

UNITED

UNTIL THERE'S A CURE

INSIDE THIS ISSUE

UK FIRST FOR
OSTEOSARCOMA
PATIENTS

FUNDING THE
NEXT
GENERATION OF
PRIMARY BONE
CANCER
RESEARCHERS

ROB SHARES
HIS STORY AND
NEW CHORDOMA
RESEARCH
PROJECT
AWARDED

NEW SUPPORT
AND
INFORMATION
SERVICE

PLUS MUCH MORE...



HAVING **ABBIE HAS
OSTEOSARCOMA**

MEANS YOU'VE GOT THE RIGHT
INFORMATION AT HAND TO GIVE TO
CHILDREN AND THEIR PARENTS.

MEET JANE,
SARCOMA CLINICAL NURSE SPECIALIST

PAGE 8

EDITOR'S NOTE

Welcome to your free issue of United!

So much has happened since our last edition of *United* and we can't wait to share with you all the incredible things we've been up to. Firstly, we would like to say a huge thank you to all our amazing fundraisers. For 2018, we asked you to help us reach £1,000,000 for the first time ever and as always, the bone cancer community got right behind us and absolutely smashed it! We raised £1,412,550; your support makes our life-saving work possible.

We have big plans for 2019, and this year we launch ICONIC, which is the UK's first ever patient registry and clinical study for osteosarcoma patients of all ages. You can read more about this ground-breaking project on page 5 along with an exclusive interview with Dr Sandra Strauss, who is leading the project and the person responsible for bringing together over 22 centres from across the UK to make this all happen.

Abbie Has Osteosarcoma, a new information resource for children and their families, is now available both in print and online. On page 8 we caught up with Jane Forsythe from the Royal Orthopaedic Hospital in Birmingham. Jane told us all about her role, why *Abbie Has Osteosarcoma* is so desperately needed and why she wanted to help us review our new book.

Our Infrastructure Grants are certainly making an impact! Now all five bone cancer centres have been awarded the grants and the number of patients approached for tissue samples has increased by an incredible 45%. Find out more on page 10.

As a charity we are dedicated to investing in future primary bone cancer researchers and we had the exciting opportunity to go behind the scenes at the University of Bradford to find out more about the research being done by Dr Falconer and PhD Student, Hannah. Read more about the research project and what the funding means to them on page 16.

We are delighted to announce that we are funding a new pioneering chordoma research project. You can find out more about the project on page 14 and 15 alongside Robert's insight into living with chordoma.

New for 2019 is our dedicated Support and Information Service. We know patients and their families sometimes need someone to speak to, point them in the right direction, give them the correct information and quite simply, just someone to be there for them. On the back page you can find all the information you need, if you ever need us.

Thank you to everyone who has contributed to our Summer issue of *United*.

DEBORAH FLYDE,
COMMUNICATIONS MANAGER



NEWS IN BRIEF

MAKING AN IMPACT

Last year we launched a year long fundraising campaign asking you to 'Be One In A Million' and help us reach £1million in a year, and for the first time ever... We did it! For every £1 you donated in 2018, we committed 87p to our charitable activities! Yes, 87% of our income we committed to our life-saving Research, Information, Awareness and Support.

We put your money where your ♥ is... Saving lives!

This is an incredible achievement, but there is still so much to do. Find out how you can get involved in 2019 at www.bcrf.org.uk/getinvolved

BONE CANCER AWARENESS WEEK

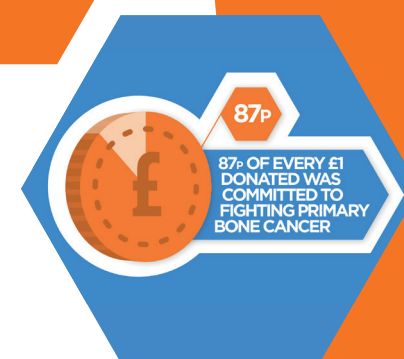
During Bone Cancer Awareness Week 2018 we asked you to get involved by watching and sharing our new symptoms awareness video and completing and sharing our symptoms awareness poster, because early detection and diagnosis saves lives. You raised crucial awareness during the week, the video was viewed over 168,000 times and our reach was over 2.1million! Bone Cancer Awareness Week 2019 will be 7th - 13th October.

To find out more about the week and how to get involved visit www.bcrf.org.uk/bcaw

BONE CANCER BALL

The 2018 Bone Cancer Ball was a spectacular event with dancing, entertainment, and some incredible prizes. Over 400 people attended and £56,070.97 was raised! The 2019 Bone Cancer Ball, sponsored by RNB Group, is on the 9th November at the Royal Armouries, Leeds.

To find out more and buy your tickets visit www.bcrf.org.uk/ball



ROYAL PARKS HALF MARATHON

At just 13 years old Jess Gower was diagnosed with osteosarcoma. Jess very sadly passed away, December 8th, 2010. Jess's mum Shirley has shared with us why she takes part in the Royal Parks Half Marathon for Team Bones.

I run for Team Bones because of our beautiful daughter Jess. She was 13 years old when she was diagnosed with osteosarcoma. Even though it was diagnosed quite quickly compared to others it was already metastatic, very aggressive and resistant to current treatments. Jess died 16 months later just before Christmas 2010. She would have been 15 in the January.

