

UNITED

UNTIL THERE'S A CURE

“ I HAVE ALWAYS FOUND THE BONE CANCER RESEARCH TRUST TO BE AN EXCELLENT SOURCE OF INFORMATION AND SUPPORT FOR FAMILIES.

MEET HANNAH,
SARCOMA CLINICAL
NURSE SPECIALIST

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DAVE TELLS US WHY
HE'S FLYING HIGH

TERRI IS STAMP-ING OUT
PRIMARY BONE CANCER

LUKE EXPLAINS WHAT
A DAY IN THE LAB
IS LIKE FOR HIM

PLUS MUCH MORE...



**BONE
CANCER**
RESEARCH TRUST
UNTIL THERE'S A CURE

EDITOR'S NOTE

Welcome to the second issue of your free magazine from the Bone Cancer Research Trust. We are excited to share with you in this issue our plans for 2018, the release of an interactive *Step-By-Step Guide for Patients*, the launch of our 2018 campaign **Be One In A Million** as well as interviews and research news.

There has been a lot happening, including a recent behind-the-scenes look at the pioneering research being carried out into primary bone cancer at The University of Sheffield Medical School as they opened their doors to us and our supporters. Turn to page 9 to find out more about the day.

We caught up with Luke, our PhD research student and he tells us more about what a day in the lab is like for him and the importance of funding from the Bone Cancer Research Trust. Turn to page 8 for the full interview.

On page 10 Sarcoma Clinical Nurse Specialist, Hannah, provides us with more information about why she wanted to be involved in reviewing our first children's information resource. Finally, you can find out how Terri is stamp-ing out primary bone cancer through volunteering with us on page 15.

We received some fantastic feedback from our first issue, and we love to hear from our supporters. If you would like to share your story in United or have any ideas for topics for us to cover, please let us know by emailing info@bcrt.org.uk.

We would also like to say a special thank you to Hannah Ellis, Luke Tattersall, Dave Harley, Lucie Gosling and Terri Bush for their contributions to the Spring issue.

Deborah Flyde, Communications Manager



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NEWS IN BRIEF

AWARD WINNING INFORMATION AND THE RELEASE OF A NEW GUIDE

We are delighted to announce that our website information resources covering all forms of primary bone cancer and our guide to clinical trials has been **'Highly Commended'** by the British Medical Association Patient Information Awards, 2017. In 2018, we are expanding our information services and will release an interactive *Step-By-Step Guide for Patients*. This guide will take patients and their loved ones through diagnosis, treatment and recovery to ensure they have access to the information and services they require.



FUNDRAISING

In 2017, we received an amazing amount of support for The Biggest Fight Against Bone Cancer - Ever campaign and we raised over £930,000 for our life-saving work! During Bone Cancer Awareness Week, in October, many people showed their support by fundraising and joining our campaign 'Bake It For Bone Cancer'. During the week we also had a BBC Radio 4 Appeal fronted by celebrity chef, author, and Great British Bake Off judge, Prue Leith and raised an incredible £17,638. This year **Bone Cancer Awareness Week** will be **8th - 14th October 2018**. On Giving Tuesday, a day in November 2017 dedicated to supporting the work of charities, our supporters raised £17,221 in just one day! Thank you to everyone who supported us and raised funds.



BE ONE IN A MILLION

In order for us to deliver *The Biggest Ever Commitment To Primary Bone Cancer* and continue on the success of last year, we have launched a new campaign **Be One In A Million!** Can you help us raise £1,000,000 in 2018? Join one of our events, hold a bake sale, organise a non-uniform day at your children's school or nominate us to be your employers charity of the year. Find out on pages 6 and 7 how you can get involved - **every one makes a difference!**



SPONSOR A RESEARCHER

You can now become a Research Sponsor. Your sponsorship ensures that we have the funding available to enable our researchers to make new discoveries and uncover new treatments for patients. In 2017, we received 9 times the number of applications that we could fund, totalling over £2 million; this means that a vast amount of promising research is being left unfunded and potential breakthroughs missed. We are determined to fund more urgently needed research. From as little as **£5 a month** you can **Sponsor A Researcher** and 100% of your sponsorship goes directly to our life-saving research. **Sponsor A Researcher** at www.bcrf.org.uk/sponsor



OUR 5 YEAR STRATEGY

2017-2022

RESEARCH WE WILL...

