

HAVE YOUR CAKES GOT THE X FACTOR?



Awareness Week 2009 is taking place from June 20th to June 27th. This year we are asking our supporters to 'Bake a Cake for Bone Cancer' to raise vital funds for research. We are delighted that X Factor finalist Andy Abraham has taken time out from promoting his new album, Even If, to support BCRT.

Hold a tea party in your garden, a cake sale at work or a cake 'tuck shop' at school. Plan a day that suits you and invite your friends, family or work colleagues to join you. Whether you are organising a picnic in the park or a cake auction, the only difficult decision is which tasty cake you should bake! Andy's favourite cake is angel cake. His recipe, along with other delicious cake ideas, will be included in the Bake a Cake for Bone Cancer fundraising pack.

To request a pack, please contact BCRT's fundraising team by emailing fundraising@bonecancerresearch.org.uk or by calling 0113 262 1852. Or visit our website to download the pack (available early April).

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Next BCRT Grant Application Closing Date - 6th April 2009 please visit our website for full information on how to apply

CHAIRMAN'S MESSAGE



release headlined "UK survival for children's bone cancer lowest in Western Europe" adding that "survival for osteosarcoma has not improved in the last 20 years".

In stark terms, this means that a generation has gone by without any real advances in patient survival outcomes. But the positive is that our funding has highlighted an urgent need for more research and all our supporters can take great pride in revealing this need. A report on Dr. McNally's paper appears on page 2.

As we go to press, BCRT will be giving Expert Witness testimony to a NICE Appraisal Committee reviewing the use and funding of the drug Mifamurtide, which in a large randomised trial carried out in North America, improved survival of patients with

osteosarcoma by around 8%. This is the most significant improvement in osteosarcoma treatment for the last 20 years. BCRT is leading the way in advocating for the introduction of this new drug into the UK so that future patients can benefit as soon as possible. We are optimistic that NICE will approve funding soon.

Both our 2009 Bone Cancer Awareness Week (June 20th - 27th) and our Annual Patients' & Supporters' Conference (June 27th at Sopwell House, St. Albans) will focus on the need to improve survival rates, and will include speakers on other BCRT funded research - plus much more!

Thanks for your continuing support - with you, we WILL make a difference.

Mike Francis
Chairman, BCRT



Getting Active after Treatment – be inspired by six former bone cancer patients, pages 4-5



Fundraising News, pages 6-7

The First Research Project Funded by BCRT is Published

A report on the findings from the research carried out by Dr. Richard McNally of Newcastle University entitled "An epidemiological study of bone tumours in children and young adults".

The aim of the study was to describe the incidence and survival from childhood bone tumours using data from northern England and the West Midlands. Data from four specialist registries: the Northern Region Young Persons' Malignant Disease Registry (NRYPMDR), the Yorkshire Specialist Register of Cancer in Children and Young People (YSRCCYP), the Manchester Children's Tumour Registry (MCTR) and the West Midlands Regional Children's Tumour Registry (WMRCTR) was used (see map). These specialist registries collect all cases of childhood cancer from defined geographical areas and include around 35% of the childhood population of England.

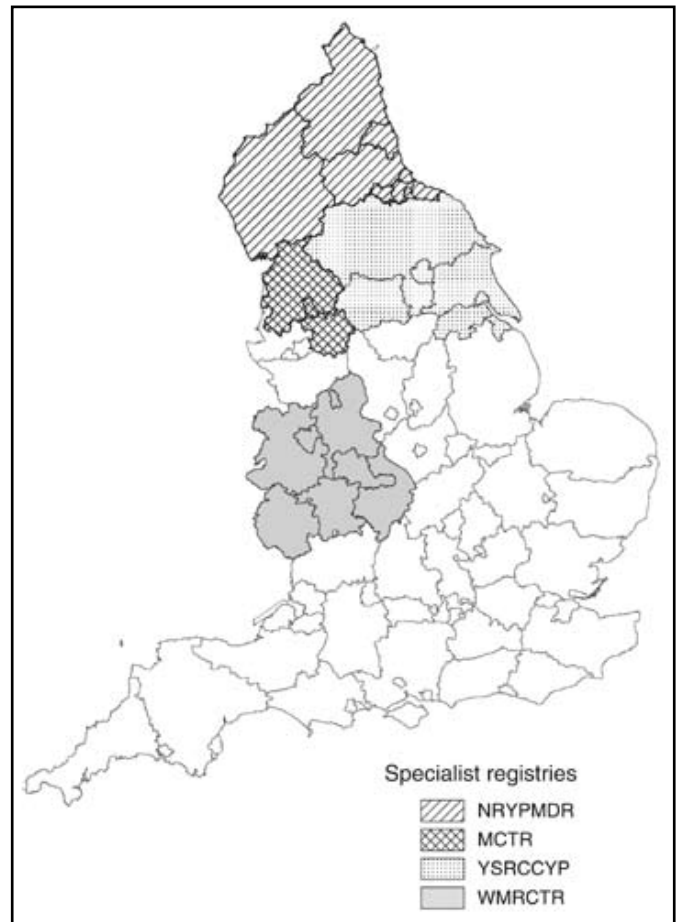
Malignant bone tumours are the seventh most common group of childhood cancers, accounting for around 3-5% of all cancers diagnosed in 0-14 year olds. In the UK every year approximately five children out of every million will develop bone cancer. The major diagnostic types of bone cancer are osteosarcoma and Ewing's sarcoma.