Our family and friends love taking part in this event. It has become something we can do together to remember Jess. I can't tell you how much it breaks your heart to lose a child to bone cancer.

The level of support from the Bone Cancer Research Trust is second to none and I'm proud to run for a charity that puts the funds raised to such good use. I never thought I would be someone to run in a half marathon but ultimately, I do it for Jess. She is always in my heart.



JOIN TEAM BONES TODAY!

Has Shirley inspired you?
If so, join her at the
Royal Parks Half Marathon!

When: **13th October 2019**
Location: **London**
Sign up at:
BCRT.ORG.UK/ROYALPARKS



A BONE CANCER RESEARCH TRUST FUNDED PROJECT

INTERVIEW WITH PRINCIPAL INVESTIGATOR DR SANDRA STRAUSS

ICONIC is the UK's first ever patient registry and clinical study to capture patient samples and complete medical data from osteosarcoma patients of all ages. ICONIC is a collaboration between all new patients diagnosed with osteosarcoma, the medical professionals involved in treating patients and scientists trying to understand the disease and find more effective new treatments. ICONIC will accelerate the discovery, testing, and delivery of new, more effective treatments for patients of all ages, and where possible personalise treatments to individual patients.

ICONIC will be led by Dr Sandra Strauss from University College London, who is one of the UK's leading researchers in the primary bone cancer field. We interviewed Dr Strauss to find out more about this pioneering project.

WHAT WILL BE THE BENEFITS TO PATIENTS?

This study is the first to provide an opportunity for every osteosarcoma patient across the UK, irrespective of age, to enter a research project to study the disease in a way that has never been done before. The aim is to understand treatment patients receive, and by analysing tumour and blood samples collected at diagnosis and beyond and correlating these findings with patient data, to improve survival and quality of life of patients.

WHAT EXCITES YOU ABOUT ICONIC?

This is the first study that brings together scientists, pathologists, oncologists and surgeons from across the UK to work with patients to better understand this challenging disease.



IN YOUR PROFESSION, WHAT WILL THE PROJECT MEAN TO YOU?

This is a unique opportunity to work with experts across all disciplines across the country to make a difference in a challenging disease and ultimately to build a sustainable platform for ongoing research in the UK. It will provide opportunities to find new treatments and collaborate more widely across Europe to deliver continued improvements in outcome for osteosarcoma patients.

HOW IMPORTANT DO YOU THINK THE WORK IS OF THE BONE CANCER RESEARCH TRUST FOR PRIMARY BONE CANCER PATIENTS?

The Bone Cancer Research Trust is the only UK charity that focuses on primary bone cancers, understands the challenges of the diseases and is dedicated to improving the lives of bone sarcoma patients. The charity provides excellent information and support for patients, as well as raising awareness of these rare cancers. It also provides funds for research where there are few opportunities for funding and their recent initiative to provide funding for such an ambitious study, and for infrastructure to support tissue sample collection, is of great importance to osteosarcoma patients.



DID YOU KNOW?

ICONIC IS OUR LARGEST EVER RESEARCH PROJECT

TURN OVER TO MEET SOME OF
OUR ICONIC COLLABORATORS...

HERE'S WHAT SOME OF OUR COLLABORATORS HAVE TO SAY ABOUT ICONIC...

1 OSWESTRY

“The outcome of osteosarcoma has not significantly changed over the last 30 years. That is why the ICONIC study is so important; to focus on improving outcomes through collaboration between different treatment centres. The study will look at all aspects that can improve outcome in patients suffering from osteosarcoma. All treatment centres have signed up to the study and are fully committed to deliver the best care we can for our patients.”



Mr Paul Cool
Consultant Orthopaedic & Oncological Surgeon and President of the British Orthopaedic Oncology Society
Robert Jones & Agnes Hunt Orthopaedic Hospital, Oswestry

2 MANCHESTER

“ICONIC will maximise the valuable resource of patient data, biological material and quality of life of patients to truly design an interventional trial based on information of current UK osteosarcoma patients.”



Bernadette Brennan
Clinical Chair in Paediatric Oncology
Royal Manchester Children's Hospital

3 BIRMINGHAM

“ICONIC's collaboration between the treatment centres is really exciting. This is the first UK-led collaboration on osteosarcoma in my time as a consultant to combine clinical and biological research at its core.”



Professor Lee Jeys
Consultant Orthopaedic Surgeon
Royal Orthopaedic Hospital NHS Foundation Trust, Birmingham

4 OXFORD

“The ICONIC study is going to bring osteosarcoma patients and researchers together in a unique new way. This trial is going to allow all osteosarcoma patients to be actively involved which is exactly what patients and researchers are desperate for.”



Dr Sarah Pratap
Consultant Medical Oncologist
Oxford Cancer Centre

7 NEWCASTLE

“The most exciting feature of ICONIC is that it finally brings together a group of clinicians and scientists who have put a lot of effort into improving outcomes for our patients over the years. It is a major opportunity to co-ordinate our endeavours and make progress more rapidly.”



Kenneth Rankin
Honorary Consultant in Orthopaedic Oncology
Northern Institute for Cancer Research, Newcastle

5 GLASGOW

“It is exciting and inspirational being part of the ICONIC project, a collaborative research initiative. ICONIC is very important looking at unmet needs in such a rare clinical entity. ICONIC will inform a more tailored approach to managing patients and cultivating patient-centred care.”