- Commit over **£2.8million** to **pioneering research** through an innovative new grant programme
- Support research at **all levels**, from initial idea through to clinical trial
- Deliver the **next generation** of world class, primary bone cancer researchers
- **Support UK surgical centres** to enable all primary bone cancer patients to contribute tissue samples for use in research

INFORMATION WE WILL...

- Develop a **Patient / Parent Pack** to offer comprehensive information to all patients on their specific primary bone cancer or tumour type
- Expand our existing portfolio of information for patients of **all ages**
- Ensure that information is available for the **clinical and medical community**
- Develop information for **carers and families** of patients with primary bone cancer
- Expand our basic information to ensure patients **in other countries** have access to relevant information
- **Signpost** relevant information that falls outside our remit

AWARENESS WE WILL...

- Ensure **all GPs in the UK** have access to the training and tools they need to identify and diagnose primary bone cancer
- Develop tools to allow **radiographers, physiotherapists** and **other medical professionals** to identify the symptoms of primary bone cancer
- Continue to fund and develop training options for **medical students** in the field of primary bone cancer
- Increase national and where possible, international, **public awareness** of primary bone cancer and the Bone Cancer Research Trust

SUPPORT WE WILL...

- Provide a **listening ear service** that allows current patients or family members to talk with someone that has been through a similar experience
- Develop digital 'community' **support groups**
- Deliver an **annual conference** aimed at uniting and supporting our community
- Actively promote the sharing of **patient stories and experiences**
- Ensure robust signposting to **other support groups and charities** where we cannot provide assistance

Our ultimate ambition is to find a cure for primary bone cancer. In 2018 we continue with our 5 year journey - *The Biggest Ever Commitment To Primary Bone Cancer*. Below is a reminder of how we will save lives and come closer to finding a cure.

We have made significant progress since 2006 and we are engaging even more with our community. In 2017 we continued to be the only organisation offering information on all types of primary bone cancer. We are making a real impact.....

IN 2017 WE...

- Funded **8** research projects across the United Kingdom
- Reached **£3.5million** invested into primary bone cancer research since 2006
- Reached **61** projects funded working in collaboration with 93 researchers
- Held **3** inspiring laboratory open days
- Awarded our first ever '**Infrastructure Grants**' at 4 of the 5 Sarcoma Centres in England

IN 2017 WE...

- Saw **75,089** uses of our online information and support web pages
- Received **2,780** enquiries and requests for our printed information and support materials
- Published our first children's recourse ***Harry Has An Operation***
- Had **5,003** information leaflets downloaded from our website
- Were '**Highly Commended**' by the British Medical Association at the Patient Information Awards for our website recourses

IN 2017 WE...

- Launched a new healthcare professional webpage which was viewed **667** times
- Continued to promote our **GP e-learning module** which has now been completed **900** times increasing understanding of primary bone cancer by **70%**
- Reached **1.2million** people during Bone Cancer Awareness Week
- Launched ***Do you know the symptoms of primary bone cancer?*** a symptoms awareness video which was watched over 73,000 times
- Received **4.5million** hits on our new website from an international audience

IN 2017 WE...

- Provided direct support to **147** individuals
- **Increased our contact** with patients, families, carers and friends of those affected by primary bone cancer
- Held the Bone Cancer Conference, bringing **196** of the primary bone cancer community together
- Held our first '**Patient and Carer Day**' in Scotland



In 2018 we have launched our new campaign **Be One In A Million**. For us to continue delivering ***The Biggest Ever Commitment To Primary Bone Cancer***, we need your help. Like our fundraisers below we are asking you to Be One In A Million and help us raise £1,000,000.

TIM ALBISTON

Tim has been raising funds in memory of his son Alexander Albiston who sadly passed away of osteosarcoma in March 2010, aged 18 Years. Tim has organised and taken part in many events, from the Yorkshire Three Peaks, the World Triathlon Leeds, London to Amsterdam Bike Ride and even a Motown Night! £33,173 was raised during 2017 in memory of Alexander Albiston.



