

# UNITED

## UNTIL THERE'S A CURE

INTRODUCING  
OUR BRAND  
**NEW**  
SUPPORTER  
MAGAZINE!



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32 YEAR OLD NIKKY TALKS TO  
US ABOUT BLOGGING HIS WAY  
THROUGH BONE CANCER



## EDITOR'S NOTE

Welcome to United, our new free magazine for supporters of the Bone Cancer Research Trust. Our first issue is packed full of news, updates, stories and interviews and we're really excited to share it with you.

Proton beam therapy is a hot topic in the news at the moment. Turn to page 16 for a clear, reliable guide to some frequently asked questions from our Head of Research and Information Dr Zoe Davison.

We have got lots to share from our fantastic researchers, too. Read page 18 to 'meet the researcher' and find out what inspired orthopaedic surgeon Kenny Rankin to enter the lab at Newcastle University. You can discover more about our 10 years of collaboration with world leading bone cancer expert Professor Adrienne Flanagan on page 15.

We are also proud to launch our five year strategy for 2017 to 2022 (unveiled on pages 5 and 6). We have outlined a clear framework that will help us to save lives and come closer to a cure during this period. Visit our website

**[www.bcrct.org.uk](http://www.bcrct.org.uk)** for a free printable and downloadable version of our new strategy document with more on the plans across our key pillars of research, information, awareness and support. We would love to hear from our readers.

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@bcrct.org.uk](mailto:info@bcrct.org.uk)**.

**ROSIE WILSON,**  
COMMUNICATIONS MANAGER



## FOREWORD

*I am extremely proud to be the Chair of Trustees of our remarkable charity. 11 years on from when it was founded, the Bone Cancer Research Trust remains the only charity solely dedicated to finding a cure for primary bone cancer.*

*Thanks to donations from supporters like you we have raised over £3.5 million to fight primary bone cancer. We've funded 93 researchers and 61 specific research projects to date – many of which are focused on innovative new treatments. We funded the first ever e-learning bone cancer module for GPs and we are the only charity to offer information across all forms of primary bone cancer.*

*And how does a small charity like us do all this? Well, by far the vast majority of our funding comes directly from our personally involved supporters, and that's where you come in.*

*Because bone cancer is considered a rare cancer, it is often ignored. The world has seen significant advances in understanding and treatments of more common cancers, but there have been no improvements to bone cancer outcomes in the last 30 years though a lack of research funding. This needs to change.*

*This year, we have launched our biggest campaign to date: The Biggest Fight Against Bone Cancer - Ever! We're aiming to raise £1.1 million to create the advances in research needed to save lives. This goes hand in hand with our new five year strategy for 2017 to 2022, which demonstrates our commitment to making tangible change happen.*

*Our small but dedicated office team are working tirelessly with our fantastic supporters to create real change for bone cancer patients and save lives. We are so grateful for your support. Here's to another decade of achievement; of working together united until there's a cure.*

**ANDY LEWIS,**  
CHAIR OF TRUSTEES



# NEWS IN BRIEF

## RADIO 4 APPEAL

We are thrilled to have been awarded a prestigious Radio 4 Appeal, which will be fronted by celebrity chef, author and soon-to-be Bake Off judge, the wonderful Prue Leith! This is a fantastic opportunity to reach a wider audience and raise vital awareness of bone cancer. The appeal will be broadcast on Sunday 8th October at 07.55 and 21.26 and repeated on Thursday 12th October at 15.27, with opportunities to listen on iPlayer in between broadcasts.



## BONE CANCER AWARENESS WEEK

Diaries at the ready! Our Radio 4 Appeal will mark the start of Bone Cancer Awareness Week, which will run from Sunday 8th October to Saturday 14th October 2017. Awareness of primary bone cancer saves lives. During awareness week we want to reach as many people as we can, to raise the profile of this rare and brutal disease. We know that time is precious so we'll have lots of quick and simple ways for you to get involved: from tuning into our Radio 4 Appeal, to baking a cake, organising your own fundraising event or simply sharing our tweets and using our digital campaign banners for a day. Whether you can spare 5 minutes or a whole day, your support could make a huge difference. Look out for more details in early September, or start organising your own event now. Visit [www.bcrf.org.uk/awareness](http://www.bcrf.org.uk/awareness) for more information.

