said,

*"Thank you to everyone who organised the event and to all who took part. Your input was very empowering and encouraging to us."*

We're already planning the BCRT Conference 2009, so put 27th June in your diaries. More information will follow in our Spring newsletter and keep checking our website, [www.bonecancerresearch.org.uk](http://www.bonecancerresearch.org.uk) for updates.

## Delayed Diagnosis by Dr Bob Grant, GP, Fife

Any discussion among those who have experienced cancer during their teenage or young adult years will quickly focus on the delay experienced by many between first reporting symptoms to their GP to the time of referral for investigation and eventual diagnosis of the cancer. This seems particularly true with bone tumours. A recent study presented to the Teenage Cancer Trust 2008 Conference noted that in 115 patients



Dr Bob Grant

subsequently diagnosed with bone tumours, the time between first symptom and diagnosis ranged from 4-184 weeks with an average of 15.2 weeks.

My bone tumour was diagnosed early in 1961 when I was 14. Despite this being so long ago, I can still recall the worry experienced by my family during the weeks between my first visit to my GP and my eventual referral for investigation. I remember having several contacts with my GP and being reassured that my discomfort, night pain and difficulty in walking were due to "growing pains." I share with many others with similar experiences a sense of bewilderment that no immediate referral was made.

Discovering why such delays occur has now been identified as a research priority by the NCRI TYA Clinical Studies Development Group. The group has established that little has been published on how young people in the 16-25 year age group use GP services. Finding out more about this seemed an important first step in trying to establish possible reasons for referral delays. A study was therefore established to review all attendances over a 12-month period by all those in the 16-25 age group in three general practices in Scotland.

6730 consultations across the three practices were analysed. The symptoms that were recorded as the reason for attending the GP were subdivided into four groups:

- A. Clearly no oncological (i.e. possible cancer related) significance
- B. Potential oncological symptoms of uncertain significance
- C. Other clinical symptoms including travel vaccines and preventative advice
- D. No clinical symptoms e.g. new patient interview

Across the three practices it was found that only 3.9% of all attendances were with symptoms of potential significance.

The conclusions formed at the end of the study were:

1. People in the 16-25 age group do utilise primary care/GP services with approx 66% attending at least once in a one year period
2. One third of this age group attend four or more times in the year
3. Attendances due to symptoms with potential oncological significance is rare (3.9%)
4. Further research is required including a large study interrogating a national GP database. In addition it is planned to review in depth case records of a significant number of teenagers and young adults who have had a diagnosis of cancer to look in depth at the route to diagnosis.

It is already clear however that those in the 16-25 age group presenting with potentially oncological symptoms form a group small in number but large in importance. Somehow through ongoing research we need to find ways to encourage GPs to focus their attention on this small group and thus ensure early referral and diagnosis.

# Fundraising News

Since the Spring Newsletter, we have seen the number of fundraising events being done by our supporters grow and grow, with new ideas and activities being planned almost daily. Here are a few of the fantastic things that our supporters have been organising and taking part in around the UK and Ireland. All of your fundraising efforts are very much appreciated, helping us to continue our vital work. As ever, we are unable to include all of your activities on these pages, but would like to pass on our appreciation to everyone who has supported us over the past six months, Thank You!

## Cycle Across America

On 27th May, Joe Millington and Dan Poole set off on a three month cycle ride across America to raise money for BCRT. Cycling for 52 days, the duo covered 3590 miles! Having cycled across deserts and over the Rocky Mountains, the route took in some of the most fantastic scenery that America has to offer.



65 days after leaving Union Station, in Washington, they rode triumphantly over the Golden Gate Bridge into San Francisco and their trans-continental journey was over. You can read the full details of their amazing challenge on their blog <http://bikingforbonecancer.blogspot.com>. So far Joe and Dan have raised over £12,000 for BCRT in support of Joe's sister, Hannah who was diagnosed with osteosarcoma in 2007.



## Having a Ball!



Lauren Winter and Alexandra Wright organised a **Charity Ball in memory of their friend Nick Pollard** at Tern Hill Hall Hotel in Market Drayton on 16th May 2008 in aid of The Bone Cancer Research Trust and Cancer Research UK.

Lauren told us, "I wanted to help raise funds and awareness for the BCRT Nick Pollard Fund as he was an amazing friend, who unfortunately lost his battle with Bone Cancer at the age of 21 on the 23rd December 2007.

He was so many great things, happy, sporty, kind, caring, determined, handsome, just to name a few. I still can't quite believe he's no longer with us, I will never forget him."