CATRIONNA MCNABB

During Bone Cancer Awareness Week Catrionna organised a Bake It For Bone Cancer event at Collis Primary School. Catrionna's daughter, Lizzy attended the school and was diagnosed with Adamantinoma at just 7 years old. The children in Year 6 helped to host the event and created posters which were put up around the school. Lizzy also came back to the school to help out. The cake sale was a great success and the table was completely cleared of the cakes that the children had baked. They raised a fantastic amount of £236.88 whilst increasing awareness of primary bone cancer.



SUSAN AND BRIAN

Susan and Brian have been busy raising funds and awareness for the Bone Cancer Research Trust. They arranged bucket collections at their local supermarket, organised a Summer Garden Party and a St David's Day Tea Party, coordinated a raffle and they ended last year with a carol concert at Saundersfoot Pier. Susan and Brian raised £9,386.39 during 2017 in memory of Daniel Bridle, aged 18, who sadly passed away of osteosarcoma.



“ It gave me a chance to shout about the Bone Cancer Research Trust. The parents were very encouraging and supportive - many of whom remembered my daughter who was diagnosed 5 years ago and spent much of her time at Collis Primary School on crutches. ”

If you want to be part of #TeamBones and **Be One In A Million** by helping us raise £1,000,000 please contact us on **0113 258 5934** or visit our website **www.bcrct.org.uk**

2017 CHALLENGE EVENTS

RUNNERS



370

CYCLISTS



89

TRIATHLETES



58

MUD RUNNERS



99

SKYDIVERS



7

SWIMMERS



36



YOU WERE ALL AMAZING IN 2017
EVERY ONE MAKES A DIFFERENCE!

TRIBUTE AND CELEBRATION FUNDS

A HUGE THANK YOU TO ALL THOSE FUNDRAISING IN MEMORY OR CELEBRATION OF...

ALEX ALBISTON
MATT ARROWSMITH
EMILY BARKER
JENNIFER CARVELL
MARY COLLARD
LAWRENCE COTTLE
RUTH GRACE CROSBY

KEN DAVIES
ALEX DAWSON
ADAM DEALEY
DILA
GUY FRANCIS
CHRISTOPHER HARDMAN
ADAM HASSALL

RHODRI JONES
ALEX LEWIS
KENNY MCCABE
ADAM PANTHER
GEMMA PICKERING
ANTHONY PILCHER
NICK POLLARD

LIBERTY SCHURER
KRYSTLE SMITH
CHRISTOPHER SPRATT
TOM STEAD
JAMES STEWART
JOSEPH WRIGHT



Q&A WITH OUR PHD RESEARCH STUDENT LUKE TATTERSALL



“ Without funding and support from BCRT my PhD research and other research currently being done to look specifically into primary bone cancer simply wouldn’t continue.

We caught up with Luke Tattersall, our PhD Research Student from The University of Sheffield and he told us more about a day in a lab and why funding is important.

WHAT DOES A DAY LOOK LIKE IN YOUR LAB?

My time in the lab involves checking my osteosarcoma cell lines are growing and are suitable for various experiments. I will then spend most of the day at the lab bench using these cells in experiments that assess important osteosarcoma characteristics – such as how quickly they grow or how much they can migrate. Some experiments can be repetitive, but it’s exciting when experiments work, and you are generating new results. In order to get the best possible data, sometimes I have to work around the clock, visiting the lab every 2 hours, even through the night to take experimental readings. Other tasks include analysing the data from the experiments, attending lab meetings, or guest lectures, reading publications and writing parts of my thesis chapters or abstracts.

WHY DO YOU THINK FUNDING IS ESSENTIAL?

Without funding and support from BCRT my PhD research and other research currently being done to look specifically into primary bone cancer simply wouldn’t continue. Without this funding it is also possible that future research ideas and opportunities will be missed. Funding is crucial to help find a cure, support research careers and encourage the next generation of researchers in the field of primary bone cancer.

WHAT DIFFERENCE DO YOU THINK YOU WILL BE MAKING TO PEOPLE’S LIVES?

My PhD research aims to uncover a suitable target for new osteosarcoma drugs to act on, when this molecule has been targeted in other cancers the results have been

very promising. We are aiming to further develop this and therefore, the research could make a massive difference as a new treatment option for osteosarcoma patients.