Rigorous statistical methods to analyse incidence and survival were used. There were a total of 374 patients diagnosed with a bone cancer during the period 1981-2002. Of these, 206 (55%) were osteosarcoma and 144 (39%) were Ewing's sarcoma. Incidence of all the diagnostic sub-types was highest in older children (aged 10-14 years) and was rare in those aged under five years. 59% of osteosarcoma patients and 55% of Ewing's sarcoma patients survived at least five years.

The analyses showed that survival in northern England and the West Midlands is lower than other parts of Western Europe. Furthermore, whilst survival from Ewing's sarcoma improved during the study period, there was no improvement in survival for osteosarcoma.

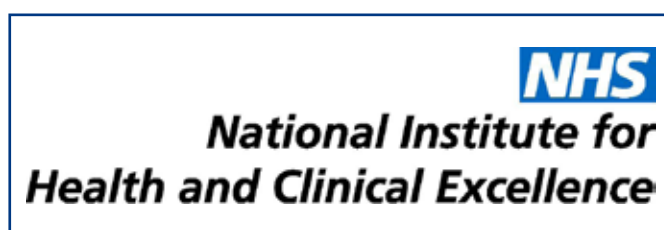
The lack of progress in achieving improved survival needs to be investigated. During the late 1970's and early 1980's chemotherapy was introduced for treating childhood bone cancer, in addition to surgery and radiotherapy. This led to improved survival. However, there has not been much change in treatment since that time. There are a number of specific factors that need to be considered further. The possible contribution of delay in diagnosis to lack of improved survival for osteosarcoma needs to be considered. Long symptom durations may be due to a number of reasons, including site and biology of the tumour. Poorer survival in the UK compared to other parts of Western Europe may also be due to differences in treatment. For example, recent German treatment for Ewing sarcoma has been much more aggressive than in the UK.

The present study has highlighted important issues of concern and has indicated the direction that further research should take. Professor Ian



Lewis, Chairman of the BCRT Scientific Advisory Panel, said "the results from the UK are obviously of real concern and emphasise why it is so important to fund research aimed at improving our understanding about this and to develop new treatments. BCRT was formed with exactly these aims. We must not be happy with second best."

NICE APPRAISAL OF POSSIBLE NEW TREATMENT FOR OSTEOSARCOMA



As we mentioned on page 2 of the Spring 2008 edition of this newsletter, a large clinical trial in the USA had produced positive results which demonstrated an improvement in survival for patients with osteosarcoma who received a new drug called Mifamurtide. During the year, progress was made when the European Medicines Evaluation Agency (EMA) approved registration of this drug. The next stage was for the National Institute for Health and Clinical Excellence (NICE) to examine the cost-effectiveness of making it available to patients in the UK.

BCRT is delighted to have gained recognition as the leading charity on bone cancer and it has accordingly been invited

by NICE to take part in the technology appraisal of the drug Mifamurtide and will also represent another charity, Sarcoma UK. When trialled in North America, results showed five year survival rates for non-metastatic osteosarcoma patients of 78% compared to 70% in those patients who didn't receive it. This is a really significant improvement, so supporting the introduction of this drug as treatment in this country is highly compatible with BCRT's aim of working towards improving the outcome for future sufferers of bone cancer.

Three representatives are required to make statements to the NICE committee, speaking from their experience and within defined roles. These will be:- Professor Tim Eden, Children's Cancer Oncologist of Christie Hospital Manchester - the Medical Expert; Mike Francis, the father of a teenage boy with osteosarcoma - the Parent/Carer Expert and Sally Hurst, who has herself undergone treatment for osteosarcoma - the Patient Expert.

This important meeting will be taking place in February and as soon as we are in a position to report the results we will do this via the BCRT website and in the Autumn Newsletter.

2009 Events

Running, walking, cycling or trekking - we have an event for you!

Join Team Bones and take part in one of our amazing fundraising events in 2009

Below are a few highlights of what we have to offer, for more go to www.bcrct.org.uk/events

Belgium to Berlin Cycle Challenge 15 - 17 May 2009

It is not too late to sign up for the Belgium to Berlin Cycle Challenge. Join us for a fantastic weekend of cycling through Belgium, Holland and Germany covering 520 miles in just three days as a team of 4. The challenge is for teams of four to cycle the 520 miles in three days, whilst raising vital funds for our work. Team entry is just £1,000 (£250 per person), and all we ask is for you to pledge to raise a minimum of £1,000! Contact us now for more information and an entry form.

