

# UNITED

## UNTIL THERE'S A CURE

“ I WILL NEVER FORGET  
THE DAY WE GOT  
OUR DIAGNOSIS; I WAS  
IN SUCH SHOCK, SO  
MUCH I COULDN'T  
BREATHE

“ US KIDS ARE  
STRONGER  
THAN YOU THINK!

MOTHER AND  
DAUGHTER SHARE  
THEIR STORY

PAGE 10

### INSIDE THIS ISSUE

GP AND OSTEOSARCOMA  
SURVIVOR EXPLAINS  
WHY AWARENESS IS  
SO IMPORTANT

INFRASTRUCTURE GRANTS  
AWARDED TO ALL FIVE  
BONE CANCER SURGICAL  
CENTRES IN ENGLAND

GET INVOLVED IN  
BONE CANCER  
AWARENESS WEEK

PLUS MUCH MORE...



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



## EDITOR'S NOTE

Welcome to United, your free magazine from the Bone Cancer Research Trust. This issue is packed full of interviews, updates, stories and news.

Since our last edition in the Spring we've been extremely busy!

We are delighted to announce Infrastructure Grants have been awarded to all five sarcoma surgical centres in England. The grants will enable a collaborative network of sample collections for use in research. Turn to page 8 to find out more from the team at the Royal Orthopaedic Hospital in Birmingham about why it's so important to fund sample collections.

We had an exciting opportunity to interview Professor Cook about our first immunotherapy research project into Ewing sarcoma. Find out more on page 12.

Back in June, Professor Burchill and the University of Leeds opened their doors to our supporters, which gave them a unique opportunity to explore the lab. Read more on page 13.

We are making great progress with our information resources and on page 9, we spoke to Pip, former Sarcoma Clinical Nurse Specialist, about why our new *Step-By-Step Guide For Patients* is so important.

On pages 6 and 7 former osteosarcoma patient and GP, Dr Green shares his story and why raising awareness amongst GPs is so important. Later in the issue mother and daughter share their emotional and inspirational story, following a diagnosis of Adamantinoma.

Thank you to everyone who has contributed to this issue of United.

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](mailto:info@bcrt.org.uk).

**Deborah Flyde, Communications Manager**



## INSIDE THIS ISSUE

### 3 NEWS IN BRIEF

*Abbie has osteosarcoma* a new resource for children, PhD Studentship Grant and *One In A Million* update

### 4 - 5 2018 BONE CANCER CONFERENCE

Find out more about the day and details about next year's conference

### 6 - 7 PATIENT STORY AND GP AWARENESS

Phil Green was diagnosed with osteosarcoma, age 17. Now a GP, Phil has shared his story and why raising awareness amongst medical professionals is so important

### 8 INFRASTRUCTURE GRANTS INTERVIEW

Carolyn and Lucy from the Royal Orthopaedic Hospital explain the difference they think the grants will make to patients

### 9 STEP BY STEP GUIDE FOR PATIENTS

Former Sarcoma Nurse Specialist, Pip explains why the guide for patients is so important

### 10 - 11 PATIENT STORY

Jessica was diagnosed with Adamantinoma when she was just 9 years old. Mother and daughter have shared their story

### 12 NEW RESEARCH PROJECT - EWING SARCOMA

An interview with Professor Graham Cook, from the University of Leeds

### 13 RESEARCH LAB OPEN DAY

Professor Burchill and the University of Leeds opened their doors to our supporters

### 14 FUNDRAISING CHALLENGE

Alistair took on an amazing dog sledding challenge in Sweden

### 15 TEAM BONES TREK

The first ever Yorkshire Three Peaks Challenge

### 16 BONE CANCER AWARENESS WEEK 8 - 14 OCTOBER 2018

Find out how you can get involved

# NEWS IN BRIEF

## NEW SUPPORT RESOURCE FOR CHILDREN LAUNCHING THIS YEAR

Meet Abbie...Abbie is a normal 9 year old, living with her family, enjoying school and playing dress up until she is diagnosed with osteosarcoma. *Abbie Has Osteosarcoma* is our newest Children's information resource and is the sequel to *Harry Has An Operation*. A cancer diagnosis is overwhelming for the whole family and until recently, there has been little information tailored specifically to younger children. This story book is an interactive resource, which will guide a child and their family through every aspect of an osteosarcoma diagnosis. *Abbie Has Osteosarcoma* will be launched as part of **Bone Cancer Awareness Week 2018**.