## NEW AMBASSADOR LAURENCE WHITELEY

We are delighted to introduce Laurence Whiteley MBE; a gold medallist para-rower who is a former osteosarcoma patient. We know how important it is for bone cancer patients to hear from others who have gone through the experience themselves and are very excited to welcome Laurence as we take on The Biggest Fight Against Bone Cancer.





# MPs BACK THE FIGHT AGAINST CANCER IN PA

Over 25 MPs from across the UK joined us to don their boxing gloves and back The Biggest Fight Against Bone Cancer at our first ever parliamentary reception on 1st February 2017.

The Biggest Fight Against Bone Cancer is our year long campaign to raise £1.1 million that will ensure we can fund more research, provide more information, raise more awareness, support more individuals and ultimately save more lives.

We're very grateful to our local MP Stuart Andrew for hosting us in the House of Commons and for his continued support to us as a charity. John Baron, Chairman of All Party Parliamentary Group on Cancer, was also in attendance



as we discussed the need for early diagnosis and called upon MPs to advocate our GP e-learning module.

Huge thanks goes to former patient Jamie Wood and his family, who gave up their time to share their story. Jamie was diagnosed with Ewing sarcoma in 2010 and underwent 16 courses of chemotherapy and 3 operations as part of his treatment.

Thank you to everyone who wrote to their MP and encouraged them to attend. MPs may previously have been unaware that their constituents have been affected by primary bone cancer, which



# BIGGEST T BONE RLIAMENT

continues to be an under-profiled and under-funded disease. We need all MPs to recognise the importance of our campaign and how crucial it is to primary bone cancer patients.

Finally, thanks to all MPs who supported the event. We look forward to working with them in the future to help raise vital awareness of bone cancer at a national level.

THE  
**BIGGEST**  
FIGHT AGAINST  
**BONE**  
**CANCER**

**EVER!**

FOR MORE INFORMATION AND  
TO SUPPORT THE CAMPAIGN VISIT  
**WWW.THEBIGGESTFIGHT.ORG**

# THE BIGGEST EVER COMMITMENT TO PRIMARY BONE CANCER: OUR STRATEGY 2017-2020

## RESEARCH

By 2022 we will have made significant progress in getting closer to a cure for primary bone cancer and more patients will be surviving the disease as a direct result of research.

### MAKING IT HAPPEN

WE WILL COMMIT OVER  
**£2.8 MILLION**  
TO PIONEERING RESEARCH THROUGH AN  
INNOVATIVE NEW GRANT PROGRAMME



We will support research at all levels, from initial idea through to clinical trial

We will deliver the next generation of world class, primary bone cancer researchers

We will support UK surgical centres to enable all primary bone cancer patients to contribute tissue samples for use in research

## INFORMATION

Every newly diagnosed patient will have access to accurate and reliable information across all forms of primary bone cancer.

### MAKING IT HAPPEN

We will develop a Patient / Parent Pack to offer comprehensive information to all patients on their specific primary bone cancer or tumour type

We will expand our existing portfolio of information for patients of all ages

We will expand our basic information to ensure patients in other countries have access to relevant information

We will ensure that information is available for the clinical and medical community

We will develop information for carers and families of patients with primary bone cancer

We will accurately signpost relevant information that falls outside our remit



Since our inception in 2006 we have made significant progress in the fight against this brutal disease; from developing new pioneering treatment methods to the creation of new training tools to aid earlier diagnosis.

## LOOKING TO THE FUTURE

Our ultimate ambition is to find a cure for this cruel disease and in order to help us get there we are embarking on a new direction of travel from 2017 to 2022. The Biggest Ever Commitment To Primary Bone Cancer outlines this new journey and provides our charity with a clear framework that will help us save lives and come closer to a cure during this period.

## AWARENESS

We will save more lives and increase survival rates through raising awareness of primary bone cancer amongst the public, healthcare professionals, researchers and policy makers.

### MAKING IT HAPPEN

We will ensure all GPs in the UK have access to the training and tools they need to identify and diagnose primary bone cancer

We will develop tools to allow radiographers, physiotherapists and other medical professionals to identify the symptoms of primary bone cancer

We will continue to fund and develop training options for medical students in the field of primary bone cancer

We will increase national and where possible, international public awareness of primary bone cancer and the Bone Cancer Research Trust

## SUPPORT

We will improve the access to primary bone cancer support for all patients, family members, carers and friends when and how they need it.