WHAT DOES THE BIGGEST EVER COMMITMENT TO PRIMARY BONE CANCER MEAN TO YOU?

To me this demonstrates how dedicated to making a difference BCRT is and that BCRT will continue to build on their previous achievements, leading to further significant progress and breakthroughs.

WHY DO YOU THINK PUBLIC ENGAGEMENT IS IMPORTANT?

In our lab group there is a huge emphasis on public engagement and we regularly hold lab open days. It is important for us to do this to share news and updates on progress we have made. It also gives BCRT supporters the opportunity to see first-hand exactly how the money they have raised is used to enable the research to be carried out and also the facilities it supports and the techniques we use on a day to day basis.

IS THERE A MESSAGE YOU WOULD LIKE TO SEND TO THE SUPPORTERS OF THE CHARITY?

I would just like to say a massive thank you for all their hard work and effort in raising funds to support BCRT and researchers like me. Every donation whether small or large can really make a difference. Personally, to me it means that I can work hard to hopefully find a new treatment for osteosarcoma, and to be the best researcher I can be to make a difference both now and in the future.

You can find out more about Luke’s work and our other research projects at www.bcr.org.uk/research



LABORATORY OPEN DAY



Professor Alison Gartland and The Department of Oncology & Metabolism at The University of Sheffield Medical School, opened their doors for the Bone Cancer Research Trust and our supporters to get an interactive behind-the-scenes look at the pioneering research they are carrying out into primary bone cancer.

The day saw patients, parents, siblings and all those interested in the research the Bone Cancer Research Trust are funding at The University of Sheffield come together to visit the laboratory and see first-hand the amazing work our supporters fund. At the event, talks were held from PhD students Luke Tattersall, Daniëlle De Ridder and Kristina Schiavone to update the audience on their work which aims to identify new treatment targets for osteosarcoma. There was also the opportunity to tour the lab for a personalised experience and insight into the different techniques used to study primary bone cancer and the results Professor Gartland and her team can gain from these experiments.

“IT’S REALLY IMPORTANT TO ME AND MY LAB THAT WE ENGAGE WITH BOTH PATIENTS AND THE CHARITY TO LET THEM KNOW WHAT WE ARE DOING AND HOW THEIR MONEY IS BEING SPENT”

**PROFESSOR GARTLAND,
THE UNIVERSITY OF SHEFFIELD**

“PLEASE KEEP RUNNING THESE DAYS AS IT WAS AMAZING. IT WAS A REALLY THOUGHT PROVOKING, INTERESTING AND INFORMATIVE AFTERNOON AND I AM IN AWE OF THE SCIENTISTS AND THEIR DETERMINATION TO HELP FIND THE BREAKTHROUGH THAT BONE CANCER NEEDS.”

PETER, A FORMER OSTEOSARCOMA PATIENT

Thank you to all those who attended the open day and to Professor Gartland, Dr Shelly Lawson, Dr Karan Shah, Luke Tattersall, Daniëlle De Ridder, Kristina Schiavone, Darren and Alex for welcoming us into their lab.

RESEARCHER SPOTLIGHT

PROFESSOR FLANAGAN AWARDED AN OBE DURING THE QUEENS BIRTHDAY HONOURS



Professor Adrienne Flanagan (Professor of Musculoskeletal Pathology at UCL Cancer Institute and Consultant Histopathologist at the Royal National Orthopaedic Hospital) was awarded an OBE for her services to cancer research on the 7th November 2017.

Professor Flanagan first began working with the Bone Cancer Research Trust in 2007 and has since carried out 6 research projects funded by the charity and has been the co-lead on many others. Her research focuses on identifying the genetic alterations involved in

the development and progression of bone and soft tissue tumours. These efforts have led to multiple high impact publications and many of these findings have already been translated into clinical practice.

Speaking about the award, Professor Flanagan said: **“It’s a terrific honour - one which wouldn’t be possible without the knowledge and experience of the exceptional people with whom I have had the privilege to work with, and the help and commitment of research organisations which have supported my research over the years”.**

We are over the moon to hear of Professor Flanagan’s well-deserved award and we will continue to work together to push forward primary bone cancer research.