Dr Ioanna Nixon
Consultant Clinical Oncologist
The Beatson Cancer Centre, Glasgow

8 STANMORE

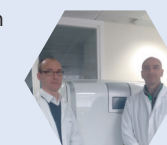
“ICONIC is an outstanding example of national collaboration. By patients being able to participate in research it will lead to improved treatments for osteosarcoma. ICONIC is absolutely essential.”



Craig Gerrard
Consultant Orthopaedic Surgeon
Royal National Orthopaedic Hospital, Stanmore

6 SHEFFIELD

“ICONIC will offer collaboration and the opportunity to learn from all the patients we treat with osteosarcoma. ICONIC will benefit osteosarcoma patients by leading to improvements in treatments and treatment outcomes.”



Robin Young
Sheffield Teaching Hospitals NHS Foundation Trust
Consultant in Medical Oncology and Honorary Senior Clinical Lecturer

9 LONDON

“By recruiting patients with osteosarcoma, collecting clinical data and tissues and aligning with other ongoing research initiatives in sarcoma, particularly that funded by the Tom Prince Cancer Trust, we will provide new insights into this challenging disease that we hope will lead to more personalised medicine and new drug targets that improve survival and quality of life for our patients.”



Professor Adrienne Flanagan
Professor of Musculoskeletal Pathology and Consultant Histopathologist
University College London and the Royal National Orthopaedic Hospital



DID YOU KNOW?

ICONIC BRINGS TOGETHER OVER 22 TREATMENT CENTRES NATIONWIDE

FIND OUT MORE AT:
BCRT.ORG.UK/ICONIC

Q&A WITH SARCOMA CLINICAL NURSE SPECIALIST JANE FORSYTHE



“ Sometimes parents worry and struggle with how to tell children about what they are going through. What words do I use? How deep do I go? What do I say not to frighten them? I always advocate you should be truthful with your child and sometimes that is very difficult for parents. Having ‘*Abbie Has Osteosarcoma*’ for guidance helps parents explain what is happening in easier terms.

We spoke to Jane Forsythe, Sarcoma Clinical Nurse Specialist at The Royal Orthopaedic Hospital, Birmingham. Jane volunteered her time to review our new children’s storybook *Abbie Has Osteosarcoma*.

CAN YOU TELL US ABOUT YOURSELF AND YOUR ROLE?

I’m a Sarcoma Clinical Nurse Specialist at The Royal Orthopaedic Hospital in Birmingham; I support patients 0-24 years old and their families going through a diagnosis of bone and soft tissue cancer. I’ve been working within the NHS Trust for 32 years and I’ve been a Clinical Nurse Specialist for 12 years.

Patients are referred to us every day from all over the country. I attend a daily Multidisciplinary Team meeting and we discuss patients that have been referred to us and who I will be supporting. They have my support throughout their journey and this includes; attending clinic, having a biopsy, undergoing surgery and their treatment.

Before they even come onto the ward, I contact them to introduce myself, answer any questions they may have, explain the whole process to them and give them practical information. This includes helping them coordinate their journey before they arrive. It’s a massive supportive role from the very beginning. The patients and their families really appreciate this support at such a difficult time.

WHY DID YOU DECIDE TO GET INVOLVED WITH REVIEWING *ABBIE HAS OSTEOSARCOMA*?

I’ve been doing my role for a long time and I have many years’ experience of looking after children with osteosarcoma and I wanted to share my expertise in this storybook. There is also no specific child friendly osteosarcoma storybook I can give to children and their families, so I wanted to be involved with the development of this essential new resource.



WHY DO YOU THINK IT IS IMPORTANT FOR CHILDREN AND THEIR FAMILIES TO HAVE ACCESS TO *ABBIE HAS OSTEOSARCOMA*?

Sometimes people go online for information and it’s not always accurate, but with *Abbie Has Osteosarcoma* you’ve got the right information at hand to give to children and their parents. I can tell them that I recommend it, I endorse it and the information is correct.

Sometimes parents worry and struggle with how to tell children about what they are going through. What words do I use? How deep do I go? What do I say not to frighten them? I always advocate you should be truthful with your child and sometimes that is very difficult for parents. Having *Abbie Has Osteosarcoma* for guidance helps parents explain to their child what is happening in easier terms.

HOW DO YOU THINK *ABBIE HAS OSTEOSARCOMA* WILL HELP CHILDREN AND YOUNG PEOPLE THROUGH THE DIAGNOSIS AND TREATMENT JOURNEY?

A lot of young children like books and it will give the family the opportunity to sit down together and read the story and look at the pictures. *Abbie Has Osteosarcoma* explains everything very simply and it will help children generate questions that I can answer.

It’s a book they can keep and go back to it whenever they want to. *Abbie Has Osteosarcoma* will support them from the start of their journey and throughout, they will be able to relate to it and will get a lot of benefit from the book.

DOWNLOAD YOUR FREE COPY OF *ABBIE HAS OSTEOSARCOMA* AT WWW.BCRT.ORG.UK/ABBIE

WHAT DIFFERENCE ARE OUR INFRASTRUCTURE GRANTS MAKING?

2016

In 2016 it was clear that not all bone cancer surgical centres had the resources they needed to collect patient samples for use in research. This meant there was a shortage of samples and research projects were suffering and, in some cases, were unable to be progressed. Here at the Bone Cancer Research Trust we are committed to allowing all patients to donate samples for use in research.