Runs

5K, 10K, 10 Miles, Half marathon or Marathon... the choice is yours. Dust off your running shoes, or buy a new pair and join over 300 other amazing runners and take part in one of our running events that we have places in this year. We have places available for the following events:

Great Manchester Run: 10K – Sunday 17 May

Run for All – Leeds 10K – Sunday 21 June

Run for All – York 10K – Sunday 2 August

Great North Run: Half Marathon – Sunday 20 September

Royal Parks Half Marathon – Sunday 11 October

Great South Run: 10 Miles – Sunday 25 October

To take part in any of these runs, please contact David Fisher or go to our website for an entry form.

If you have a place in any other running events and would like to run in support of BCRT, please get in touch and we can provide you with fundraising materials, sponsor forms and a t-shirt to help raise awareness of our work.



Overseas

Have you been inspired by Radio One's Chris Moyles and friends climbing Kilimanjaro? Why not follow in their footsteps and those of our supporter, Mark Robinson and his friends Sat and Jindy Mann and take on this amazing challenge for BCRT! Mark, Sat and Jindy took part in the Kilimanjaro Challenge in October 2008 and raised over £1,000.

If Kilimanjaro is not for you, we have plenty of other great challenges for you to consider, all offer a truly amazing experience at the same time as raising vital funds towards our work. Go to the events section on our website for full details of all of our challenges.

Have your say?

Join the BCRT Focus Group and help shape the future of our work. As we look to develop our information and support services, we would welcome your views and ideas to ensure that we meet the needs of our users. To join the focus group or to find out more information, please email kate@bonecancerresearch.org.uk

Trustee News

Recently there have been two changes to BCRT's Board of Trustees.

We are sorry that Rob Grimer, Consultant Orthopaedic Surgeon and one of the founding trustees, has decided he is unable to stand for re-election. We are grateful for all that he has contributed. However, we are delighted that he will be continuing in his other role as a member of the Scientific Advisory Panel, using his professional expertise in evaluating submissions for research funding.

The Board has been pleased to welcome Roger Paul as a Trustee. He brings his experience of finance and investment to BCRT at a time when the best management of the charity's income is of particular importance.

BCRT Job Opportunity

The BCRT are recruiting an **ADMINISTRATOR** to join their team. The Contract is Fixed Term for a period of 9 Months to cover Maternity Leave 22.5 hours per week

Based in our Leeds office, the successful candidate will have at least 2 years administration experience and will be a team player.

Closing Date: 25th March

Interview date: 1st April

For a full job description and details of how to apply, please email kate@bonecancerresearch.org.uk or call 0113 2621852

Getting Active

We're always being told that keeping fit and healthy is important for our wellbeing. But if you find it daunting. You might need to change the way you practice your chosen sport - by adapting your equipment, it, even if you have to try something new. Whether you're aiming for Paralympic glory or just

Laurence Whiteley



In 2006, before my diagnosis, I was the British Triathlon Yorkshire and Humberside champion for my age group. I was 14 years old. But in June of that year I was diagnosed with osteosarcoma. My tumour was at the top of my tibia just below my right knee.

Half way through my chemotherapy I was given two options for my surgery: amputation above the knee or limb salvage surgery where the cancerous dead bone is removed and replaced with metal. I decided to have limb salvage surgery even though I was told that my chances of returning back to any level of competitive sport would be virtually nil.

For the next six months my right leg was in a full hip-to-ankle cast. After I finished chemotherapy I began a 12-month programme of intensive physiotherapy. Basically I

had to learn to walk all over again. Slowly but surely my leg began to get stronger but any question of me running or kicking a football again were gone because I've been left with drop foot.

In the beginning of January 2008 I decided I wanted to get back to sport and start swimming again. This was something I'd done since I was three years old. I started training once a week with Richmond Dales Swim Club and as the weeks went by and I got stronger and fitter the competitive side of me started to come out.

My dad made some enquiries into Disability Swimming and in March 2008 after only six weeks' training I was asked to swim as a guest for Yorkshire at the National Youth Championships at Ponds Forge Sheffield. This gave me the spur to carry on and train hard.

I now do three sessions in the pool each week and three sessions in the gym to help build up my upper body strength. In November 2008 I swam at the National Championships at Ponds Forge where I was up against some of the Beijing Paralympics swim team.

When I get classified I hope to be invited on to the World Class Development Programme. This aims to produce swimmers capable of winning medals at London 2012. For the next three years I still have to attend check ups every three months but with determination and a positive attitude cancer does not have to end your hopes and dreams. If anything it makes you more determined to succeed.