## URGENT APPEAL UPDATE - PHD STUDENTSHIP GRANT

As part of our 5 year strategy, we committed to funding one PhD studentship in 2018 but thanks to your support and response to our recent appeal we are delighted to announce the funding of an additional PhD Studentship Grant to Dr Robert Falconer at the University of Bradford. The four year project is aiming to dramatically reduce the severe side effects of Methotrexate, a chemotherapy agent used in the treatment of osteosarcoma. Current side effects include low blood counts, hair loss, mouth sores/ulcers, nausea and diarrhoea. It is also hoped that this pioneering project could see the increased efficiency of the drug and improve its ability to treat osteosarcoma. It will also train a young scientist in the field of primary bone cancer. Visit [bcrt.org.uk/research](http://bcrt.org.uk/research) for more information.



## ONE IN A MILLION UPDATE

Thanks to the support of the bone cancer community we are doing incredibly well at working towards reaching our fundraising target of £1,000,000 in 2018. We've seen our amazing supporters take on incredible activities and challenges from the London Marathon, trekking the Yorkshire Three Peaks, running the Sahara Desert, holding the most mouth watering bake sales to the most sponsored haircuts we've ever seen! Each and every one of you have been **One In A Million!** Your support has never been more important, get involved in our 2018 campaign at [bcrt.org.uk/million](http://bcrt.org.uk/million).





# BONE CANCER CONFERENCE

## OUR COMMUNITY TOGETHER

The 2018 Bone Cancer Conference brought together patients, families, researchers and medical professionals at one of the most inspirational events we have held to date! The theme of the conference 'Our Community Together' offered a forum like no other. The day covered inspirational stories, supportive sessions and informative presentations.

### SHARING PATIENT STORIES



Mother and daughter - Jane and Daisy, shared their story of Daisy's diagnosis of Ewing sarcoma when she was just 8 years old.

“ It was great to hear patient stories as it motivates us to continue to research to try and find better treatments

**Biobank Assistant**



Dr Phil Green was diagnosed at 17 years old with osteosarcoma and shared his story and why raising awareness of the 'Red Flag' symptoms with GPs is so important.

“ Very personal experiences and gives me hope for the future

**Patient**



Sarah Dransfield was diagnosed with osteosarcoma and shared her emotional story - one year, ten rounds of chemo, seven operations, one amputation and five years later, I'm still here, all down to the Bone Cancer Research Trust.

“ It was a fantastic day for us. It was great to hear about all the work going on, and to hear the inspirational stories of patients and their families. We got to chat to quite a few people during the day, and in particular Pete - hearing about his battle with methotrexate in addition to his cancer really put our project into focus.

**Researcher**

# REGISTRATION IS NOW OPEN



## SUPPORT SESSIONS



Damian Harper is an osteosarcoma survivor and amputee. Damian shared his experience of osteosarcoma and also provided attendees with more information about the Amputation Foundation and how we are working together to support those affected by primary bone cancer.

“ A lovely warm family feeling. A great mix of patients, families, researchers, trustees and staff. Good arrangement with round tables and the groups of mini sessions (support) and important times to mix and talk.

**Family or Friend of Patient**



Gill Johnson, Trustee at the Bone Cancer Research Trust held Round Table Discussions during the day. Delegates had the opportunity to choose the topics and themes, these included mental health and living with an amputation.

“ It was my first conference and I have never been as inspired as I have been today, I felt so welcomed and part of an amazing community. Thank you so much for everything you have done today it was truly amazing.

**Family or Friend of Patient**

## RESEARCH UPDATES



Researchers joined us on the day to update our supporters about current research projects and newly awarded projects in 2018. These included an Explorer Grant and PhD Studentship Grant for Ewing sarcoma and a PhD Studentship Grant aiming to eradicate the side effects of methotrexate, as well as making it more targeted for osteosarcoma patients.

“ All very informative, educational, interesting and held my attention. Also not too heavy.

**Family Member of Patient**

“ A very informative and enjoyable conference. Very well organised and great to see so many professionals and families attending. Great to hear about the exciting research projects being funded.

**Family Member of Patient**



We were also delighted to announce that Infrastructure Grants have now been awarded to all five bone cancer centres in England. The centres now have the resources they need to give patients the opportunity to be included in future research by donating samples. This is an enormous step forward for involving patients in research and for the primary bone cancer community.

**THANK YOU TO ALL OUR PRESENTERS, PARTNERS, PATIENTS AND THEIR FAMILIES AND FRIENDS FOR JOINING US ON THE DAY. WE HOPE TO SEE YOU NEXT YEAR!**

**2019 BONE CANCER CONFERENCE**

**DATE: SATURDAY 29TH JUNE 2019 LOCATION: LEEDS**  
VISIT [BCRT.ORG.UK/CONFERENCE](http://BCRT.ORG.UK/CONFERENCE) OR CALL US  
ON 0113 258 5934 TO BOOK YOUR PLACE TODAY!