Q&A WITH SARCOMA CLINICAL NURSE SPECIALIST HANNAH ELLIS



“ Having any operation is always a scary time, so knowing what to expect and having resources available to help children process this information is really important.

We spoke to Hannah Ellis, Sarcoma Clinical Nurse Specialist at The Royal National Orthopaedic Hospital, Stanmore. Hannah volunteers with us to review our information resources, including our new children's resource *Harry Has An Operation: A Guide For Children With Bone Sarcoma*. With the help of healthcare professionals such as Hannah we have been able to create award winning information materials supporting patients of all ages.

CAN YOU TELL US A BIT MORE ABOUT YOURSELF AND WHAT A TYPICAL DAY LOOKS LIKE FOR YOU?

I work as a paediatric and adolescent sarcoma clinical nurse specialist, so I work with children, teenagers, and their families throughout the diagnosis and treatment of their bone cancer. One of the things I love about my job is that no two days are ever the same, but a typical day will usually involve spending time with families either on the ward or in clinic. I often meet families when they are admitted to hospital for investigations to diagnose their tumour. This is a scary time and families really appreciate someone to talk through what's happening and what might happen next. Many parents will call for advice or support so I spend time speaking to families on the phone, addressing concerns or queries. I also spend time in meetings with other professionals, discussing patients and their upcoming treatments and care.

WHAT MADE YOU WANT TO GET INVOLVED IN REVIEWING OUR FIRST CHILDREN'S INFORMATION RESOURCE AND HOW DID YOU HELP OUT?

I have been using information booklets produced by



BCRT for years now and have always found them to be an excellent source of information and support for families. These tumours are rare, so reliable information specific to these tumour types can be difficult to find, which is why the resources produced by

BCRT are so valuable. When BCRT approached me to be involved in reviewing this new booklet I was thrilled to be involved as I think there was a real gap in the market for this. I was able to look at the draft copies and provide feedback to ensure the content was accurate and included all the important points.

WHY DO YOU THINK IT'S IMPORTANT FOR PATIENTS, AND THEIR FAMILIES, TO HAVE ACCESS TO RELIABLE INFORMATION SUCH AS *HARRY HAS AN OPERATION*?



Having surgery for their bone tumour is a huge part of treatment and it's really important that children, and their parents, feel prepared for this. Having any operation

is always a scary time, so knowing what to expect and having resources available to help children process this information is really important. Now this new booklet has been completed I have been able to share copies with the play specialists who are able to use the booklets when talking to children about their upcoming operation. So far these have been well received and have proved a valuable tool in the preparation process.

If you are a healthcare professional or someone affected by primary bone cancer and would like to help us review our information, please contact us at info@bcrt.org.uk

DAVE TELLS US WHY HE'S FLYING HIGH



Now a qualified private pilot after successfully passing his medical following his diagnosis and treatment of Ewing sarcoma, Dave tells us about his journey from his early symptoms to life after primary bone cancer.

WHAT WERE THE FIRST SIGNS OR SYMPTOMS YOU EXPERIENCED?

The first signs of a problem appeared in 1982 at the age of 32. Around 18 months before diagnosis I started to get intermittent pain in my left knee. My doctor diagnosed "loose ligaments" and advised wearing a knee support. Despite this there was no improvement and further visits to the doctor were inconclusive. I decided I would have to live with it.

HOW WERE YOU DIAGNOSED?

Following a game of squash the pain became very severe. My doctor suggested a possible strained muscle, prescribing painkillers and advising me to rest my leg for 2 weeks.

The pain increased and 2 days later the doctor referred me to A & E. After an examination, including an X-ray, I was sent home with some stronger painkillers and a referral to a Sports Injury Specialist who provisionally diagnosed a stress fracture of the left femur, immediately referring me to an Orthopaedic Consultant, who then arranged for a biopsy resulting in a diagnosis of Ewing sarcoma. The affected part of my femur was removed during the biopsy.

WHAT TREATMENT DID YOU HAVE AND HOW DID IT MAKE YOU FEEL?

My chemo regime was to be every 3 weeks for 2 years combined with 3 weeks of radiotherapy. My first treatment was as an inpatient, it was awful. I was violently ill and the following day I barely had the energy to talk. From then on I would have my chemo as an outpatient. I gradually got into a steady routine spending 2 weeks at

work, chemo on a Tuesday and then a week off to recover. Then 8 months into treatment my femur broke apart at the original tumour site. Amputation was discussed, but during surgery the bone was secured with 4 titanium rods called Enders Nails.