Useful Contacts: British Swimming (National Disability Office) - telephone 01625 440 434 or email disability@swimming.org

I lost my leg to bone cancer in 1990 and felt that my active life was behind me. However within a couple of years I was lucky enough to be contacted about sports opportunities for people with disabilities. I started off by getting involved with amputee football, played on crutches at speed and involving a high degree of fitness and expertise. I was lucky enough to excel at this and went on to play for the England team from 1996-2003 representing them in three world cups and travelling the world to such destinations as Russia, USA, Ukraine & Brazil - all with

the support of the Football Association. The football also introduced me to other amputees and helped me realise that other people had similar struggles to me and gave me an informal support network.

Since 2003 I have also kept fit by taking up distance running on crutches. This involves taking off your artificial leg and using your crutches to propel yourself over the distance. I have completed two 10K runs in Leeds as part of Jane Tomlinson's Run for All, raising money for the Bone Cancer Research Trust in 2007 & 2008. I recorded times of less than 1 hour



30 minutes. I also swim and attend the gym three times a week using rowing machines, treadmills and free weights to keep myself in shape.

I feel it is very important for amputees to remain physically active. Putting on weight after an amputation can cause many problems with the fitting of the leg. This often makes it a lot harder to get a comfy fit. Sport and fitness at any level is important and disability should not be a barrier in any way to participating.

Useful Contact: www.limbless-association.org/pages/la-amputee-football.html

Nick Bones



Marc Woods



I was 17 when I was diagnosed with bone cancer and had a below the knee amputation. That was 22 years ago now and over the years I have come to realise that I am capable of doing anything that I put my mind to. However, when I first got

diagnosed I didn't really know what being an amputee would mean to me. What would I be able to do and not do?

I started swimming the day after I had the stitches out of my leg. It gave me a sense of freedom I felt I'd lost and I thrived on it but more importantly it kept me fit and active which I am sure played an important part in my long-term recovery.

Despite being a county swimmer before my operation, within six months I was swimming quicker with one leg than before when I had two. Eighteen months later I went to my first Paralympic Games.

After five Paralympic Games and 12 medals I retired at the 2004 Athens Paralympics but I needed to find new challenges in my life.

The first challenge has been building my business as a motivational speaker which has me travelling and working around the world. The second is a passion for mountaineering, which in 2009 and 2010 will take me back to the Himalayas to attempt to climb Mount Everest.

Both require an exceptional level of fitness but also an exceptional artificial limb and Dorset Orthopedic have never let me down, providing

me with a leg that I can walk around on all day everyday at work but also undertake some of the hardest mountaineering in the world.

Being active has been a way of life for me and has enabled me to live life to the full. I hope you can enjoy being active too.

Read more about Marc at www.marcwoods.com.

Useful Contact: The British Mountaineering Council - telephone 0161 445 6111 or visit www.thebmc.co.uk



After Treatment

You're adapting to a disability following cancer treatment, getting back into exercise can seem like a challenge. Your bike, for example. Chances are, if you enjoyed sport before your operation, you'll still love it. If you want to enjoy the great outdoors again, these former bone cancer patients will inspire you.

Kelly Cumming



I found a lump on my shin and was diagnosed with osteosarcoma in 2003 when I was 15 years old. I had to have my leg amputated in October 2003.

I then had three more sessions of chemo and two blood transfusions, and then on the 31st of December 2003 I was allowed home. This was a very emotional time as I was still very ill.

I was fitted with my artificial limb and received physio to learn how to walk with it.

Five years on I have a completely different life.

I am always on the move, never at home for very long! I also have my own car, which is a necessity for my independence.

I now have a 'fancy' leg and

a 'sporty' leg from Dorset Orthopaedic. These legs have been funded from many different groups of people - Diced Cap Charitable Trust (Grampian Police charity), The Westhill Community, Friends and Family, Subsea 7, Westhill & District Round table and Rotary and many more! I wouldn't be where I am today without them.

In March 2008 I raised £4,500 for charity by trekking through Cuba for five days; this was a major challenge and an amazing experience. This has encouraged me to undertake more challenges in my life and I am now training to do the New York Marathon in the hope of running it in a few years' time. In order to train for this

I am going to the gym three times a week and trying to go swimming too at least once a week. I am also hoping to walk/jog the Baker Hughes 10K in May and the Moonwalk in June, in order to help me prepare for the Marathon. When I set my self a target I intend to achieve it!

I enjoy speaking to other patients from the hospital to tell them my experience to give them hope and to make them see that your life doesn't end once you've had your leg amputated. I find this very rewarding and it's good to see other people coming through cancer and amputations too.

Useful Contact: Dorset Orthopaedic - telephone 01425 481740 or visit www.dorset-ortho.com



Surgery done, chemo finished, back to school. What about sport? Before all this I was a fit and active eleven year old who loved sport. We all understood that some sports would be out of the question, but I was keen to get active again and with my parents we set about making this happen.