2017

We opened applications for Infrastructure Grants

2018

All 5 bone cancer surgical centres in England were awarded with a grant

BIRMINGHAM
THE ROYAL ORTHOPAEDIC HOSPITAL

“The collection of patient samples helps us to understand how cancers grow, where they originate from, and importantly it helps us to develop new, innovative treatments for the future. This has an impact not just on our patients here in Birmingham, it will have an impact on patients that suffer from these rare bone cancers across the UK and worldwide.

Professor Phil Begg
Executive Director for Strategy and Delivery

STANMORE
ROYAL NATIONAL ORTHOPAEDIC HOSPITAL

Without the support of BCRT, a mere fraction of samples would have been collected and made available for research.

Professor Jeremy Whelan
Consultant Oncologist, UCLH

OXFORD
NUFFIELD ORTHOPAEDIC CENTRE

“I cannot remember a time when the 5 UK surgical centres worked as closely as they are doing now. This is in part due to the Bone Cancer Research Trust's Infrastructure Grants and their funding of national clinical studies.

Mr Tom Cosker
Consultant Orthopaedic Surgeon

OSWESTRY
THE ROBERT JONES AND AGNES HUNT ORTHOPAEDIC HOSPITAL

“Particularly in rare cancers like sarcoma, it's important to have a better understanding of the genetic background of these tumours which is why we set up the Biobank of Health and Disease with funding from the Bone Cancer Research Trust.

Mr Paul Cool
Consultant Orthopaedic and Oncological Surgeon

NEWCASTLE
FREEMAN HOSPITAL

“In the short term patients are keen to see their samples used for research so the vast majority are happy to donate them. In the longer term these samples will start to make a difference in terms of identifying new therapeutic targets. One osteosarcoma patient who was keen to donate samples helped validate MT1-MMP as a therapeutic target and now two bone sarcoma patients have been referred to The Christie for consideration of an early phase clinical trial.

Kenneth Rankin
Consultant Orthopaedic Surgeon

ALMOST ALL SAMPLES WERE SENT FOR GENE SEQUENCING IN THE GOVERNMENT FUNDED 100,000 GENOMES PROJECT. BECAUSE OF OUR INFRASTRUCTURE GRANTS SARCOMA WAS THE LARGEST REPRESENTED GROUP OF CANCERS

2019

1,167 samples were collected during the year

14 projects are now being supported with samples

CHORDOMA PROJECTS
• Chordoma Multi'omics

OSTEOSARCOMA PROJECTS
• Osteosarcoma circulating tumour cells
• Osteosarcoma RNA-Sequencing
• Osteosarcoma recurrence and metastasis
• The 100,000 Genomes Project - osteosarcoma extension

GIANT CELL TUMOUR OF THE BONE PROJECTS
• Characterisation of Giant Cell Tumour (malignant and benign)

EWING SARCOMA PROJECTS
• Ewing sarcoma ctDNA
• Euro Ewing 2012 biological studies
• Ewing's Genotype
• GenoEwings
• rEECur - International Randomised Controlled Trial of Chemotherapy for the Treatment of Recurrent and Primary Refractory Ewing Sarcoma

CHONDROSARCOMA PROJECTS
• Chondrosarcoma ctDNA
• Chondrosarcoma miRNA sequencing

ALL PRIMARY BONE CANCER AND PRIMARY BONE TUMOUR PROJECTS
• The 100,000 Genomes Project



PHOEBE
CONSENTING
TO GIVING A
SAMPLE



EVIE
GIVING A
SAMPLE

FUNDRAISING



MEET OUR FUNDRAISERS AND FIND OUT HOW YOU CAN GET INVOLVED

We'd love for you to join Team Bones but we do understand that running marathons, climbing mountains and jumping out of planes isn't everyone's cup of tea! Fear not, there are lots of other ways that you can get involved! Here are just a few ways, but the possibilities are endless!

BAKE IT FOR BONE CANCER

"The Bone Cancer Research Trust is a charity very close to my heart, as in 2004 I was diagnosed with osteosarcoma. It means a lot to me to support BCRT and to help raise awareness of bone cancer. Bake it for Bone Cancer is something I love to do, and each year, I am overwhelmed by the support and generosity of my friends and family. My daughters, who are 7 and 3, love to get involved and help me bake. They also love to eat the cake! We will continue to hold these events and to support BCRT as much as we can."

Marnie Keenan, Former Patient

Raise some dough by hosting a bake sale, afternoon tea or coffee morning! Bake it or fake it, sweet or savoury - by getting together with friends and family to share some tasty treats you will help make all the difference.

Request your Bake it for Bone Cancer pack by visiting - bcrt.org.uk/bake



STAMP APPEAL

"We decided to collect stamps for the Bone Cancer Research Trust because we want to help people with bone cancer. It's really easy to save your stamps, every stamp counts and will make a difference."

Thomas, age 11 and Jamie, age 7

Collecting used stamps is a really simple way to raise money and save lives! Invite your friends, family, classmates and colleagues to join you and turn your everyday post into funds to support our vital work and help stamp out bone cancer.