# PHIL'S STORY



GP and former osteosarcoma patient, Dr Phil Green, shares his story and why he thinks raising awareness amongst medical professionals is so important.

In 1987 at age 17, I started with a vague gnawing discomfort in my left knee, but the pain progressed. My doctor assured me it was probably growing pains, so I tried to continue as normal.

But the pain slowly magnified, never allowing me any peace and I began to dread the night time as I would lie awake for hours in pain. I returned to see my GP and his response was very different this time and I was urgently referred to an orthopaedic surgeon.

By this point the pain was unbearable, like a hot skewer being driven through my knee; each wave took my breath away, leaving me feeling nauseated and drenched in sweat. My parents took me to A&E where I was X-rayed, admitted overnight, then transferred to Glenfield Hospital in Leicester for a bone biopsy.

The doctor told us: "I'm afraid you have a malignant neoplasm... unfortunately it's bone cancer". I don't remember hearing anything else – my senses were utterly paralysed. **I was 17: I didn't even know you could get cancer of the bone.**

The type of limb salvaging surgery I would have would be based on the success of the pre-operative chemotherapy. Chemo was horrible. I lost my hair, had persistent nausea and vomiting and painful mouth ulcers. Unfortunately, the treatment wasn't enough to save my leg: a CT scan showed there had been no significant response to the chemo. I pretty much decided on an amputation there and then. There was no other option as far as I was concerned.

After having so much pre-operative chemo I was adamant that I wanted to minimise any risk of recurrence, which I was told was quite high with any sort of limb salvaging surgery.

**In one sense, amputating my leg was the easiest decision I've ever made because it was so clearly the route that would give me the best chance of survival. It gave me the opportunity of totally eradicating the cancer.**

It also offered a strange sense of relief because I always saw the cancer as something of an alien, a parasite that didn't belong in me and which I was desperately keen to be rid of.

Monday February 15th, 1988 was D-Day. My parents took me to the hospital, and my dad was asked to sign the consent form. He found it incredibly difficult and later told me **he felt as though he had signed my leg away.**

After the surgery I woke up and had to ask the nurse if they'd actually carried out the operation because I could still feel my leg. They told me my leg was gone and that I was experiencing phantom limb pains. That was it, the cancer was gone! I could now think of moving on and it was from that point that life restarted.

I was out of bed the day after surgery to start physiotherapy and was well enough to be discharged just 3 days after the amputation. I was fitted with a basic prosthesis 6 weeks later.

I learned to walk, and picked up with sports, and later that summer I even managed to start playing competitive cricket matches. I had to continue with chemotherapy after surgery and at the same time I returned to 6th form college.

Since then, I've qualified as a doctor, travelled the world and worked as a flying doctor in Australia. I continued to play most of the sports that I loved before my illness.



but also discovered new sports. I had the opportunity to scuba dive on the Great Barrier Reef and I was even asked to join the Paralympic Volleyball Team.

In 1998, I had my 10 year follow up appointment with the oncologist. I was told that it would be my last appointment and that I was cured. 1998 was also

the year my wife gave birth to our first daughter. Having been told that the chemotherapy would probably make me infertile, my daughter's arrival was nothing short of a miracle to us. Since then we've had a second daughter, another miracle that I never expected and for which, I feel so incredibly blessed.



## Q&A WITH DR PHIL GREEN



With over 20 years' experience as a GP, Dr Green explains more about the importance of the Bone Cancer Research Trust GP e-learning module and why it is so essential for GPs to be aware of the symptoms of primary bone cancer.

### WHY DO YOU THINK IT'S IMPORTANT FOR GPs TO BE AWARE OF PRIMARY BONE CANCER SYMPTOMS?

Primary bone cancer is rare and therefore, the average full-time GP is likely to see between zero and one case of bone cancer throughout their whole career.

30% of all GP consultations are for musculoskeletal disorders and it is therefore very difficult for GPs to sieve through them and spot the serious presenting pathologies. A heightened awareness and a good knowledge of the presenting features is critical for a GP to make an early diagnosis and thereafter, to follow the correct rapid-referral pathways.