A friend recommended a cycle shop that was able to make a bike to cope with limitations in movement, so we set off (via Stanmore for a leg-lengthening session) to the North West Midlands where we found a happy team of people who were keen to get me cycling! They had me sit on a bike frame that could be adapted in all sorts of ways and decided that I needed a shorter crank on the left pedal, as my knee flexion on this side was about 35 degrees.

A few weeks later we took delivery of the new bike, complete with a specially made short crank which was very impressive. I couldn't wait to try it out! Thankfully we live very close to a park with a perfect flat cycle track, the place where I had first learned to ride without stabilisers years before. I managed a mile on my first day! I had quite extensive surgery to my thigh, having the whole femur replaced, and losing quite a lot of muscle. Cycling has improved my knee flexion as well as general fitness and my knee is now up to 55 degrees. More importantly I am so pleased to be mobile again on my smart new pair of wheels! As my fitness and knee flexion improve, I plan to be out sailing a dinghy again this summer.

Useful Contact: Longstaff Cycles in Newcastle under Lyme, telephone 01782 561966, website www.longstaffcycles.com

Jonathan Currell



Carol Starkey



I am naturally an active person, so when usual activities became increasingly difficult due to constant pain and lack of movement in my right shoulder (I am right-handed), obviously I was frustrated. I love watersports; previously spending my summers gaining qualifications and helping out at a local centre. I was about to take my Windsurfing Instructor qualification; I cancelled when my shoulder trouble started. A backpacking expedition to Honduras for two weeks trekking through the jungle and learning to scuba dive was my last adventure before diagnosis.

Just after starting University in October 2006 when I was 19 I ended up in A&E and was referred to Birmingham for tests. Nine months after I had first noticed the discomfort, I was told I had cancer, osteosarcoma. It all seemed to fit into place; the lack of sleep and pain even at rest. After the initial shock I was just grateful to finally be taken seriously, when I felt my doctor hadn't.

My consultant explained about reduced function after treatment, and admitted I would not windsurf again. I was determined to return to the water, but accepted that I would probably have to change sports.

Whilst still receiving radiotherapy, I climbed 'The Canon' on Tryfan in North Wales. A week camping and walking in the Lake District followed immediately after I finished treatment. A month later I returned to Durham University, my hair was still extremely short but I didn't want to wait another year to return.

Previously at University I had been keen to start coxing for rowing, having been assured the only requirements were to be small and able to shout. I felt like I fitted the bill and thought it would be a great non-physical way for me to get back out on the water. I loved it straight away and now train most days coxing my college's Senior Women's VIII at 6.30am before lectures.

Last June I completed the Three Peaks challenge, raising money for the BCRT.

In the summer I worked on a children's activity camp and was able to participate in kayaking, canoeing, mountain biking and rock-climbing. It was great to be able to do activities that I had done before without a second thought. Having regained confidence on a bike, I cycle to university everyday with a slightly adjusted steering technique! I can drive a normal car and swim regularly; breaststroke is fine and a one-handed crawl.

Now, two years since I had my surgery I am still discovering things I can do. Some everyday tasks like brushing your teeth and handshakes are difficult; I do not have that forwards or upwards movement. I have grown to accept that there are just a few things that I will not be able to do and there are ways around everything else. I plan on going sailing and scuba diving again at some point in the future and I have always wanted to try skiing too.

Useful Contacts: Sailing - telephone 0845 345 0403 or visit www.rya.org.uk/ Sailability, Canoeing - visit www.bcu.org.uk/our-sport/paddleability.

Fundraising Office: 0113 2621852

Fundraising News

As ever, our supporters have been doing amazing things to raise money for us, without which, we wouldn't be able to continue our work. Thank you very much to everyone who has taken part in an event for us or who has supported one of our fantastic fundraisers!

A Run in the Park



On Sunday 12 October, 108 people took part in the first ever Royal Parks Half Marathon in support of BCRT, raising over £50,000 for our work in the process! We would like to thank

all of our runners who joined Team Bones for this great event. The day was helped by some great autumn weather, and our tent in the charity village was bustling with activity as runners prepared for the run and then gathered to meet their friends and family when they had finished.

Team Virgin

We had a great team of 35 runners taking part from Virgin who raised over £10,000, all running in support of the Adam Dealey Foundation which also held its annual golf day two days earlier, raising an additional £18,000. Thank you very much for the support from all at Virgin!

If you would like to join Team Bones for the 2009 Royal Parks Half Marathon on 11 October, please contact us for more information!



Jumping for Rose



Calvin Haggis and Tayo Davey took to the skies on Sunday 18 January, and jumped from 12,000 feet from an aeroplane high above the English Countryside.