The charity ball included a sit down buffet, a raffle, an auction and a dance, in total raising a fantastic £6,000.

On 26 September, Keira Hall and Jenny Denton organised an **Autumn Ball at the Citrus Rooms in Barnsley** in support of one of their friends who has Ewing's sarcoma.

Over £6,000 was raised on the night which included a raffle and a band. In addition there was an auction with lots up for grabs ranging from original props from the Harry Potter films to an original Storm Trooper Helmet!!



## Running, Crawling and Dancing

Paul Gavin was diagnosed with osteosarcoma in September 2007. Having completed months of chemotherapy, Paul is now concentrating his efforts on getting better and raising money for BCRT along with his family and friends.



the Asics Liverpool 10k on the 5th October. Thank you very much to Paul and his supporters who have so far raised over £4,500 for our work!

Fundraising activities have included a family fun day at Vauxhall Motors and a fancy dress pub crawl organised by Paul's friend Kayleigh McMillan. Paul also held a Charity Evening with his friends and family to celebrate finishing his treatment which included an auction and a disco and 16 of Paul's friends and family ran



## G-Fete



nearly £3,000 for the Guy Francis Bone Cancer Research Fund, one of our founding member charities.

The organisers hope that this will be the first of many G-Fetes to come after so many people supported the event and had such a great time.

## Sherborne School Fundraising

Harper House, at Sherborne School in Dorset, have been holding fundraising events throughout the year for BCRT, in support of former pupil, Peter Franklin who is currently undergoing treatment for Ewing's sarcoma. Their Krispy Kreme Doughnut Sale on 9th May was such a success that they were sold out by lunchtime! Through all of their fundraising efforts, including a cross country run earlier in the year, a sponsored abseil and an auction at their annual house day, Harper House at Sherborne School have raised over £8,000 – A huge thank you for all of your efforts!



One pupil decided to take on the challenge of swimming across the English Channel. Raising money for BCRT and two other charities, Ollie Crosthwaite-Eyre completed the swim and has raised over £1,800 for our work, well done!

In addition to this, Sherborne School for Girls raised a fantastic £600 through a collection at their end of year school service.

## Chipping Chicks



Chipping Chicks soccer player Anna Griffin, 12 years old, was diagnosed with osteosarcoma early in 2008. Anna has had tremendous support from her teammates who have held various fundraising events including a tombola and raffle, raising a fantastic £1,000 for BCRT!



## London to Paris Cycle Ride

Team Bones, who featured in our Spring Newsletter, successfully completed the London to Paris Cycle Ride in June, raising over £22,000! As well as being sponsored for the cycle challenge, the team got family and friends involved in a vast range of fundraising events to reach this fantastic total. These included a river scramble, an iron-athon, a bed push, pub quizzes and various runs. The girls also received support from a number of schools and companies who held fundraising events in support of BCRT. We would like to congratulate Harriet Webb, Milly Bell, Rachel Holloway and Jenny Reid on completing the challenge and to thank them for their continued fundraising efforts!!

## Peaks and Parks



George Neville-Jones and Zannah Palmer have successfully completed two fantastic

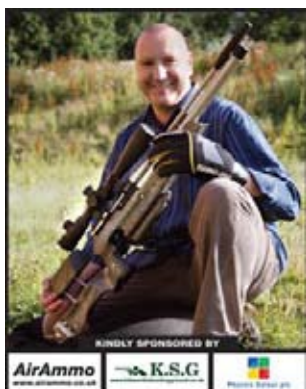
feats in order to raise money for BCRT. First of all, along with their friends, James Strang and Edd Clifford, they completed the UK Three Peaks Challenge, climbing Ben Nevis, Scafell Pike and Snowdon in just 22 hours and 48 minutes! Not happy with climbing three mountains, George and Zannah joined 108 other BCRT Team Bones Runners to take part in the first ever Royal Parks Half Marathon on 12th October 2008.

**Fundraising Office: 0113 2621852**

# What our fundraisers have planned!

Here are a few of the amazing things that our supporters have planned over the next few months to raise money for BCRT. We would like to wish all of our supporters who have fundraising events planned the best of luck, and apologies that we do not have the space to mention you all individually!

## World Record Field Target Shooting



On 25th October Chris Large will be attempting a Guinness World Record to raise money for BCRT. The record he is attempting is 'The most number of 40mm targets hit from 30m in a straight eight hours with a target rifle'. In order to succeed Chris will need to hit one target every seven seconds, so Chris and his team are praying for good weather. Held at his local shooting club in Leicester, there will be a barbeque and other activities to keep the spectators busy! So far Chris has raised over £1,200 – Thank you and Good Luck with the record!