Become a Team Bones Stamp Champ by visiting - bcrt.org.uk/stamps



FUNDRAISING

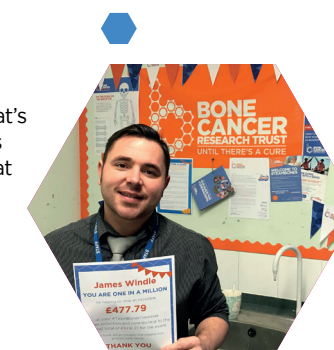
COINS FOR A CURE

"I decided to take part in Coins for a Cure, as bone cancer is an under-funded area of research that's relatable to my students based on the number of children it affects. The students really back this campaign because they realised that their small daily donations - the change from their bus fare, or what they had left from their dinner money - really began to add up and make a difference."

James Windle, Science Teacher at Parkside School

Our cardboard money boxes are perfectly sized to hold £30 worth of coins - that's enough to pay for one hour of our vital research. Request a box today and use your spare change to help save lives and find a cure for this devastating disease.

Order your free money box at bcrt.org.uk/coins



TEAM BONES TAKEOVER

"Volunteering has helped to create stronger bonds between my friends and colleagues, and for me to grow personally. Primary bone cancer is often ignored and isn't funded by larger UK cancer research charities - this was a great opportunity to raise awareness in the wider community."

Mandy Gill, Volunteer from BT

Donate your time and volunteer during Sarcoma Awareness Month, July or Bone Cancer Awareness Week, 7th-13th October and help us paint the town orange by taking part in a bucket collection in your local area. By organising your own, or joining one of ours, even giving up just an hour of your time to collect will help save lives.

To get involved please visit bcrt.org.uk/takeover



JINGLE BONES

"Our son Jude was passionate about raising awareness and funds to improve treatments and outcomes for bone cancer. Being involved with BCRT, especially after Jude died, has been so therapeutic for us. By taking part in Jingle Bones, his little brothers feel they are making a difference and that something positive can come from them losing their much-loved big brother."

Helen Anderton, Jude's Fund

Raise festive funds by organising a Jingle Bones Christmas Jumper Day on Friday 13th December, or whichever day suits you! Dust off your favourite winter woolies, festive fleeces or Christmassy knitwear and wear them proudly knowing that you are helping take us one step closer to finding a cure.

To find out more please visit bcrt.org.uk/jinglebones



DO YOUR OWN THING

"I decided to do the sponsored haircut as raising money for BCRT was our way of sharing what we were going through with people but putting it in a positive light, and it also gave us something to focus on during the early stages of Chris' treatment. And of course, it was for a very worthy cause!"

Kirsty Yule

Have you got your own idea to raise money? Some of the best fundraising events are those created by our amazing supporters. From extreme haircuts to Zumbathons - we love to hear about what you are planning and we will support you every step of the way, providing event inspiration, top tips and materials to help make the most of your very own event.

To get involved please visit bcrt.org.uk/ownthing



IF YOU WOULD LIKE TO GET INVOLVED, WE'D ABSOLUTELY LOVE TO HEAR FROM YOU!

WE'RE A FRIENDLY BUNCH, SO DO GIVE US A CALL ON 0113 258 5934 OR EMAIL [FUNDRAISING@BCRT.ORG.UK](mailto:fundraising@bcrt.org.uk)

KIRSTY, KATE & LAUREN, COMMUNITY FUNDRAISING TEAM

ROBERT'S STORY

Robert Sargieson was diagnosed with chordoma on 6th February 2012, after four years of misdiagnosis. Robert has kindly shared his story with us.



January 2008, 24 years old and celebrating the birth of our daughter, I started having pain in my coccyx. I decided to see my GP to see if there was anything wrong. I had fallen backwards in the garden earlier in the year and my GP said it sounded like I had damaged my coccyx and to take ibuprofen and paracetamol for the pain.

I was advised to come back if it persisted over the coming months. As the months passed the pain continued and I was referred to see a specialist in musculoskeletal medicine and I was diagnosed with coccydynia. I then noticed that there was a lump where my coccyx is, so I went back to my GP who referred me back to a specialist, I spent 2011 on different pain killers. In November, I again saw my GP who requested a second opinion and possibly an MRI. I was told this could take a while, so I decided to see a specialist privately and I was recommended for a coccyx manipulation to bring the coccyx back in line as it was clearly bent to one side.

In the meantime, as we had been engaged for six years, Michelle and I thought it would be a good time to get married. We had picked our venue for the following year, ordered our invitations and was looking forward to our big day, what could go wrong?

January 2012, after four years of pain I was about to have my coccyx manipulated under general anaesthetic. Off to sleep I went, I woke to the news that they could feel a lump and that an urgent MRI had been requested. A few days later I saw the consultant again, he told me that the mass was 16cm at its largest point, and that I would need a biopsy to determine what it was.

On the 6th February 2012, our worst fears were confirmed. The biopsy result came back, and it was official I had cancer, I was now officially a one in a million person, I had chordoma.

I was then referred to a specialist surgeon at Birmingham Royal Orthopaedic Hospital for surgery and I was also referred for proton therapy.

I had my surgery at the end of March and when I returned home there were only three weeks until our wedding. When the big day came around the sun was out, and the church was full. After all the heartache and stress of the first six months of the year, we had one of the most beautiful and perfect days of our lives.