Rose Allocca, aged seven, has inspired friends and family to dig deep and even jump out of aeroplanes since being diagnosed last March with osteosarcoma. The efforts of Calvin and Tayo,

who have raised over £15,000 through their skydive have been the main focus while other friends of the family have been holding coffee mornings, running half marathons, and selling everything from Christmas Cards to cakes.

In addition to the Skydive, a further £5,000 was raised by a team of five fantastic fundraisers led by Julia Smith who took part in the Run to The Beat Half Marathon on a very wet Sunday morning in October!



Going through Hoops



Phil Hull and his fellow students at Burleigh Community College in Loughborough held a charity basketball game on Friday 13 February. The match was held in memory of their friend Tom Walker who died on 15 February 2008. The event was very

emotional as Tom was a good friend of all those playing, and they managed to raise a magnificent £500 for our work in Tom's name.

Dancing the Nights away!



Two charity dances were held in Biddenden, Kent in support of Lewis Fuller, who is currently undergoing treatment for Ewing's sarcoma, raising an amazing £7,000 for BCRT. The events, organised by Jason, Lewis's Dad, included auctions, magic by Lewis himself, and an Elvis impersonator. Thanks to Jason and his family for organising these great events to support our work.

Kara Evans

Kara Evans was diagnosed with osteosarcoma in 2007, and is now in remission, getting her life back on track. Kara's auntie, Maha Mancassola, owns a beauty salon and raised an amazing £968 by holding a raffle with prizes of beauty treatments for her customers. Thank you very much to Maha and her customers for their support!

(Picture of Maha Mancassola with her certificate from BCRT)



Hello, Hello, Hello, what's this fundraising here then?

Helen Harrison and her colleagues on the Initial Investigators Course at the Scottish Police College raised over £1,300 for BCRT whilst on their four week course at the end of 2008. They held a quiz night, a race night and an auction along with a raffle to keep them entertained and to raise vital money towards our work. Thank you to all on the course, especially Helen for nominating us in memory of Guy Francis.



Crossfit Challenge



A group of BCRT supporters took on a week-long Crossfit Challenge at their local gym in memory of their friend Rhodri Jones. The challenge included six brutal workouts over six consecutive days. Day one included a one mile run, 100 pull ups, 200 press ups, 300 squats and another one mile run! If that wasn't hard enough, each day got progressively worse until the final day with a workout affectionately known as 'Goliath!'. Over the six days, Owen worked out that he had lifted over 97,000kgs over the week. They raised over £600 from their friends, colleagues and other gym members during the week. Thank You very much for your support, a great effort!

Let's get Quizzical

Ewing's sarcoma patient, Samantha Johnstone recently held a quiz night in Banchory, Aberdeenshire for her friends and family and raised an amazing £2,250 for BCRT. Samantha was inspired to fundraise for BCRT following a tea party that her friend held for us in Awareness Week last year!

Chris Large – on target for BCRT

Chris Large successfully entered his name into the Guinness World Record Book and raised over £1,800 in the process. Chris managed to hit 4,059 targets to gain the record for 'The most number of 40mm targets hit from 30m in a straight 8 hours with a target rifle!'. In tough conditions, with a cold start and a wet and windy finish, Chris and his support team dug deep to find the extra push they needed to succeed. Congratulations to Chris on his new World Record, and for raising such a fantastic amount for our work!

NEWS IN BRIEF

£121 was raised by the George Spencer School in memory of Thomas Clifford

Chris Wade raised £150 by taking part in the Women's 5K in Hyde Park

Churches Together in Longridge raised £150 by holding a fun run in support of Anna Griffin (see photo)



Wigton Moor Junior Football Club raised £1,200 at their second annual pre-season Fun Day in memory of Luke Tunstall

Pam King donated £135 in lieu of presents for her 60th Birthday in memory of Claudia Burnand

Mrs Oliver donated £400 in memory of Samantha Clowe Cheryl Fairbrother raised £340.25 through various events in support of her son, Jordan

£2,134 has been raised in memory of Tamara Bomford-Smith by the 1st Bracebridge Heath Rainbow Guides, Naveby Methodist Church, St John's Community Primary School and Phil Barlow

The Annie Tranmer Charitable Trust made a donation of £1,000

Donations totalling £968 were made in memory of Gareth Wilkinson in lieu of flowers at his funeral

Tessa Hope & Kira Hagan held a Bangers and Mash night, raising a brilliant £566

Carol Steingold donated £80 in support of Anna Griffin

Elizabeth Sadler made a donation of £2,500

Legal Costs Negotiators made a donation of £250

Ann Todd raised £93.50 by holding a jewellery sale in support of Peter Franklin

Blueberry Mortgage donated £30

Diana Hunt made a donation of £800 towards our research work

Rosey Godsmark completed a tandem skydive and raised £125

St Wilfred's in Longridge raised £70.90 at the Family Mass Collection in support of Anna Griffin