## Run and a Jump for Rose

Six year old Rose Allocca was diagnosed with osteosarcoma in March and is currently undergoing treatment at the Marsden and Stanmore. Having successfully completed a limb salvage operation and tumour removal, Rose is now going through an additional 20 weeks of chemotherapy. To support Rose and her family, Calvin Haggis and Tayo Davis have decided to skydive from 12,000 feet on Sunday 23rd November. So far they have raised over £10,000 and are still going strong. Good luck to Calvin and Tayo, your support is very much appreciated!

In addition to the skydive, another group of Rose's supporters have completed the Run to the Beat Half Marathon in London on Sunday 5th October. Well done to Julia Smith and friends! Their efforts have to date raised almost £5,000.



## Cuba Cycle Challenge

Paul Roffey and Billy Hall have decided to take on the challenge of a lifetime. They will be cycling across Cuba from Havana to Vinales, covering 338 kilometres on their 11 day trip. They will cycle along coastlines, through pine forest and over Mountains along the way. They are in full training for the challenge and are hoping to raise over £5,000 for BCRT.

## British Military Fitness - Kinabalu Challenge

Mike McCann, Caroline Guppy, Dawn Yell and Hannah Marsden are taking part in the British Military Fitness Kinabalu Challenge in support of BCRT. The nine day challenge from 14th to 22nd November will see them doing jungle runs, mountain biking, white water rafting, raft building and a kayak relay race. They will finish the challenge with the ascent of Mount Kinabalu (4100m) before a well earned celebration party. As part of their fundraising efforts they held a fundraising night at the Territorial Army unit in Liverpool. They are now training hard for the actual challenge and can't wait for it to start.

## Inspired? – Get involved!

If you are feeling inspired after reading about all of our fundraisers activity, why not take on a challenge yourself or organise your own event. Big or small, whatever you can do to raise money for BCRT means that we can fund more vital research into the causes and treatment of primary bone cancer!!

### Cycling – get your lycra on for our own Belgium to Berlin Cycle Challenge

Why not join us on the first ever BCRT Cycle Challenge from Ghent to Berlin. We are hoping to have over 20 teams cycling the 540 mile route in relay over the weekend of 15th – 17th May 2009.

### Running – from 5K to a half marathon – we have an event to suit your level!

We have places available in the major Great Run

Series events, the Leeds 10K and the Royal Parks Half Marathon for 2009. We are also looking at other running events, but will be happy to offer fundraising support to anyone with their own place in any runs, large or small.

### Trekking – from a weekend taking on Scotland's Highest Mountain to a fortnight tackling Africa's, we have a trek for you.

We work with a number of charity challenge event organisers who have a whole range of trekking events around the world which you can take part in to raise money for BCRT.

### Do your own thing – tea party, quiz night or fancy dress ball

Organise your own event and have a great time raising money with your friends!

Our supporters raise a huge amount by organising their own events. Over the past six months we've seen cross country runs, fancy dress bar crawls, gigs and coffee mornings. Anything goes when you are organising your own event, as long as it is legal, you can do it and we will support you in your efforts by providing fundraising materials and BCRT information for your event! Just don't forget to tell us what you are doing so we can help you!

**For information on any of these, please contact David Fisher, Head of Fundraising either by email [david@bonecancerresearch.org.uk](mailto:david@bonecancerresearch.org.uk) or telephone the office on 0113 2621852.**

**Information on all of these events can also be found on our website [www.bcrt.org.uk](http://www.bcrt.org.uk)**

**[fundraising@bonecancerresearch.org.uk](mailto:fundraising@bonecancerresearch.org.uk)**

## NEWS IN BRIEF

Andrea Whitehead sent in donations of £225 in memory of her father

Donations totalling £5,139.33 were made in memory of Tom Walker

£450 was donated in memory of Laura Weston

Barbara Dunphy raised £200 at a coffee morning in memory of her grandson, Joseph Thompson

The Katy Cairns School of Dance raised £250 in memory of Sian North

The Assessment Network donated £470 in memory of Lewis Oglesby along with £436 collected at Lewis's funeral

£814.60 was raised at a non-uniform day at Sir William Borlase's Grammar School

The Sally Prout school of Dancing raised £1,536.33 from their production of Cinderella

£3,735 was raised by Joan and Bob Grant, Alison Weir, Gary and Helen Harrison and Julia Flockhart who all completed the Great Edinburgh Run