My case was then approved by the proton panel and I was off to Jacksonville in Florida. Shortly after my return we travelled back to Birmingham for my first follow up. I had my MRI and we waited for the results. "I'm really sorry", three little words I was going to hear a lot over the next six years, the scan showed spots in my hips and pelvis. The following year, now into 2014, I had Radiofrequency Ablation. A technique that is like sticking a hot needle into the tumour to burn it out. I also had another follow up scan, and it was now in my spine and on a rib.

The lumps on my sternum and rib grew fast, and in 2015 I met a surgeon in Sheffield that could help me. I was in and out of Sheffield Northern General within a week. The next scan was also followed by those three words, I had more radiotherapy to my spine just before Christmas and in January 2016, I started on a drug called Imatinib. One of the disadvantages of being one in a million is that little is known about the disease and so there aren't many options, in fact there are no options following surgery or radiotherapy.



After six months it was obvious that Imatinib was not working for me.

Another drug being mentioned was Afatinib, there was news that a trial was upcoming, they agreed to let me try it on a compassionate basis. By this point, chordoma was now in all my vertebrae. I began the drug in October 2016, and for the first time we began to hear the word "stable". My trial of Afatinib lasted eighteen months and in 2018, I decided to cash in my pension and spend time with my family and go travelling. Although having cancer can take up a lot of your time and energy you can't let it run your life.

I then started having pain in my left leg, my scans were showing that one of my spinal lumps was pushing into the cord and I had to have decompression surgery. I had parts of vertebrae removed and rods and screws were used to strengthen my spine.

We had booked a trip to Disney World in Florida; my surgeon was confident that I would be well enough to go. As the weeks passed by, I started to get headaches and one day I started being sick and my balance was off. Michelle took me to Weston Park Hospital. I had more tests and we heard "I'm really sorry" again, the chordoma was now in my head. A 2x3cm lump somewhere behind my eye and in from my ear.

The team in Sheffield reviewed my case and recommended stereotactic radiosurgery. This is another type of targeted radiotherapy also known as Gamma Knife. A cage is fitted to your head and the dose is given in one day at multiple angles over 2-3 hours.

I didn't want chordoma to beat me and to take away a chance to make more memories with my family. We flew out to Disney as planned, and we had an amazing time!

January 2019, I received a phone call from The Christie to say that they had a drug which targeted a protein that had been identified in my samples.

With nothing to lose I signed up. The trial started well



but I began to have more pain in my spine, the pain had become too much. I had an MRI and two other spinal lumps were now pressing onto the cord. It was decided that I could have radiotherapy to relieve the pain. After this was given I was able to restart the second cycle of the trial which brings us up to the present.

I am booked in for a CT scan to assess how things are going, again if they are within tolerance I will stay on the trial. I have been told that further surgery is no longer an option, so trials are my only way forward. Having knowingly had chordoma for seven years I am extremely grateful for the time I have had, I know of some success stories and remain positive that I can beat this. I remain hopeful that something can be found for me in time.

I intend to make as many memories as possible in the time I have, and I'm determined to make it last as long as I can.

Read Robert's full story at

[BCRT.ORG.UK/ROB](https://bcrt.org.uk/rob)



NEW CHORDOMA RESEARCH PROJECT TO FIND TREATMENTS FOR PATIENTS LIKE ROBERT.

Chordoma is a rare slow-growing bone cancer that can occur in any of the bones from the base of the skull to the coccyx. Given its close proximity to the spinal cord, chordoma is difficult to treat, and very few drugs are available for patients.

We are delighted to announce that we have awarded funding to Dr Adam Cribbs and Dr Lucia Cottone. The main goal of the new research project is to use chemical compounds and epigenetic drugs to identify and validate new tractable targets for the potential treatment of patients with chordoma. Find out more about this pioneering research project at

[BCRT.ORG.UK/CHORDOMA](https://bcrt.org.uk/chordoma)

MEET PHD STUDENT HANNAH SPENCER AND DR ROBERT FALCONER

In the 1950s researchers from Bradford were amongst the earliest pioneers of a revolutionary treatment, chemotherapy. Now, over 60 years later, we are funding today's forward-thinking innovators at the University of Bradford with a PhD Studentship Grant, providing the next generation of researchers with the funds to work towards finding kinder and more effective treatments for osteosarcoma patients.

We interviewed Dr Robert Falconer and PhD student Hannah Spencer to find out more and take an exclusive behind the scenes tour of their lab.

CAN YOU TELL US ABOUT THE RESEARCH PROJECT?

We're focusing our attention on Methotrexate, a chemotherapy drug routinely used to treat osteosarcoma patients. While Methotrexate is a useful drug, it also acts on normal cells in the body, which means another drug (leucovorin) also needs to be given to minimise any unwanted effects. Methotrexate needs to be given in very high doses and can cause potentially serious side-effects to the liver and kidneys.

We aim to chemically modify Methotrexate so that it will be inactive in the bloodstream and normal tissues, until it reaches the tumour where it will be 'activated', but before we can test this approach in patients we need to do work in the laboratory.

WHY DID YOU DECIDE TO TRY AND CHEMICALLY MODIFY METHOTREXATE?

We were having a conversation with a clinician and I will never forget it! It was shocking to hear what patients go through. The clinician said, *'please, is there anything you can do with Methotrexate for osteosarcoma?'* and it started there.

WHY IS IT SO IMPORTANT FOR UNIVERSITIES TO RESEARCH RARE FORMS OF CANCER?