### MAKING IT HAPPEN

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

We will develop digital 'community' support groups

We will deliver an annual conference aimed at uniting and supporting our community

We will review all patient experiences held by us and begin to engage with new patients to encourage the sharing of more stories and experiences

We will ensure robust signposting to other support groups and charities where we cannot provide assistance



## Q&A WITH RESEARCH & INFORMATION OFFICER HANNAH BIRKETT



### Why is reliable information so important? Our Research and Information Officer Hannah Birkett explains all.

#### HOW DO YOU DECIDE WHAT INFORMATION TO PRODUCE?

We are constantly speaking to patients, family members and medical professionals to gain a better understanding of what information and support patients with primary bone cancer want and need. Our most recent launch of information during Bone Cancer Awareness Week in October 2016 allowed us to proudly become the only charity providing information on all forms of primary bone cancer. We found that there was little-to-no trustworthy information on some of the much rarer forms of bone cancer, such as chordoma or adamantinoma, and so we set out to change this. Similarly, we became aware that many of the calls and emails we were receiving requesting information were in relation to clinical trials and so we recently published a guide on our website to aid the decision making of taking part in a clinical trial, as well as a list of all the clinical trials currently available for primary bone cancer patients. Ultimately, we aim to provide information that is truly required and will make a difference to patients; no matter the rarity of their cancer.

#### WHY IS IT DIFFICULT FOR BONE CANCER PATIENTS TO ACCESS TRUSTWORTHY INFORMATION?

The forms of primary bone cancer we have produced information on are extremely rare. It is hard to find information on these rare cancers as the incidence rate is so low that there is still a lot to learn about their behaviour. For this reason, there is little-to-no information available aside from scientific reports,

which are certainly not informative or digestible for all readers, or information on websites that are not necessarily reliable or accurate.

It's really important to look out for the 'Information Standard' logo, either on websites or printed materials. This is a sign that the information you are reading has been written under strict guidelines and has been checked by multiple experts to ensure its accuracy. We are delighted to have been accredited by the Information Standard since 2011.

#### WHAT DIFFERENCE WILL THIS NEW INFORMATION MAKE TO PATIENTS?

It's crucial that every patient has a supportive and informative place to turn to when receiving a diagnosis. Our wealth of information across the different tumour types and of clinical trials allows us to be confident in the knowledge and advice we provide, both in our information materials and when speaking with patients or family members on a one-to-one basis. We hope to give individual patients a wider understanding of their tumour type, and their options, empowering them to share their opinion and have input into the management of their care and their day-to-day lives.







# BLOGGING ABOUT BONE CANCER

32 year old Nikky has shared an honest and open account of Ewing sarcoma and amputation on his blog 'Bad to the Bone'. We chatted to him about why he chose to blog about his experiences.

## HI NIKKY. WHAT INSPIRED YOU TO CREATE YOUR BLOG AND SHARE YOUR EXPERIENCE WITH OTHERS?

After being diagnosed with bone cancer for a second time and needing a below knee amputation I found myself reaching out to others who had been in a similar position, hoping that they could offer me some advice on what I was about to go through. Thankfully the Bone Cancer Research Trust put me in touch with two amazing people who were able to answer questions I had about surgery and life as an amputee. It was this that motivated me to write about my own experiences in an attempt to help someone somewhere going through a similar ordeal. I used a blog as the platform for what I had written because I knew it could be shared easily through social media sites such as Facebook, Twitter and Instagram, giving it the chance to reach a much wider audience. The plight of cancer sufferers is well publicised yet there is still so much more that can be done to help those faced with the disease and all that comes with it. Sharing my story and my experiences was the least I could do.



## YOU'RE CURRENTLY UNDERGOING REHABILITATION THERAPY. COULD YOU TELL US A BIT MORE ABOUT THIS AND HOW IT'S ALL GOING?

It was a real shock to the system at first; not just

physically but mentally also. I had expectations of myself that were unrealistic and I was left a little deflated when I couldn't instantly run up and down the room of the mobility centre.

I managed a couple of lengths of the room where I was having my physiotherapy. I walked up and down between a set of bars and began to understand that it would take time to adjust but as long as I did as I was told it wouldn't be too long before I was walking around freely.

## DO YOU HAVE ANY WORDS OF ADVICE OR ENCOURAGEMENT FOR CURRENT PATIENTS; PARTICULARLY THOSE WHO MAY BE FACING AN AMPUTATION?

You will surprise yourself at just how strong you can be. There will be times when you'll need a helping hand so don't be afraid to ask for one; no one is expecting you to face cancer on your own. Talk to someone about the way you are feeling and if like me it doesn't come easily then keep a diary. It was a huge help throughout my first diagnosis.