£891.05 was raised at a golf day in memory of Aaron Robinson

Darren Uren, Edward Roberts and Jonathan Lloyd-Jones raised £1,877.44 in sponsorship for the Great Manchester Run

£7,000 was donated by the Adam Panther fund

The McCartney family raised £250 at a fancy dress party in memory of Stephanie McCartney

An open house at the Burnand's was held in memory of Claudia Burnand raising £1,567.60 during awareness week



Toby Clements ran the Tromso Midnight Sun Marathon in Norway and raised £1,902.20 in support of Pete Franklin

Churches together in Longridge raised £630 at a Coffee Morning in support of Anna Griffin

James Maffin made a donation of £1,000

The Dickens Foundation made a donation of £1,000 as sponsorship towards Dan Poole and Joe Millington's cycle across America

The 7th Feltham Sea Scout Group raised £560.66 at a charity dinner

Claire Bostel raised £250 at a charity fun day in support of Bradley Mills

Carol Starkey completed the 3 Peaks Challenge and raised £102

Family members donated £215 in memory of Joe Wright

Falling Park High School raised £1,126.11 at an auction and a further £75 through mobile phone recycling in memory of Daniel Round

Kay Hylton completed the London Triathlon and raised £2,045

£2,730 was raised at the Kevin Pearson memorial Golf Day

Rebecca Carter completed the Asics British 10K and raised £941

Richard and Gwyneth Parry completed the Rotterdam Marathon and raised £1,014

£1,000 was donated by Paul Howell

Friends and family of Krystle Smith donated a total of £5,512.37

Heather Williams raised £276 in memory of Sam Clowe, by taking part in Ravelympics (knitting something within the timescale of the Olympics)

£5,959 has been raised in memory of Alex Dawson

Hilary Heatcote raised £408 at a coffee morning held during awareness week

Ceris Crow raised £1,916 by competing in the London Marathon in memory of Guy Francis

Jessica Trahar completed the Springfield Triathlon and raised £210

Michelle and Holly Weston raised £355 by taking part in the race for life in memory of Laura Weston



# Bone Cancer Awareness Week 2008

Along with the media coverage that our awareness week campaign was able to generate, many of our supporters also took the opportunity to hold their own fundraising events to help raise money and awareness during and around Bone Cancer Awareness Week 2008. Thank you very much to all who organised or took part in an event, your support is as always very much appreciated by us all!

## Anthony Pilcher Bone Cancer Trust Summer Ball

The Anthony Pilcher Summer Ball was held on the 14th of June at the Dean's Place Hotel in Alfriston, East Sussex. A three course meal was followed by an auction featuring a signed Harlequin's rugby ball. After some dancing, a prize raffle featuring a large teddy and lots of wine and chocolate followed. Over £1000 was raised which will help fund research into bone cancer.



## Bed Push through Plymouth

On Saturday 21st June, Harry Flower, Caroline Franklin, Alick Mildmay-White, Venetia Maitland, Harriet Webb, Jamie Orchard, Yohanna Franklin and Lucy Walker dressed up in rather fetching pyjamas and nighties and pushed a decorated hospital bed three miles around Plymouth. The weather held off and the eight of them stayed dry the entire way round, catching shoppers in the city centre with buckets for spare change. Having already raised over £500 through sponsorship they managed to raise over £900 on the day, with pledges still coming in they are hoping to raise over £1500 in total.

## Leeds 10K, Jane Tomlinson's Run for All

Over 150 BCRT runners took to the streets of Leeds to take part in the second Leeds 10K on June 22nd. This was by far the most people we have had taking part in a single fundraising event for us, and sponsorship money is still coming in as we aim to raise over £30,000 from the event.

We had people taking part from all over the UK, and of all abilities, from super fast runners to walkers, and even one participant, our trustee, Nick Bones taking part on one leg with his crutches. The run was followed by an after event brunch barbeque at a pub in the centre of Leeds.



## Wigs and Hats Day to mark visit from the Queen

Staff and pupils from St Cecilia's RC Technology College in Longridge staged a hats and wigs day in support of 12-year-old Anna Griffin who has osteosarcoma. The day was organised by Anna's classmates, who lined the streets and rattled their buckets to welcome the Queen on her official visit to the town. Along with a number of other fundraising initiatives the school has raised a fantastic £590 for our work.

## Virgin Family Fun Day

Everyone had a great day with football, egg & spoon races, it's a knockout, face painting etc. and a lovely BBQ and what's more the sun shone! With £644.59 raised for the Adam Dealey Foundation in support of the Bone Cancer Research Trust, it was a fantastic day all round!