£100 was donated by Karen Kennedy in memory of Claudia Paul

The Brent Charlie Charitable Fund donated £250 in support of Sarah Gordon's fundraising event

£75 was donated by Mr & Mrs Malins instead of sending Christmas Cards

£1800 was raised by David Curran who took part in the Pikeman Challenge in memory of his daughter, Nicola

The Burnand family, Alice Murphy and the Shirley Pipe Band raised £265 in memory of Claudia Burnand

£161.25 was donated in lieu of flowers in memory of Frank Brezine

£668 was donated by friends and family in memory of Paul Donnelly

Cherry Trees Preparatory School raised £21.50 by selling Christmas decorations

Mrs S Scott made a donation of £20 in memory of Guy Francis

Jill Miley took part in a tandem skydive and raised a fantastic £255.30

£1,576 was raised by Colin and Sandra Smith who took part in the Great Scottish Run

Over £3,400 was raised by Team Bones runners in the Great North and Great South runs

Nearly £10,000 has been raised by friends and family of Paul Gavin supporting him as he goes through treatment for osteosarcoma

Hannah Chamberlain has made a donation of £1,337

Helen Atkinson made a donation of £30 in support of her son

Lucy Coyne and Hannah Firth both took part in the Robin Hood Half Marathon raising £400 for BCRT

Riversidesoul raised £261 in memory of Emily Blunt

Jamie Evans, Lee Morris, David Meredith and Glyn Meredith raised over £1,300 by taking on two half marathons and a marathon in one month in memory of their friend Rhodri Jones

The Edge Pub held a school disco and raised £896, and Bormere Heath C of E Primary School raised £93 at their superheroes day both in memory of Nick Pollard

Cyril and Val Hayles donated £467 which they received in lieu of presents for their Ruby Anniversary in memory of Adam Panther

Danny Gallagher raised £528 in memory of Kenny McCabe through 3 Euro 2008 syndicates

Jenny Steer (see photo) raised over £1,000 and Laura Bryce raised £160 by taking part in last year's Run to the Beat in the pouring rain!



Winstanley Tennis Club raised £105 at their Joe Wright Shield competition

Jack Steele completed a fun run and raised £25, Subs Sandwich Bar collected £51 in their collection box & Georgie Steel raised £15 by Carol Singing all in memory of Jennifer Carvell

Nutfield Priory Health and Leisure Club have recently donated £69 collected in their collecting tin which they hold in memory of Martin Matthews.

Richard Forth raised £2,000 at a Posh Frocks and Black Tie night held at Hull Kingston Rovers Stadium, and included a Kylie Minogue Tribute Act

What our supporters have planned!

These are just some of the events and activities that our supporters have planned for the next few months! Good luck to all of our fundraisers who are supporting us in 2009. If you would like to organise your own event, please get in touch with the fundraising office and we will be able to provide you with all you need to get you going.

London Marathon 2009

On Sunday 26 April, ten fantastic BCRT supporters will be joining 32,000 other amazing people taking part in the Flora London Marathon. The day will be the climax of months of hard work training, injuries, and fundraising, and will be a great experience for them all. BCRT wishes all of our London Marathon Runners the best of luck for the 26th and we look forward to you sharing your experiences with us. Thank you very much for your support.

If you would like to sponsor any of our runners, you can find their just giving pages on our website!

Brathay Windermere Marathon

Chris Newman will be taking part in the 2009 Brathay Windermere Marathon on Sunday 17 May. This picturesque marathon follows a fantastic route around England's largest lake, Windermere in the Lake District.



James Bond Casino Night

Maria Harvey is organising a night of 007 entertainment including music from the hot new band, The Vanity Girls and solo artist Kat Kennedy at the Godolphin Club in Helston on Saturday 4th April. The event is in memory of Gary Scott and they are hoping for a great turn out and hope to raise a fortune on the casino tables!

Andy's Angels



Andy Greig was diagnosed with osteosarcoma in February 2008 at the age of 41 and has had his right knee replaced with a titanium one and has had six months of chemotherapy.

This was followed in November, by the removal of secondary tumours in both lungs. Andy is now finishing a course of radiotherapy and is feeling fit and well. A good friend of Andy's felt that he should do something to support him, and as such, Andy's Angels was created. They are a loosely-knit team of runners, including, Stuart Pendred, along with Andy's wife and sister, taking part in several races throughout the year. Good luck to Andy's Angels! You can keep up to date with their efforts on the fundraising section of our website over the year.

Rock n Roll Night

Nick Allsopp is organising a Rock n Roll night at the Limes in Market Drayton on Saturday 21st March in memory of his friend, Nick Pollard.

Ewing's Walk (Harrogate)

Ten teams of friends, family and colleagues will be taking part in Ewing's Walk 2009 in aid of a number of charities, including BCRT. The group are planning walks of



between 25 and 100km over the weekend of 4th and 5th of April on the outskirts of Harrogate. They are all walking in support of five year old Triya, who was diagnosed with Ewing's sarcoma in April 2008.