Believe in yourself, have faith in your own ability and be proud of who you are and what you have achieved. You are capable of absolutely anything. I have set myself a personal challenge for August/September 2018: joining the Bone Cancer Research Trust team to climb Kilimanjaro!

**VISIT [NIKKYGIBBO.WORDPRESS.COM](http://NIKKYGIBBO.WORDPRESS.COM) TO READ MORE ABOUT NIKKY'S EXPERIENCES.**



# A GUINNESS WORLD RECORD FOR TEAM BONES!

Long-time supporter Paul Cousins has beaten the Guinness World Record for fastest male marathon runner in a 3D aircraft/helicopter costume! Intrigued? Read below for the inside scoop!

## WHAT INSPIRED YOU TAKE ON THIS CHALLENGE FOR US?

My first ever run was the Royal Parks Half Marathon for the Bone Cancer Research Trust; this was in support of friends Andy and Sue Collard, who had lost their daughter Mary to bone cancer. I knew I wanted to do my bit. I absolutely loved the whole experience and have gone on to run marathons, half marathons and a Tough Mudder for the charity. When I got a ballot place for this year's London Marathon I knew I had to run for the Bone Cancer Research Trust again, but this time I wanted to do something more; having dressed up for the last 2 marathons I had to do it again! I had met the World Record holder of the fastest phone box marathon at the Bath Half, and the seed was planted! After a little more research I decided to try and set a record myself; what better way to try and raise the profile of the charity?

## WHICH 3 WORDS SUM UP YOUR EXPERIENCE?

Emotional, exhausting and exhilarating.

## HOW DOES IT FEEL TO BE A WORLD RECORD HOLDER?

A little surreal, especially after watching Roy Castle's Record Breakers as a child....to think I am now a record breaker! The whole experience was great - lots of ups and downs, costume problems, injuries

and logistics of getting the costume around, but the one thing that sticks in my mind is from when I was out training in the helicopter. A car pulled over and a little boy got out and gave me his pocket money: a £1 coin for the charity. If anybody out there thinks they couldn't do this then think again; it's hard but well worth the effort. You will surprise yourself as I have done.



## HUGE CONGRATULATIONS TO

ROBERT WEST  
FRANCESCA RAWLINGS  
SCOTT PARSONS  
CHARLOTTE O'REILLY  
STUART DOIDGE  
SONIA HILL

PENNY BRITT  
ELEANOR SMALE  
STEVE MITCHELL  
IAN WEARE  
CHARLOTTE JONES  
RIKKI MOLONEY



GUNGE? MOUNTAINS?  
INSPIRED FANCY DRESS?  
OUR TEAM BONES FUNDRAISERS  
NEVER STOP AMAZING US...



**THANK YOU  
TO ALL OUR  
INCREIBLE  
FUNDRAISERS!**

## TO ALL OUR 2017 VIRGIN LONDON MARATHON RUNNERS

JACK ROWSE  
KEIRON WHITE  
CLAIRE COPPERWHITE  
SOPHIE HOLBOROW  
JUSTIN MOIR  
ANDREW MCLENNAGHAN

REBECCA CUSATO  
ALISON LEWIS  
PAUL COUSINS  
IVONNE BONE  
TAMLYN WILLIAMS  
TIMOTHY BENNET

LYNDSEY KIDD  
JOANNA STEVENS  
ALISON STEWART  
AMY HALLIGAN  
ADAM WATTS  
FRANCESCA EVATT

LEE COOK  
HELEN HATCHER  
JOANNE NICHOLSON  
BETHANY POLLARD  
KATHERINE WATTS

# THE FUTURE OF OSTEOSARCOMA RESEARCH

Our Head of Research and Information Dr Zoe Davison outlines some key priorities.



Osteosarcoma has been recognised as a priority by the National Cancer Research Institute (NCRI) Sarcoma Clinical Studies Group for a number of reasons. Firstly, survival rates for patients

with osteosarcoma have remained unchanged for a number of decades. Secondly, there is currently a lack of biological studies and clinical trials in this disease. There has not been an international phase III clinical trial since EURAMOS-1, which closed in 2011 and there are very few early phase trials targeting recruitment of patients with osteosarcoma. Thirdly, there have been no trials for patients over 40 years old with osteosarcoma, and so the optimal treatment in this patient group is still not fully understood.