## Emily Blunt Run

Friends and family of Emily Blunt turned out in their hundreds to pay tribute to her memory at a fun run which took place in Gloucester just two days after her death following a yearlong battle with osteosarcoma. Kath, Emily's twin sister had been organising the event to support her sister, which the family decided should still go ahead in Emily's memory. Kath was delighted with the turnout and believed that Emily would be very proud with the number of supporters who took part in the event which has raised over £14,000 for BCRT.

The run was one of two being organised in support of Emily, along with a fun run organised by Airbus in Hamburg which was also raising money for BCRT in support of Emily. Emily's Dad, Ian, works at Airbus in Hamburg and was delighted to be able to nominate BCRT as the charity to benefit from the event which took place on Sunday 22nd June and raised well over £3,000.

Thank you very much to the Blunt family and their friends for supporting BCRT, especially with the additional media coverage that Kath and Emily raised in the lead up to Bone Cancer Awareness Week on national TV and press.



## Marnie Fraser Tea Party

Marnie Fraser held a fundraising tea party in aid of BCRT at her house and was delighted when around 45 people turned up for tea and cakes, raising an amazing £600.

**Thank you to all of our supporters for helping to make our inaugural Bone Cancer Awareness Week such a success. We are planning even more activity for Bone Cancer Awareness Week 2009, so look out for details of what you can do in the next newsletter and on our website towards the end of the year!**

# Focus On... CHORF

Christopher first complained of pain in his leg in December 2001 and after several visits to hospitals and doctors was diagnosed with growing pains. It wasn't until I insisted on an x-ray that he was referred to a specialist and diagnosed with osteosarcoma in June 2002.

Christopher took the news exceptionally well that he would have to have his left leg amputated above the knee and also undergo eight months of chemotherapy. As a member of the London (YMC) and Liverpool Magic Circles, Christopher used his time in hospital to practice and improve his skills and entertain fellow patients and the staff when he was well enough to do so.

He was fitted with a state of the art artificial limb in early 2003 which enabled him to walk without the aid of crutches and carry on life as normal as possible. Christopher returned to school and had obtained work at dinners and in local restaurants as a magician which he hoped would be the start of a career in something he loved to do.

In March 2004, he started to have pains in his thigh and back, and it was discovered that the cancer had returned to his pelvis and he also had secondary cancers in his lungs. Following a terminal diagnosis, Christopher decided



to continue to live life to the full, determined to do everything he could for as long as possible, taking holidays, day trips and entertaining with his magic.

Christopher lost his fight with osteosarcoma on 25th October 2004 at the age of 15.

During Christopher's illness, it became apparent that there was a lack of research being carried out into osteosarcoma because it is such a rare cancer. Due to this we set up the Christopher Hardman Osteosarcoma Research Fund. Over £120,000 has been raised in Christopher's memory through many events ranging from Golf Days to Fashion Shows.

I saw a letter in the Daily Mail from Gill Callar, who was in a similar position to me, having set up a charity to raise money for research into osteosarcoma. We met, along with several other family groups raising money for primary bone cancer research and we set up BCRT to pool our resources in order to make a real difference.

PATRICK HARDMAN



## 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.

## 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.

### Christmas Cards

- |                                |                                   |                             |              |              |              |
|--------------------------------|-----------------------------------|-----------------------------|--------------|--------------|--------------|
| 1. Warm Welcome<br>14cm x 14cm | 2. Three Kings<br>11.5cm x 11.5cm | 1. Snowdrops<br>14cm x 14cm | <b>£3.95</b> | <b>£3.50</b> | <b>£3.95</b> |
|--------------------------------|-----------------------------------|-----------------------------|--------------|--------------|--------------|



Packs contain 10 cards with envelopes. The greeting inside all three cards reads: 'With Best Wishes for Christmas and the New Year'

Please use this form to order your Christmas cards, or order them online at [www.bcrf.org.uk](http://www.bcrf.org.uk)

#### CHRISTMAS CARD ORDER FORM

Card	Cost Per pack	Quantity (packs)	Cost
1: Warm Welcome	£3.95	_____	£ _____
2: Three Kings	£3.50	_____	£ _____
3: Snowdrops	£3.95	_____	£ _____
<b>Total cost</b>			<b>£ _____</b>
<b>Postage: £2.95 (orders under £30), £4.95 (orders £30 and over)</b>			<b>£ _____</b>
<b>Total cost (including P&amp;P)</b>			<b>£ _____</b>



#### 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