### HOW USEFUL IS THE BONE CANCER RESEARCH TRUST E-LEARNING MODULE FOR GPs?

I have used the BCRT e-learning module and it is superb. It covers everything a GP needs to know about the 'Red Flag' presenting symptoms and signs of bone cancer, some theoretical background of the various forms and places great emphasis on the critical relationship between early detection and improved prognosis. All GPs are aware of bacterial meningitis but many will never see a case. The same should apply to bone cancer because a missed diagnosis can be

equally catastrophic. That is the reason GPs should take a few minutes to complete the e-learning module.

### ARE GPs TRAINED IN PRIMARY BONE CANCER SYMPTOMS? IF NOT, WHY NOT?

GPs are not specifically trained in primary bone cancer as it is not a specified component of the GP trainee curriculum. It may be that their knowledge comes from seeing a case in practice or via background reading but no mandatory training in this area of medicine is required to become a qualified GP.

### AS A FORMER PATIENT AND A GP WHAT MESSAGE WOULD YOU GIVE TO PATIENTS OR OTHER MEDICAL PROFESSIONALS?

It is critical to be persistent as a patient if you feel that your symptoms have a potentially serious underlying cause and insist that further investigations are performed. As a medical professional, the opportunity to make a significant difference to a patient's prognosis and future life is a gift but missing a case by delaying or missing a diagnosis is catastrophic, not only for the well-being of the patient but also that of the medical professional.

**TO FIND OUT MORE ABOUT THE E-LEARNING MODULE, PLEASE VISIT [BCRT.ORG.UK/GP](http://BCRT.ORG.UK/GP)**



## Q&A WITH CAROLYN AND LUCY



Infrastructure Grants have been awarded to all five sarcoma surgical centres in England. The Grants enable a collaborative network of sample collections for use in research.

**Carolyn and Lucy from the Royal Orthopaedic Hospital in Birmingham explain more about why it's so important for the Bone Cancer Research Trust to fund their work collecting samples.**

### **CAN YOU TELL US A BIT ABOUT YOUR ROLE AND YOUR INVOLVEMENT IN THE INFRASTRUCTURE GRANTS?**

The Royal Orthopaedic Hospital has been awarded essential infrastructure funding from the Bone Cancer Research Trust to help us grow our tissue collection capabilities which are the foundations of many of our bone tumour research programmes. We worked closely with colleagues Professor Lee Jeys (Consultant Orthopaedic Oncology Surgeon) and Dr Graham Caine (Head of Pathology) to identify gaps in current resources and ways in which these could be addressed to ensure that we can collect tissues from all patients who have consented to take part in our growing portfolio of bone cancer research programmes. We realised that resource had to be dedicated to two key areas to coordinate tissue based studies, and to support the surgeons in theatre to prepare the research samples and manage all of the associated administration. Our team works closely with the wider orthopaedic oncology team and with the research nurses to ensure that there is a seamless process in place to deliver research tissues that are of the highest quality to enable this vital research.

### **WHY DO YOU THINK IT'S SO IMPORTANT FOR THE BONE CANCER RESEARCH TRUST TO FUND TISSUE SAMPLE COLLECTIONS?**

Having access to many different types of bone tumour tissues which are well preserved and therefore of high quality enables scientists to undertake important research

into what causes these tumours to develop, which biological factors influences treatment response and how we can improve our ability to detect bone cancers and predict patient outcomes. This research can help us to develop a deeper understanding of the causes and behaviours of these types of tumour and therefore in the long term, better more targeted treatments. With the additional insights gained from whole genome profiling and the 100,000 Genomes Project we may also be able to develop much more personalised treatment pathways for patients with bone tumours in the future.

### **WHAT DIFFERENCE DO YOU THINK THE INFRASTRUCTURE GRANTS WILL MAKE FOR PATIENTS?**

Without this infrastructure far fewer tissues would be collected for research purposes within the Trust and those collected may not be received by the researchers in an optimum condition. Research samples need additional documentation and different collection, storage, transportation, processing and preparation than those taken as part of routine care. By dedicating resource to this process, we can ensure that these aspects are delivered in accordance with ethically approved protocols and in line with the patients' wishes.

### **IS THERE A MESSAGE YOU WOULD LIKE TO SEND TO OUR SUPPORTERS?**

We would like to express our sincere thanks to BCRT supporters who have made the creation of this essential infrastructure possible. It will give us the capacity and capability to deliver more bone cancer research to the highest quality standards for years to come.