## IDENTIFYING NEW TARGETS FOR TREATMENT

Although there have been many studies across the world examining the genetics of this disease, the genetic characteristics remain largely unknown and new targets have remained elusive. There is a pressing need for the research and clinical community to come together to conduct large scale collaborative biological studies and to develop new innovative clinical trials that can test new treatments in parallel

and in a much more efficient manner.

## 100,000 GENOMES PROJECT

In the last few months, there has been a huge national drive in osteosarcoma research: this cancer will be extensively studied as part of the 100,000 Genomes Project, which will give an incredibly detailed picture of the genetics of this disease, in combination with a detailed history of the patient and their family members. Professor Adrienne Flanagan will conduct a range of complementary studies alongside the sequencing, and data from these studies will be available to other researchers to stimulate further ideas and research into osteosarcoma.

## INFRASTRUCTURE GRANTS

Osteosarcoma is a rare cancer and to get an accurate picture of what is causing and driving the cancer, it is important to study samples from a large number of patients. It is therefore very important that all primary bone cancer centres work together and contribute to the 100,000 Genomes Project. To aid this the Bone Cancer Research Trust has just awarded brand new 'Infrastructure Grants', which will



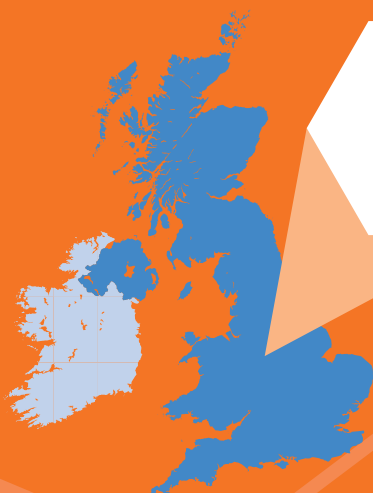




provide funding and resources to the 5 primary bone cancer surgical centres in England to enable them to collect patient samples for use in research.

### **NATIONAL, COLLABORATIVE RESEARCH**

This huge investment into national and collaborative osteosarcoma research presents a unique opportunity to tackle the gap in understanding the biology of osteosarcoma and the stimulation of clinical trials in this disease.



**160**

PEOPLE  
DIAGNOSED  
UK WIDE  
EACH YEAR

### **PUSHING LAB RESEARCH ONE STEP CLOSER TO THE CLINIC**

The Bone Cancer Research Trust is releasing a call for significant funding - the largest grant in the charity's history - so that researchers can continue this step-change in osteosarcoma research. The funding will be aimed at pushing laboratory research one step closer to patients in the clinic and following up on any 'new leads' identified by the 100,000 Genomes Project or other complimentary osteosarcoma research. This combined financial commitment to osteosarcoma research by the Bone Cancer Research Trust, other charitable donations and Genomics England totals around £2.5 million and is the largest that the UK has seen since the EURAMOS trial, with the ultimate goal of getting several new treatments into a sophisticated trial, which has arms open to all osteosarcoma patients irrespective of age, grade and past treatment. This programme of research will also work to catalyse further osteosarcoma research. This is the greatest opportunity to date for the UK to lead the way into osteosarcoma research.

**WANT TO FIND OUT MORE? VISIT**  
**[WWW.BCRT.ORG.UK/RESEARCH](http://WWW.BCRT.ORG.UK/RESEARCH)**



# HOW CAN JUNIOR DOCTORS IMPROVE THEIR KNOWLEDGE OF BONE CANCER?

In the United Kingdom, there are currently no designated modules on the undergraduate medical curriculum on sarcomas, and fewer than 20 designated centres treating sarcoma patients.

Many medical students graduate with little or no knowledge of sarcomas and even after graduation, the opportunities and time to learn more about sarcomas are scarce.

To address this problem, a team at the Royal Liverpool and Broadgreen University Hospitals Trust, led by Mr CR Chandrasekar, have been conducting a National Sarcoma Awareness Project for medical students and junior doctors since 2013, funded by the Bone Cancer Research Trust. Dr Charlie Zhou completed a week-long placement at the Royal Marsden Hospital, shadowing a sarcoma specialist. We caught up with him to hear about what he made of the experience.



## WHAT INSPIRED YOU TO APPLY FOR THE NATIONAL SARCOMA AWARENESS PROJECT?

I have had a keen interest in cancer since my studies as an undergraduate. As a result, I have for a long time been contemplating a career in oncology. The National Sarcoma Awareness Project seemed like a natural progression where I could appreciate the role of specialist centres in the treatment of a rare condition and observe the very cutting edge of medical research.