I think universities have a responsibility to do research into rare forms of cancer because a lot of companies choose to focus on cancers with the largest numbers of patients, so universities can make a real difference. I often get challenged when progressing projects like this, because the patient population is really small so commercially speaking it's not very attractive. I do, however, always make the argument that the reach to the clinic is possibly much faster because there is such a desperate need. There's currently nothing else, and clinicians have often told us that if we've got an agent that proves promising, they are willing to consider trying it in patients.

HOW IMPORTANT DO YOU THINK IT IS TO FUND A FOUR-YEAR PHD STUDENTSHIP?

It's difficult to get funding for PhD Studentships, funding bodies lean towards grants for Postdoctoral Fellowships, but with a PhD studentship a student gets the opportunity to immerse themselves in a project and it provides a springboard for students like Hannah to be an expert in this area for her career.

Also, to fund a four-year PhD studentship, which are often three years, allows the PhD to evolve how it should do, and to do everything in three years is sometimes impossible, realistically not everything can be done in the three years.

IF YOUR RESEARCH IS SUCCESSFUL HOW LONG COULD IT TAKE FOR PATIENTS TO START EXPERIENCING THE BENEFITS?

Methotrexate is already being administered to current patients, however the work Hannah and I are carrying out means it will be a new chemical entity (i.e. a new drug) and would still need to go through regulatory approval. The PhD is four years and if everything was on target, it could potentially be two to three years after the PhD has been completed.

OVER TO YOU HANNAH... CAN YOU TELL US WHY YOU WANTED TO BE INVOLVED IN THE RESEARCH AND SPECIALISE IN PRIMARY BONE CANCER?

I've previously studied Clinical Sciences and a Master's degree in Biomedical Sciences and that's when I stepped into research. I wanted to look at research and specifically; how cancer develops, why it develops and how we can target it.

Before starting my PhD I was working with a number of researchers on different projects. I aided in developing novel compounds for targeting colon cancer as well as looking at peptide activity in Alzheimer's disease.

Learning how awful osteosarcoma is for patients and the impact any novel treatment could have, is what drew me to this project. Knowing how awful Methotrexate is and what patients have to go through during treatment with this drug, I've become aware that a small change will make the biggest difference in someone's life. If someone I cared about was diagnosed I would want to know someone is working towards a similar outcome.

My PhD is my foundation and it will mould the way I learn. It may be that after my PhD I continue researching primary bone cancer and I find different ways of testing drugs using all the methods I've been taught here. I do hope that this is the case because research in this area is very important.

HOW DOES IT FEEL TO BE PART OF TEAM BONES?

I'm so happy because the team at the Bone Cancer Research Trust are so involved and engaged, I like that it is a community. You have a community of researchers working towards a similar goal and I've been in touch with the researchers and they have shared information and it's opened a lot of doors.

I attended the Bone Cancer Conference, the children you see and the stories about amputations makes you think, 'is that necessary? if we can make a drug more effective, it's going to make their life easier, it's going to make their life expectancy better.' That's the driver for me, that's what I'm working towards. That's it now... time to focus.



**THANK YOU! YOUR SUPPORT
OF OUR APPEAL IN SPRING 2018
MADE THIS PROJECT POSSIBLE.**

INTERVIEW WITH PAM KEARNS

At the Bone Cancer Research Trust, we fund the highest quality research into primary bone cancer and to ensure this happens we follow a rigorous review process. This process includes an Independent Scientific Advisory Panel (ISAP) and we had the pleasure of interviewing Professor Pam Kearns, Chair of our ISAP. Pam explains more about the role of ISAP and how they determine which projects are recommended for funding.

CAN YOU TELL US A LITTLE ABOUT YOURSELF AND YOUR BACKGROUND?

I'm a Professor of Clinical Paediatric Oncology at the University of Birmingham, I work as a consultant in Paediatric Oncology at Birmingham Children's Hospital. I'm also a Director of the Cancer Research UK Clinical Trials Unit at the University of Birmingham, which means I'm responsible for an academic unit that designs and delivers clinical trials. One of our largest portfolios is the children's cancer trials with 43 trials currently active. More recently I started a new role as President of the European Society of Paediatric Oncology, which is an organisation representing all professionals working in the field of Paediatric Oncology across Europe.

WHAT IS ISAP AND THE AIMS OF THE PANEL?

The Independent Scientific Advisory Panel (ISAP) is a panel of experts with a wide range of backgrounds and expertise covering science, clinical oncology and patient perspective.

There are 6 members on the panel and we jointly review funding applications submitted to the Bone Cancer Research Trust. Our aim is to ensure we look at applications for funding to make sure they are scientifically sound, feasible to deliver and fulfil the aims of the charity to ultimately improve the outcomes for patients.

HOW DID YOU GET INVOLVED WITH BCRT AND ISAP?

A colleague, who was the ISAP Chair at the time made me aware of the Bone Cancer Research Trust and suggested I joined the panel. I joined in April 2013 and became Chair December 2016. By joining the panel, I could bring my knowledge of science and clinical aspects of bone cancer treatment. I don't directly do research into bone tumours, but I have an interest in this area, therefore I could bring my experience and knowledge to the panel without there being a conflict of interest with the applicants.



WHAT IS YOUR ROLE IN ISAP?

My role as Chair of the panel is to ensure every applicant gets a good and fair review and to ensure that only the highest quality scientific research gets funded by the Bone Cancer Research Trust.