WHAT IS LIFE LIKE AFTER YOUR TREATMENT?

After the initial euphoria I became depressed, possibly due to perceived lack of attention and feeling insecure without regular treatment. This lasted for a few weeks and I gradually returned to a relatively normal life with regular check ups until 1995 when I was finally discharged, 12 years after initial diagnosis.

To celebrate my 50th birthday I fulfilled a long term ambition and commenced flying lessons. However, I was informed that prior to going solo I would have to undergo a full medical by a Civil Aviation Authority approved Doctor. Following extensive questions about my medical history and a delay whilst enquiries were made I was finally declared medically fit to fly, going solo on the 30th July 2001 and qualifying as a Private Pilot in 2003.

HOW ARE YOU FEELING NOW?

Now aged 67 it is 34 years since my original diagnosis. I am very lucky, I still have my leg. There are of course some long term effects and the pain in my leg varies from day to day. I'm retired with many interests and leading an active life. I have been lucky enough to see my two daughters grow up and now enjoying the same with two grandchildren.

You can read Dave's full interview at www.bcrct.org.uk/patientstories



RESEARCH NEWS

INFRASTRUCTURE GRANTS

At the Bone Cancer Research Trust we are committed to ensuring that all patients have the chance

to donate samples for use in high-quality research projects. However, this is a resource intensive activity which centres have struggled to support, meaning many patients have not been approached to consent to sample donation and research projects have faltered.

We have provided funding through our new Infrastructure Grants to the surgical centres across England to ensure a collaborative network of sample collection is possible. There are a large number of world class projects that rely on patient samples to give the best picture as to what is happening in the cancer cells and how new drugs may be designed to target these cells.

Our Infrastructure Grants will allow centres to direct funds according to where they need them to support these research projects. While these grants will not go directly to a singular research project, they are already supporting national osteosarcoma, chondrosarcoma, Ewing sarcoma and chordoma projects that may not have been possible without our investment. More details on these exciting projects will be coming soon.

OSTEOSARCOMA RESEARCH FINDINGS FROM OUR FIRST EVER PHD STUDENTSHIP

With little recent improvement in osteosarcoma outcomes, identifying new drugs is critical. Back in 2013 we funded our first ever PhD student, Dr Harriet Holme, to carry out a project aiming to identify potential targets for drugs to treat osteosarcoma that could be translated into clinical use.

Dr Holme began her research by comparing genes that osteosarcoma cells were dependant on to those from other cancer types. She found that osteosarcoma cells were more reliant on genes from skeletal development pathways, such as FGFR1 and that these tumour cells

were more sensitive to drugs which target the FGFR1 gene. She also looked at the Retinoblastoma 1 gene (RB1) which is frequently mutated in osteosarcoma patient samples. Dr Holme found that osteosarcoma tumour cells that had a RB1 mutation were especially dependent on a gene called DYRK1A and targeting DYRK1A increased the death of osteosarcoma tumour cells. Both findings form evidence that paves the way for further work confirming if drugs targeting FGFR1 or DYRK1A may be potential treatments for osteosarcoma.

This research has resulted in the production of the first ever genetic dependency maps of multiple osteosarcoma tumour cell line models on this scale. This data-set has now been made a publically available resource to aid future research in the genetics of osteosarcoma and has led to a number of very attractive drug targets that have the possibility of entering clinical trial in the future.

Dr Sandra Strauss, Harriet's PhD supervisor said **"Harriet has made a significant contribution to our understanding of genetic dependency in osteosarcoma."**

We would like to congratulate Harriet on passing her PhD and also for the excellent research she produced.

RESEARCH PLANS AND FUNDING FOR 2018

A major part of our 2017-2022 strategy is our commitment to research. To date, researchers have not had the necessary funding and career pathways in place to enable research or specialism in the field of primary bone cancer. It is crucial we support this research and in order to do so we have committed to funding over **£2.8 million over the next 5 years.**

To kick-start this, we are delighted to announce that the Bone Cancer Research Trust held a call for PhD studentships towards the end of 2017 and plan to award this studentship in 2018. A PhD allows researchers to gain the qualification they need to continue their research career while researching a specific area of primary bone cancer for up to 4 years. 13 applications were submitted; the most we have ever received. More details of the PhD student receiving the award will be shared soon!