**FOR MORE INFORMATION ABOUT OUR INFRASTRUCTURE GRANTS VISIT [BCRT.ORG.UK/RESEARCH](http://BCRT.ORG.UK/RESEARCH)**



# NEW STEP-BY-STEP GUIDE FOR PATIENTS

**ALL THE INFORMATION YOU NEED AT YOUR FINGERTIPS!**

**We spoke to Pip Large, former Sarcoma Clinical Nurse Specialist and current BCRT Trustee. Pip, explains more about her time as a nurse and why she thinks our new 'Step-By-Step Guide For Patients' is so important.**



## **CAN YOU TELL US ABOUT YOUR ROLE AS A SARCOMA CLINICAL NURSE SPECIALIST?**

During my long nursing career (I will celebrate 50 years next year) I have been involved in a variety of specialist roles – a bit of a jack of all trades I believe! But in all this time I have done little with cancer care, and as an orthopaedic trained nurse I was enthusiastic to take the opportunity to combine orthopaedics and cancer, joining the Oxford Sarcoma service as a Clinical Nurse Specialist (CNS) in 2010.

The responsibilities of the CNS role as I saw it, were acting as advocate, both to the patients and to their families. Having a cancer diagnosis, coping with the symptoms, diagnostic processes and treatment, which can be long and unpleasant, and leaves many feeling vulnerable and confused, frightened and distressed. The work undertaken by the CNS role and the support and direction offered can go some way to alleviating some of these concerns. Becoming a 'family friend', a link between all the services and trying to join these up allows for a 'smoother' pathway and less stressful experience. I supported patients all the way through their journey. I could be visiting them when they were undergoing surgery and when they were having their chemotherapy.

## **FROM YOUR EXPERIENCE AS A SARCOMA CLINICAL NURSE SPECIALIST, WHY DO YOU THINK THE STEP-BY-STEP GUIDE FOR PATIENTS IS SO IMPORTANT?**

The Step-By-Step Guide For Patients is fab. At Oxford the

team spoke about the need for a patient information pack so I know how useful and needed this guide is. I hope that every patient newly diagnosed will be offered a guide and be helped and encouraged to use it to its best advantage. It is a discretionary use but I do hope that patients will find it useful, practical, supportive and ultimately invaluable while going through treatment, and then after when life gets back to some normality, acting as a memoranda of a unique life experience.

## **HOW USEFUL DO YOU THINK HEALTHCARE PROFESSIONALS WILL FIND THE STEP-BY-STEP GUIDE FOR PATIENTS?**

For professionals, the pack will be a tool to support and inform patients and families when discussing and coping with difficult topics and situations. It has the potential to be a communication tool between professionals and the patient by being a written record that can inform staff of the wealth of information around diagnosis, treatments or problems that have occurred both in the treatment centre but also at other hospitals or treatment centres. It can reinforce and support the information given by staff, often difficult for patients to retain during a consultation. It allows staff to ensure contact information is available and recorded along with medical information.

## **IS THERE A MESSAGE YOU WOULD LIKE TO SEND TO OUR SUPPORTERS?**

From a retired clinical specialist and research nurse the *Step-By-Step Guide For Patients*, which has been long overdue, is going to be a huge helping hand, to both patients and families, providing all the information needed to guide and support those trying to cope and get through a bone sarcoma diagnosis. I would like to send a big thank you to all the BCRT supporters, your support has allowed this guide to become a reality.

**VISIT [BCRT.ORG.UK/PATIENTGUIDE](http://BCRT.ORG.UK/PATIENTGUIDE) TO DOWNLOAD OR ORDER YOUR COPY.**

# JESSICA'S STORY

Jessica was diagnosed with Adamantinoma when she was just nine years old. Maxine, Jessica's mum has shared their story and Jessica explains in her own words how her diagnosis made her feel.

January 2015, Jessica was sitting on the sofa one evening and I felt quite a large lump on her leg. I made an appointment for Jessica to see the GP. The GP didn't really know what the lump was so said he would send an urgent referral to the orthopaedics department at the hospital.

The following day I received a phone call from the hospital, asking me to take Jessica straight to the hospital. I was shocked and winded, so much I couldn't breathe. I knew it was serious if the hospital wanted to see Jessica so urgently. Jessica was taken for an X-ray and she gave blood samples. They could see a mass in her X-ray on her right leg and an MRI confirmed it was a tumour.

My maternal cousin died at 37 of Ewing sarcoma so we were beside ourselves at this point.

Jessica was referred to Birmingham Royal Orthopaedic Hospital for a biopsy. All this was within 9 days of discovering her tumour. The NHS were marvellous. We then had the longest 10 days of our lives to wait. The results were in and originally Jessica had Osteofibrous Dysplasia and the consultant decided to just keep an eye on her for the time being.