## WHAT WAS YOUR UNDERSTANDING OF SARCOMA BEFORE YOU EMBARKED ON THE PROJECT?

My understanding of sarcoma prior to the project was extremely rudimentary - I knew that it was a rare cancer that was often associated with a poor prognosis. In particular, I was lacking knowledge regarding red flag symptoms, the diagnostic pathway and appropriate investigations as well as suitable treatments.

## DID ANYTHING SURPRISE YOU ABOUT THE WAY SARCOMA IS DIAGNOSED OR TREATED?

The most surprising thing was when I was told that sarcoma chemotherapy treatment had largely remained unchanged for 30 years (or even longer), despite cancer being one of the most active areas of medical research.

## WHAT DO YOU THINK JUNIOR DOCTORS SHOULD BE MOST AWARE OF WITH REGARD TO SARCOMA?

The safest doctors are those that recognise when to call for help. Sarcoma prognosis is inversely associated with size at presentation. Unfortunately, the vast majority of sarcomas are greater than 10cm at the time of diagnosis. I would say that junior doctors should be aware of the 4 red flag symptoms and if these are present a specialist opinion should be sought.

**The Bone Cancer Research Trust has committed to funding the National Sarcoma Awareness Project for a further year. If you are a final year medical student or F1/F2 doctor interested in taking part, please contact [sarcoma.awareness@rlbuht.nhs.uk](mailto:sarcoma.awareness@rlbuht.nhs.uk) with your name, designation and email contact to find out more.**

## DID YOU KNOW?

BONE SARCOMA IS ANOTHER TERM FOR BONE CANCER



# PROFESSOR ADRIENNE FLANAGAN ON 10 YEARS OF COLLABORATION

“““

I WOULD LIKE TO THANK THE BONE CANCER RESEARCH TRUST FOR YOUR CONTINUED SUPPORT, WHICH MAKES SUCH A BIG DIFFERENCE TO ALLOWING US TO UNDERTAKE OUR RESEARCH ON RARE CANCERS

**PROFESSOR ADRIENNE FLANAGAN**



Professor Adrienne Flanagan specialises in the pathology of bone and soft-tissue tumours and is the lead of the International Cancer Genome Consortium for bone tumours. She is based at University College London and has carried out some of the most successful research in the bone cancer field, working with osteosarcoma, chondrosarcoma and chordoma. Professor Flanagan first began working with the Bone Cancer Research Trust in 2007. Since then she has carried out 5 research projects funded by the charity and was the co-lead on another, producing 10 research publications that discuss the findings of her work funded by the Bone Cancer Research Trust.

## OSTEOSARCOMA BREAKTHROUGH

Back in 2011, we provided funding to support a Biobank Technician in Professor Flanagan's laboratory, which enabled the team to generate osteosarcoma patient samples to be used in research.

Recently, these samples allowed researchers at the Wellcome Trust Sanger Institute and their collaborators at University College London Cancer Institute and the Royal National Orthopaedic Hospital NHS Trust to confirm that a subgroup of patients with osteosarcoma could be helped by an existing drug. In the largest genetic sequencing study of osteosarcoma to date, scientists discovered that 10 per cent of patients with a genetic mutation in a particular growth factor signalling genes may benefit from existing drugs, known as IGF1R inhibitors.

## A NEW BIOMARKER FOR CHONDROSARCOMA?

As well her work with osteosarcoma, Professor Flanagan has become an expert in the gene profiling of other forms of primary bone cancer. Professor Flanagan's work with us aims to identify what is known as 'biomarkers' of chondrosarcoma, allowing clinicians to determine the grade and severity of chondrosarcoma earlier on – which is currently quite difficult. Using gene sequencing to identify these biomarkers will allow clinicians to make appropriate decisions regarding the treatment plan and surgical procedures for individual patients, while predicting the behaviour of the chondrosarcoma tumour. It is hoped that in the future these findings will be introduced into the clinic as potential treatment targets, aiming to improve patient outcome.

FOR MORE INFORMATION ABOUT ADRIENNE'S WORK VISIT  
**[WWW.BCRT.ORG.UK/RESEARCH](http://WWW.BCRT.ORG.UK/RESEARCH)**

# PROTON BEAM THERAPY



Proton beam therapy is a hot topic in the news. Our Head of Research and Information Dr Zoe Davison responds to some frequently asked questions to help patients understand more.