Q&A

WITH EXTENDED
SCOPE PRACTITIONER
LUCIE GOSLING



Lucie is an Extended Scope Practitioner (Specialist Physiotherapist in a Young Adult Hip Service) at The Royal Orthopaedic Hospital in Birmingham. We spoke to her about the work physiotherapists can do to help with earlier diagnosis, as well as their crucial role in rehabilitation.

CAN YOU EXPLAIN WHAT KIND OF WORK YOU DO AS A PHYSIOTHERAPIST DEALING WITH PRIMARY BONE CANCER PATIENTS?

From 2006-2013, I managed the Physiotherapy Gym at the Royal Orthopaedic Hospital, Birmingham and led the land based rehabilitation for patients who had had limb-salvage surgery for primary bone tumours.

During my time working with patients with primary bone tumours, one of the main things that I found, which caused significant distress for patients, was the length of time they had waited to be diagnosed and the numerous misdiagnoses they had received in the meantime. This led me to believe that we could do much more in terms of recognising symptoms earlier. Although I have moved out of the Physiotherapy Gym and work mainly with Consultants in the assessment of hip joint pain, I continue to feel passionate about this area of delayed or misdiagnosis.

WHY IS THE ROLE OF A PHYSIOTHERAPIST SO IMPORTANT?

Physiotherapy is obviously important in the post-operative role following limb-salvage surgery; to strengthen muscles, improve movement and increase function. It is integral to achieve the most benefit from surgery.

However, I also feel there is another key role and that is physiotherapists are now often the first healthcare professional that patients will see with initial bone tumour symptoms. This has increased through self-referral pathways, where patients can refer themselves directly for physiotherapy without seeing their GP. If we can educate all physiotherapists, GPs and other Healthcare Professionals who see patients at the

first point of care for joint pains, regarding early bone tumour symptoms, I feel we could help to improve early diagnosis.



COULD YOU TELL US A BIT ABOUT YOUR CURRENT RESEARCH PROJECT AND HOW YOU AIM TO INCORPORATE YOUR FINDINGS INTO YOUR WORK WITH PATIENTS?

In 2015, I conducted a project where I interviewed patients with a primary bone tumour around the knee about their symptoms. I also interviewed Consultants and Allied Healthcare Professionals who have experience with patients with primary bone tumours about the symptoms they thought patients presented with.

The results showed that the early symptoms patients experience present more like normal joint pains or soft tissue injuries, and that the current guidelines describe the later symptoms. I feel that this may be a key reason as to why we have not reduced delays in diagnosis over the last few decades as the early symptoms are not well known and are therefore being missed. I would therefore like to do a larger study to look at the symptoms of all lower limb primary bone tumours and to confirm these findings. I feel that identifying what the early symptoms are, and being able to distinguish them from normal joint pains and injuries, is a key way to help Healthcare Professionals reduce diagnostic delays for patients.

CORPORATE PARTNERSHIPS



Rachel Wallace, Corporate Partnership Manager here at the Bone Cancer Research Trust tells us why **“Just one nomination from YOU can make such a big difference”**

We are grateful to all the businesses who made a difference to our work in 2017. From prize donations, fundraising and sponsorships, to supporting Bone Cancer Awareness Week, our corporate partners play a vital role in our work.

As a small charity representing a rare disease we may not be at the forefront of an employer's mind when it comes to choosing which charities to support. Sometimes it takes just one nomination to make it happen. This happened with Atrium Underwriters, a leading specialist insurance and reinsurance business based in London.

A team of 15 took on the difficult challenge of the London to Brighton bike ride. They had a fantastic day as a team and raised enough to fund over 300 hours of research. By asking their customers to donate too, it helped to raise the profile of primary bone cancer at the same time.

HOW CAN YOU AND YOUR COMPANY GET INVOLVED?

As we continue to deliver our 5 year strategy, the support of businesses will be evermore vital and that's where you come in. Whether you work for a small start-up or a national chain, taking a few minutes to nominate us for your company's support could have a huge impact on families facing primary bone cancer.