**By April Jessica was experiencing some discomfort and pins and needles in her foot. An MRI showed the tumour had turned into Adamantinoma. The consultant decided it was time to operate and remove the tumour.**

Jessica was given the option of a bone donor graft or using her own bone from her fibula. The words 'you can have some bone from a dead person' did not go down well with Jessica so she decided on the latter. Her operation was booked in for 4th June 2015.

The day of surgery approached. 4 hours after surgery she returned with a huge metal contraption on her leg. This was because the tumour was 8 x 6cm in size and therefore the surgeon removed 12cm of her tibia bone

with the fibula put in its place. On the X-ray it looked like two coke cans and a straw in between.

Jessica refused to look at the mechano set until we saw a little girl no more than 3 in age with an amputated leg and I pointed out to Jessica how lucky she was that the surgeons saved her leg. After that, Jessica seemed to be accepting of this fact and then actually became proud of the fact she had survived cancer and was on the road to recovery.

The next few weeks was really hard as Jessica struggled to move. I had to get her out of bed, wash her, dress her as she had zero mobility. I also had to clean her pin sites (frame holes) every week meticulously. Jessica was wheelchair bound at this point but after two weeks of rest Jessica went back to school. She is a bright girl and didn't actually miss too much of school and even the bits she did miss she soon caught up.

Over the next few months Jessica gradually learnt to use crutches which gave her a small amount of self-mobility and five months later her metal mechano set was removed and replaced with a nice purple pot. Jessica was fitted some weeks later with a supporting splint. This was because although the bone had fused this was not enough to support her weight. Jessica continued to use her crutches for some more months gradually decreasing the usage and then walking free with her splint. In time her splint was removed for small periods and then gradually removed all together.

We are now almost three years down the line and I look back and think how did I manage, but you do, you get on with it and cope. Jessica so far has made a full recovery and we now have annual check ups. **I pray every time for good news as you just never know what is round the corner and how things can just change your life at the drop of a hat.**







My name is Jessica,  
I have Adamantinoma bone  
cancer, my treatment was  
surgery and a frame fitted to  
keep my bones together.

It made me feel trapped because  
I couldn't do anything, I was kind  
of bed bound but my mother  
and my best friends helped me

through. I was worried about it coming back but worse and in a more  
serious way.

My message to others is to stay strong no matter what happens  
because the only thing stronger than you is your love for  
yourself and no-one can tear you down.

I wanted to share my story with others because a lot of  
people underestimate us kids for either being a wuss or  
just not strong enough but in reality we are stronger  
than you think!

Everyone should support the Bone Cancer Research  
Trust and help to make others feel happy!

X





## Q&A WITH PROFESSOR GRAHAM COOK



Professor Graham Cook, from the University of Leeds tells us why funding our first ever immunotherapy research project - Oncolytic Virus Therapy for Ewing sarcoma is so important and the difference it will make to patients and researchers of the future.

### WHAT ASPECTS OF THIS PROJECT MAKE IT REALLY STAND OUT FROM OTHER EWING SARCOMA RESEARCH TAKING PLACE AT THE MOMENT?

Our research looks at new treatments being used in other cancers and applies them to Ewing sarcoma. These drugs work by getting the patient's immune system, the way we normally get rid of coughs and colds, to attack Ewing sarcoma this is called immunotherapy and it is working well in other cancers. However, we won't turn our back on the existing treatments. We think that combining treatments is the way forward, using new immunotherapy drugs alongside chemotherapy and radiotherapy.

### HOW IMPORTANT IS THE FUNDING PROVIDED BY THE BONE CANCER RESEARCH TRUST FOR THIS PROJECT?

It's vital. We could not do the work without BCRT's support. Funding the work over four years allows us to tackle a big problem. Also, I can't pretend that research is always plain sailing, you sometimes go down blind alleys and biology doesn't always work the way you think it should. With longer term funding you go deeper, learn more and make more progress. There is another important aspect to this funding. It is funding a PhD Studentship. We need to invest and train young scientists, they represent the future of research and how it will shape and improve treatment in the years to come.

### WHAT DIFFERENCE WILL THIS PROJECT MAKE FOR EWING SARCOMA PATIENTS IN THE FUTURE?

The agents we are testing in the lab are in clinical trials in other cancers. This reduces the time between lab-

based research and a clinical trial. If we get promising results in the lab then we can work with our clinical colleagues to start trials in Ewing sarcoma.

### WHAT WOULD YOU SAY TO OUR SUPPORTERS THAT ARE RAISING FUNDS FOR RESEARCH?

Keep up the good work! Ewing sarcoma is a relatively rare cancer and doesn't attract the level of research funding that some of the more common cancers do. However, it remains a very challenging condition for all patients and their families and more research is needed to tackle it. Your support makes that happen. Thank you.