## **WHAT IS PROTON BEAM THERAPY?**

Conventional radiotherapy uses x-ray beams to kill tumour cells; however, the doses that can be delivered are limited because the beams affect normal, healthy tissue in front of the tumour and behind it. Think of it as a spotlight, delivering the same dose of radiotherapy to the tumour and the normal tissue around it.

A newer version of x-ray radiotherapy is called intensity modulated radiotherapy. The x-ray beams can be shaped to target the tumour more accurately and are delivered from a number of different directions to limit the effects of the x-rays on normal tissue.

Proton beam therapy uses proton beams instead of x-ray beams; these beams cause very little damage to the tissue they pass through and are very good at killing the tissue at the end of their path. Scientists can work out exactly where the tumour is and ensure that the proton beams come to an end within it. This means that doctors can administer a higher dose of radiotherapy, while having little effect on normal, healthy tissue.

## **WHY ARE BONE CANCER PATIENTS SEEKING PROTON BEAM THERAPY ABROAD?**

There are limited treatment options for primary bone cancer patients, especially for metastatic (cancer that

has spread to other sites within the body) and relapsed patients. Conventional radiotherapy is not effective in many forms of primary bone cancer as the doses that can be delivered to ensure that normal tissues are not affected aren't high enough to kill the cancer cells. Many patients, at this stage, look to alternative treatment options such as proton beam therapy.

## **DOES THE NHS FUND PROTON BEAM THERAPY ABROAD?**

The NHS does fund proton beam therapy abroad for some patients. This type of treatment has proven benefits in a number of cancers and it is patients with these types of cancers that tend to have this funded. The NHS has a 'UK proton panel' that assesses cases one by one to see which are eligible for NHS funding. Patients wishing to apply for this funding require a referral to this panel by a member of their clinical team.

## **WHEN WILL PROTON BEAM THERAPY BE AVAILABLE IN THE UK?**

The UK was one of the first places to use proton beam therapy; however this is low energy proton therapy and is used successfully to treat eye cancer. High energy proton beam therapy requires sophisticated technology and equipment and needs a dedicated facility. The UK Government committed



# PY



# Q&A

WITH  
DR. ZOE  
DAVISON



£250m to developing two proton beam therapy centres at the Christie Hospital in Manchester and at UCLH in London. These are due to start treating patients in 2018 and 2020 respectively.

## HOW EFFECTIVE IS PROTON BEAM THERAPY FOR BONE CANCER SPECIFICALLY?

There have been very few studies looking at the effectiveness of proton beam therapy in bone cancer patients specifically. One study in America looked at its effectiveness in osteosarcomas of the spine, pelvis and skull base, and showed that it was effective in some patients. Once the UK is treating patients, more thorough studies will be needed to fully assess the effectiveness of this treatment in primary bone cancer. To support the development of improved radiotherapy for bone cancer patients more widely, the Bone Cancer Research Trust has funded a significant piece of research by Dr Fran  l le Grange and Dr Beatrice Seddon firstly assessing the use of intensity modulated



radiotherapy and secondly, preparing processes and protocols in preparation for proton beam therapy being established in the UK.

**HAVE ANY QUESTIONS?**  
EMAIL US AT [INFO@BCRT.ORG.UK](mailto:info@bcrt.org.uk)

# MEET THE RESEARCHER: KENNY RANKIN

## WHAT INSPIRED YOU TO GO INTO BONE CANCER RESEARCH?

I did my basic surgical training in Newcastle and decided to do a laboratory research degree before going on to orthopaedic specialist training. Two years into specialist training the opportunity came up to continue as an NIHR Academic Clinical Lecturer which provided protected time for research.

I had enjoyed my time in the laboratory so much that I was keen to return and spent another full year in the laboratory, and was able to get funding in order to supervise my first post-doctoral scientist.

Following appointment as a Consultant in 2014, again with protected research time, I have been able to continue building on my research projects, the core of which are into osteosarcoma. The research work involves long hours but is incredibly stimulating and I am hopeful that we are heading in a direction that will produce some useful new therapies, particularly for the surgical management of bone sarcomas.



## YOU WERE THE WINNER OF LAST YEAR'S STRICTLY RESEARCH COMPETITION AT OUR ANNUAL CONFERENCE. NOW WE ARE A YEAR ON, ARE THERE ANY UPDATES ON THE PROJECT THAT YOU CAN PROVIDE US WITH?