Find out what opportunities there are within your business to:

- **Nominate us as your charity of the year**
- **Sponsor an event or project**
- **Fundraise or take on your next challenge event**
- **Request match funding from your employer**

If you would like to find out more or would like some help with putting forward your nomination, email us at info@bcrt.org.uk

ATRIUM UNDERWRITERS

YOU ARE ... ONE IN A MILLION!



“ Our colleague based her nomination for BCRT on a personal connection with Alex Lewis, who died from osteosarcoma in 2011. BCRT was attractive to us as it was a small charity and because it focussed on primary bone cancer research which is often overlooked or underfunded by the larger mainstream cancer charities. The support from Atrium both to raise awareness and contribute financially would make a huge difference in helping to advance the cause further.





TERRI IS STAMP-ING OUT PRIMARY BONE CANCER BY JOINING US AS OUR STAMP APPEAL VOLUNTEER

Terri has been volunteering with different charities for 25 years and this year we were delighted to welcome Terri to #TeamBones. As a volunteer for the Bone Cancer Research Trust, Terri has supported us with the launch of our first ever Stamp Appeal. Below Terri tells us about the Stamp Appeal, why she decided to join us and her experience so far.

CAN YOU TELL US ABOUT THE STAMP APPEAL AND YOUR ROLE?

We started a Stamp Appeal in October 2017; it's a really simple way to support the Bone Cancer Research Trust. You collect your used stamps; small stamps, large stamps, new stamps, franked and international stamps and post them to us. We collect all of the stamps and they are then sold on to stamp collectors.

WHY DID YOU DECIDE TO GET INVOLVED WITH THE BONE CANCER RESEARCH TRUST?

I heard about the Bone Cancer Research Trust from a family member. I was astonished to find out that there had been no significant improvements to primary bone cancer survival rates for nearly 30 years and yet around 600 new cases are diagnosed each year in the UK and Ireland. Because of this I decided that I wanted to support the charity through volunteering and doing my own fundraising events such as 'Bake It For Bone Cancer' during Bone Cancer Awareness Week 2017 and I managed to raise £1,066.

WHAT DID YOU WANT TO GET OUT OF BEING INVOLVED WITH THE BONE CANCER RESEARCH TRUST?

I was looking for a new challenge and I wanted to support the charity by promoting their work to wider audiences. I have had experience in Stamp Appeals and I thought this would be a simple way to raise funds for the charity.

WHAT SKILLS HAVE YOU DEVELOPED THROUGH YOUR EXPERIENCE OF VOLUNTEERING?

Volunteering has definitely increased my confidence. I have developed my computing skills and worked alongside the Fundraising and Communications Team to develop press releases and increase awareness via their channels and new ones.

WHAT DO YOU ENJOY ABOUT VOLUNTEERING FOR THE BONE CANCER RESEARCH TRUST?

I have made new friends whilst volunteering for the Bone Cancer Research Trust and it is incredibly rewarding to know I am making a difference to people's lives.

You can find out more about our Stamp Appeal and how to get involved at www.bcrtr.org.uk/stampappeal

HOW TO BECOME A VOLUNTEER...

If like Terri, you would like to volunteer for the Bone Cancer Research Trust and join #TeamBones, wherever you live. Please contact us at info@bcrtr.org.uk.



BONE CANCER CONFERENCE 2018

 23RD JUNE 2018

 VILLAGE HOTEL -
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LS27 0TS

 FREE

Whether you're a patient,
former patient, family
member, supporter,
researcher or medical
professional - **everyone is
welcome** to join us at our
annual conference.

The theme of our 2018
Conference is 'our community
together'. We will create a
supportive and informative
environment for anyone
affected by primary bone cancer.



REGISTER OR FIND OUT MORE NOW AT
BCRT.ORG.UK/CONFERENCE OR BY CALLING US ON 0113 258 5934

THE BONE CANCER BALL

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Editorial: Deborah Flyde, Mat Cottle-Shaw Design: BW DESIGN



CONTACT US

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10 Feast Field
Horsforth
Leeds LS18 4TJ

 www.bcart.org.uk

 @BCRT

 /BoneCancerResearchTrust

 0113 258 5934

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