**This pioneering project will run for four years and will be co-funded by the Ewing's Sarcoma Research Trust. It will be a PhD Studentship, supporting the next generation of researchers in the field of primary bone cancer. To find out more visit [bcrt.org.uk/research](http://bcrt.org.uk/research)**



**Professor Cook with Senior Researcher Fiona Errington-Mais**





# LABORATORY OPEN DAY



This year we were delighted to award funding to Professor Sue Burchill and Professor Xuebin Yang in partnership with Ewing's Sarcoma Research Trust at the University of Leeds.

The new research project aims to develop a unique pre-clinical tool, which combines both Ewing sarcoma and non-cancerous cells from the tumour micro-environment to give a more realistic model of Ewing sarcoma. This project will use this model to understand how the cells surrounding the tumour affects how Ewing sarcoma responds to treatment and to develop more effective treatments that target the self renewing, chemo-resistant cells, thought to be responsible for relapse.

Professor Burchill and the University of Leeds opened their doors to our supporters, which gave them a unique opportunity to; look at Ewing cells under a microscope, practice pipetting, tour the lab and find out more about the pioneering research being carried out into Ewing sarcoma.

Thank you to all that those who attended the lab open day and to Professor Burchill and her team.

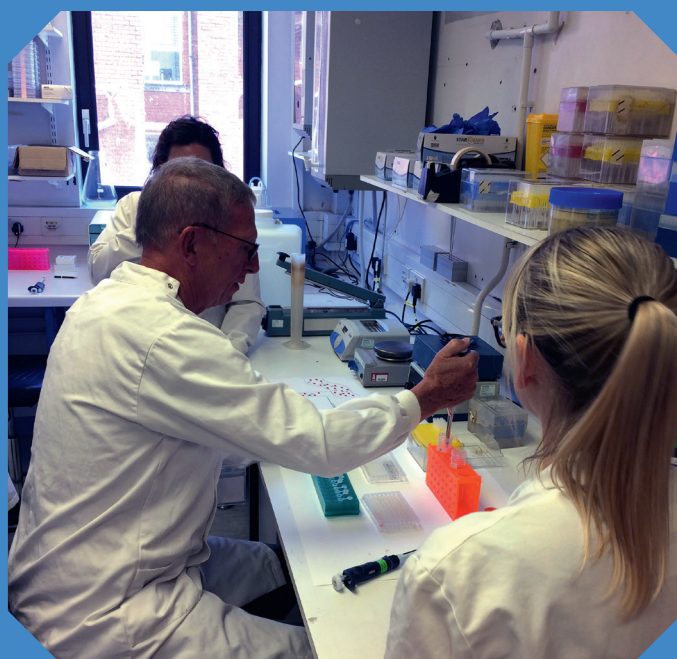
“ It is both humbling and rewarding when patients, their families and carers visit the lab to find out more about the work we do. Without the financial support of BCRT our innovative research developing tools to help create more personalised treatment to improve outcomes would not be possible. The funding from BCRT and ESRT has been especially valuable in maintaining the programme of research. The lab visits and BCRT conferences provide an opportunity to meet and find out what patients and families want to know about, what they care about, what is important to them. Connecting with those who have been directly affected by this disease keeps our research relevant and focused, so that together we can eradicate Ewing sarcoma.

**Professor Sue Burchill**



“ Many thanks to Sue and her team for a fascinating “hands on” visit to the research lab. It was very informative. Their dedication and perseverance towards finding a cure is so inspiring.

**Dave Harley, Former Ewing sarcoma Patient**





# DOG SLED CHALLENGE

Alistair took on a dog sledding challenge in Sweden after finding out his Great Aunt was diagnosed with bone cancer. Alistair covered 200 Kilometres of frozen landscape driven by a team of huskies in temperatures of -35 degrees.

**“** Sweden was challenging but also amazing, one of the best experiences I have ever had! This is something I wanted to do for my Great Aunt and the Bone Cancer Research Trust because they do such fantastic work. I managed to raise £3,067.00!

**Alistair Charlton**

## DAY 1

The day has finally arrived, I'm excited yet nervous. We flew to Stockholm in the early hours of the morning, we could see the frozen lakes and forests, it was breath-taking. After about an hour and half flight we landed in the snow!

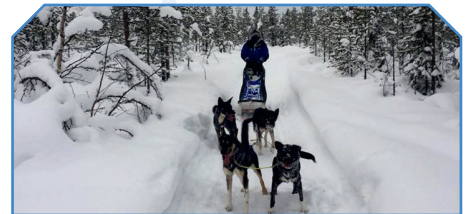


## DAY 2

We arrived at the kennels and were matched with our huskies. My team of huskies consisted of: Moni, Divi, Nina, and Busta. 3...2...1.... and we were off! It really is spectacular, whizzing through the snow, just an expanse of snow and trees as far as the eye can possibly see.