I work very closely with Dr Zoe Davison, Head of Research and Information at the Bone Cancer Research Trust to coordinate the meetings and to review the minutes and outputs.

As Chair of the panel I really appreciate everything the panel members do. They are incredibly thorough and want to ensure that it is the best researchers who are funded and, in a caring way, they support the younger researchers who are coming through to deliver high quality research for bone cancer. They really are the most incredibly dedicated and committed panel.

HOW DO YOU FEEL ABOUT BEING A MEMBER OF ISAP AND WORKING ALONGSIDE BCRT?

I feel privileged to be part of the Bone Cancer Research Trust's ISAP, it's a great charity. There isn't enough research done into bone cancer and to be working with a charity that are so committed to this field and to working with the best scientists and best clinicians to find ways to improve outcomes is fantastic. You get to see some excellent science coming through, it's a huge privilege and a great charity to work with.

One of the really nice things about the Bone Cancer Research Trust is it really wants to promote the best research for bone cancer through its funding, and if we have a good robust project that ultimately might have future benefits for patients they will look at every possibility to find a way to fund it.

HOW DOES THE PANEL DETERMINE WHICH RESEARCH PROJECTS ARE FUNDABLE?

The most fundamental and important part is to have a clear research question. We need to know what is the question the researcher is trying to answer and the background to why they think it's a good research question alongside a very clear description of the experiments they plan to do to answer that question. Remember to...

Be realistic... If it's a two-year project, what can you realistically achieve in that time?

Clearly explain... What are the steps involved?

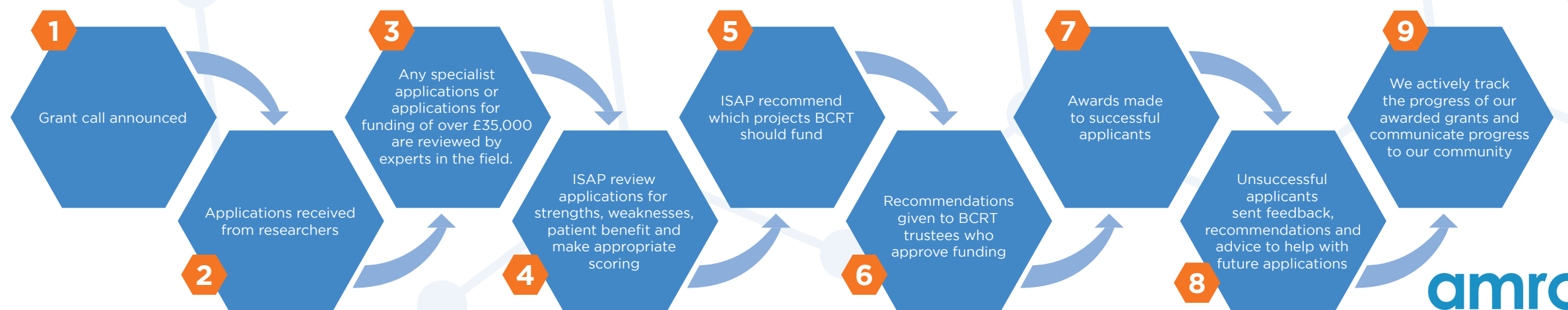
Provide clarity... Where is the project going in the future?

Think design... Use statistics and have a discussion with a statistician before applying

We also don't just look at what they say they are going to do but also have they got the expertise within their team to do it, what's their track record, and that's really important!

In some grant rounds we may receive eight applications and there is only funding available for two, therefore we must be very rigorous in our approach and it isn't about someone deciding which is their favourite project. The projects are all carefully scored against benchmarks. Sometimes there can be really good projects but this time round there just isn't enough funding available within the charity. Then the charity does look to see what can be done at a future date.

HOW WE FUND HIGH QUALITY RESEARCH INTO PRIMARY BONE CANCER



amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

We would like to say a very special thank you to all our ISAP members, who kindly volunteer their time to help us fund the highest quality research.

Professor Pam Kearns, Chair, Director of the Cancer Research UK Clinical Trials Unit, Birmingham

Professor Robert Brown, Deputy Chair, Institute of Cancer Research

Professor Andy Hall, Emeritus Professor, Newcastle University

Simon Allocca, Lay member and Father to Rose who passed away from osteosarcoma

Piers Gaunt, Senior Statistician, Cancer Research UK Clinical Trials Unit, Birmingham

Dr Richard Grose, Bart's College, London Society of Paediatric Oncology

NEW SUPPORT AND INFORMATION SERVICE

We are delighted to announce the launch of a new Support and Information Service to ensure we continue to offer help when you need it.

In 2018 we received an increase in support and information requests from the bone cancer community. We were contacted by 463 individuals for support and we distributed 16,668 support and information resources to patients, their loved ones and the bone cancer surgical centres. Because of this increase and the feedback provided by patients and families, we have identified there is a desperate need for a dedicated primary bone cancer Support and Information Service for our community.

Leading the service is our Support Manager and Registered Adult Nurse, Louise Kirby.

“My career as a nurse has helped shape my vision of what cancer patient support should be. We want all our community to know that we are here for you! Whether you are a current or former patient, a family member or a friend, don't be afraid to contact us.



DO YOU NEED SUPPORT?

☎ 0800 111 48 55

✉ support@bcrt.org.uk

🌐 www.bcrtrg.org.uk/support

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