The organisers are asking for volunteers to help over the weekend, if anyone is interested please visit www.ewingwalk.com

Land's End to John O'Groats Cycle Ride



On June 22nd 2009 Dr Stephen Griffin and his friend Dr Cameron Wilson are setting out on a cycle ride from Land's End to John O'Groats

(1100 miles) in support of Stephen's daughter, Anna, who was diagnosed with osteosarcoma in March 2008 and has just finished her treatment. They are taking on the ride with the support of Stephen's brother, Andrew Griffin who will be keeping them stocked up with supplies of Sudocrem and energy drinks. They are aiming to complete the ride in less than 2 weeks. The aim of the ride is to raise money for The Bone Cancer Research Trust and to help raise awareness of bone cancer.

Donate as you shop

Easyfundraising

BCRT has teamed up with Easy Fundraising to provide our supporters with the chance to donate to BCRT

easyfundraising
.org.uk

every time they shop online at over 600 Brand Name retailers. Easy Fundraising provides a FREE service where you can shop with your favourite online stores and at no extra cost raise funds for BCRT. All you have to do to raise vital funds for our work is to do any online shopping that you would normally do via www.easyfundraising.org.uk/bcrt. For every purchase you make, the shop will make a donation to BCRT.

Maverick Interiors

Maverick Interiors is a small family business specialising in making unusual, contemporary hand crafted metal work art sculpture and functional metal art for the home or corporate environment. If you are interested in viewing their art or craft work then please visit their website and if you wish to make a purchase, 10% of the sale price will automatically be donated to Bone Cancer Research Trust in memory of Jennifer Carvell. For more information go to www.maverickinteriors.co.uk



Legacies

By making a Will and leaving a gift to The Bone Cancer Research Trust you will help us to plan our research funding over the longer term. Together we can bring better treatments and outcomes to all those living with primary bone cancer. If you decide to make BCRT a beneficiary of your Will, any money left is untaxable and therefore of extra value to us.

We have produced a guide to making a will which will take you through the process of making or changing your will. It is available on our website, or you can request a copy by contacting the office.

Focus On...

Family & Friends of Krystle Smith



The story began at Christmas 2000, the first time in her life at aged 17 years Krystle attended a local GP with the flu and a back pain. The doctor made no diagnosis and just gave a course of antibiotics. The back pain continued intermittently for the next four months and we put it down to carrying a heavy school bag.

A swelling appeared on Krystle's back at the end of April 2001. On the 10th of May 2001 Krystle was x-rayed and at first nothing was found, but after I investigated the matter it was suddenly re-examined and found Krystle had Ewing's sarcoma on the 10th rib. Results first showed it was only on one part of the rib, but on a bone marrow biopsy on the 24th of June it was discovered that Krystle had a one cell cluster of Ewing's sarcoma in the bone marrow. We were told in July 2001 that Krystle would only be offered chemo and radiation treatment and that she had about six months to live.

Krystle began six courses of chemo and tests done in September 2001 found that her bone marrow was clear and there were no signs of Ewing's anywhere else. She started five weeks of radiation treatment in January 2002. Krystle died on the 15th of March 2002, aged 18 years.

We as a family never received any information about the disease at anytime throughout the treatment and Krystle was not offered any clinical trials. I came across The Adam Dealey Foundation website and phoned John Dealey. In time John asked me to help with fundraising for research. In 2004 we joined with other families to form a national charity, BCRT, and since then we have been working to bring about better treatments and in time a cure.

The words of John F Kennedy inspire me "All this will not be finished in the first one hundred days. Nor will it be finished in the first thousand days, nor in the life of this administration, nor even perhaps in our lifetime on this planet. But let us begin"

PATRICIA SMITH



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.

BCRT Conference 2009 - Sopwell House, St Albans

The 2009 Patients' and Supporters' Conference is taking place on **Saturday 27th June** at Sopwell House in St Albans. The one day conference is for bone cancer patients, their families and friends. The conference will include:-

Talks by current and former patients

Plenty of opportunity to meet other patients and families and put questions to the specialists

Presentations by international experts about diagnosis and treatment

News of the latest medical research

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

Please go to www.bcr.org.uk or call **0113 262 1852** for more information and to book your place(s).

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

Registered Charity Number: 1113276

Registered Charity Address: Bone Cancer Research Trust, Children's Day Hospital, St. James's University Hospital, Beckett Street, Leeds, LS9 7TF

Bone Cancer Research Trust, Fundraising & Administration Office, Suite 7, Gledhow Mount Mansion, Roxholme Grove, Leeds, LS7 4JJ

Tel: 0113 2621852 Fax: 0113 2625391 Email: info@bonecancerresearch.org.uk Web: www.bcr.org.uk