I was very grateful to receive the award last year to test a novel 'theranostic' which holds the potential to enhance our MRI scans and allow us to improve our preparation for our bone sarcoma operations. A theranostic is a compound that will be activated by a particular type of cancer and can release drugs or agents to improve imaging scans prior to surgery. The theranostic is due for delivery shortly and we will get underway with the necessary experiments in the lab as soon as it arrives..

## HOW IMPORTANT IS IT TO RESEARCHERS LIKE YOURSELF TO RECEIVE THIS FUNDING IN ORDER FOR YOUR RESEARCH TO PROGRESS?

It is vital for us to receive this type of funding to progress our research. The £10,000 idea grants have kickstarted two major projects for me. The first was the detection of circulating tumour cells in bone sarcoma project which started in 2015 and is still running having recruited over 30 patients from around the UK. The second is the theranostic project; the £10,000 was used for the synthesis of the theranostic and we have secured other funds to provide for the testing of it. Obtaining this funding relatively early on from the Bone Cancer Research Trust has allowed me to get the agreements with universities in place and to obtain the theranostic, which has actually saved time and allowed my research to progress.

FOR MORE INFORMATION ABOUT KENNY'S WORK VISIT

**[WWW.BCRT.ORG.UK/RESEARCH](http://WWW.BCRT.ORG.UK/RESEARCH)**



# TIPS FROM WHIZZ-KIDZ



How can you get into sport after life-altering surgery? We spoke to Ray Davis, who is a Regional Services Coordinator for the charity Whizz-Kidz.

## WHAT DO YOU THINK THE MAIN BARRIERS ARE FOR PEOPLE WHO HAVE THE MOTIVATION BUT CAN'T SEEM TO FIND THE RIGHT ACTIVITY FOR THEM?

There's such a wide range of activities out there but many of them aren't well known and it can be difficult to find information, particularly about small local clubs that aren't always very good at advertising themselves. It's a struggle to find the right activity if you don't know where to look. I think many people can also be nervous about trying a sport for the first time, particularly if they weren't particularly sporty before their surgery. Plus there can be some anxiety around taking up a disability sport as it means you are accepting yourself as having a disability.

## WHAT WOULD YOUR TOP TIPS BE FOR SOMEONE TRYING TO FIND A NEW CLUB OR SESSION IN THEIR AREA?

Parasport is a good place to start to get a feel for what's out there. Or if you'd rather hit the gym than play

a sport, the English Federation of Disability Sport has a list of accessible gyms.

Lots of local areas have their own umbrella sport organisation, many of which work to promote disability sports and run taster days. For example, Sport Birmingham run the Birmingham Inclusive Sports Fest every year, which offers taster sessions in a wide range of inclusive sports. These organisations aren't always well promoted but searching for your local area or nearest large city plus 'disability sport' will usually get you to the relevant website.

Once you've found something in your local area my top tip would be give it a go! It's fine to try a sport or activity once and decide it's not for you, but if you don't try it you'll never find the one that is the right fit. Many clubs will offer a free taster session so you can give something new a go at no cost. Most clubs are very welcoming and happy for you to bring a friend or family member along with you.



**A HUGE THANK YOU TO EVERYONE IN OUR INCREDIBLE COMMUNITY FOR ALL YOUR SUPPORT TO DATE. TOGETHER, WE ARE UNITED UNTIL THERE'S A CURE.**

## **DATES FOR THE DIARY**

- BBC RADIO 4 APPEAL: TUNE IN ON **SUNDAY 8 OCTOBER** AT 07:55 AND 21:26
- BONE CANCER AWARENESS WEEK: **SUNDAY 8 OCTOBER TO SATURDAY 14 OCTOBER**
- ROYAL PARKS HALF MARATHON 2017: **SUNDAY 8 OCTOBER**
- VIRGIN LONDON MARATHON 2018: **SUNDAY 22 APRIL**
- COLUMBIA THREADNEEDLE WORLD TRIATHLON LEEDS 2018: **SUNDAY 10 JUNE**
- RIDE LONDON 2018: **SUNDAY 29 JULY**

**WANT TO GET INVOLVED? VISIT [WWW.BCRT.ORG.UK/EVENTS](http://WWW.BCRT.ORG.UK/EVENTS) FOR MORE INFORMATION.**

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**Editorial: Rosie Wilson, Mat Cottle-Shaw Design: BW DESIGN**



## **CONTACT US**

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10 Feast Field  
Horsforth  
Leeds LS18 4TJ

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

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[0113 258 5934](tel:01132585934)

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