## DAY 3

My highlight today was winding in and out the trees before opening up to a frozen lake. We were shown how to get water from the lake without falling down the hole! This of course is going to be vital for our trip. Later in the day we arrived at our new home 'The Wilderness Cabin'.



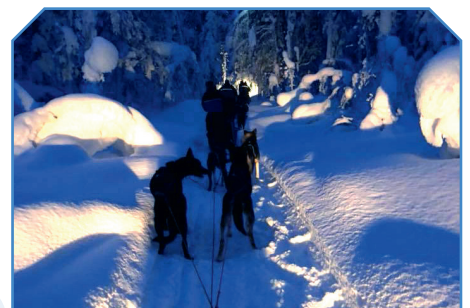
## DAY 4

My team of dogs were all running very well, and they had the opportunity to eat snow or dip their head in, simply to cool down and hydrate themselves. Then disaster hit! The snow was deep and it was hard to judge what was the edge of a lake and safe land. With uneven snowfall team members held on for dear life, some losing their sledges and their dogs would run off into the distance. I helped the others get up and collect their dogs.



## DAY 5

It was extremely cold today and the snow ever so deep and past my waist! Again, a difficult terrain led to a team member falling of their sledge and the dogs running off. I couldn't leave them behind, so we shared a sledge, which was challenging as we both had to balance on either side so we didn't fall. We caught up with the group, but it then became extremely dark and everyone had their head torches on. You could just see a line of head torches winding throughout the darkness and frozen landscape.



## DAY 6

The temperature dropped a lot today, but this wasn't going to affect my last day. We went across a few lakes; the ice must be around three metres thick. We arrived back at base camp where we received our expedition medals. I unharnessed my dogs and sadly said goodbye to my team. I will certainly miss the view, trails and my dogs.





# THE YORKSHIRE THREE PEAKS: #TEAMBONESTREK



On July 15th 2018, we held our first ever Team Bones Trek. The event saw 40 walkers come together to trek the Yorkshire Three Peaks; Pen-Y-Ghent, Wharfedale and Ingleborough. The group climbed 5,200ft and walked 24 miles!

“ I finished with my brother Geoff and friend Jason. The whole trek was tough but amazing with fantastic views, weather was hot but brilliant. Many thanks to all who have supported me in raising funds for the valuable research and support work done by BCRT into this devastating disease and in memory of our greatly missed daughter Emily. Thanks to BCRT for professionally organising the event and to our guides. It was a day I'll definitely remember.

**Steve**



“ I was really inspired speaking to you all who work for the charity and finding out more about your work. I don't think I have ever come across a charity where you get the personal feel. Everyone is a credit to the team.

**Philippa**



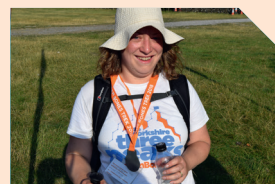
“ Everyone at Team Bones was brilliant and so supportive in the run up to the event and especially on the day. It was definitely one of the hardest things I have ever done and it was both physically and emotionally exhausting. I'll never forget the day or the amazing people I met on the walk. My whole body ached for days after, but it was so worth it and I feel so proud of myself and my friends. We did it!

**Kerry**



“ I have never taken on a challenge this big before. The day was harder than I thought it would be. However it was really lovely meeting the families of people who were affected by bone cancer. Also the guys leading the walk were amazing, pushing you along at the right time and encouraging us all the way.

**Jean**

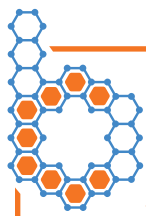


A fantastic amount of **£20,000** has been raised from the Team Bones Trek to help continue the fight against primary bone cancer. Thank you to all our walkers!

IF YOU WOULD LIKE TO BE PART OF TEAM BONES AND TAKE PART IN A CHALLENGE EVENT VISIT [BCRT.ORG.UK/EVENTS](http://BCRT.ORG.UK/EVENTS) TO FIND OUT MORE.







# BONE CANCER AWARENESS WEEK

8-14 OCTOBER

Bone Cancer Awareness Week 2018 will focus on raising crucial awareness of primary bone cancer symptoms. Why? Because early diagnosis can **save lives and limbs!**

## How to get involved...

### SHARE YOUR EXPERIENCE OF SYMPTOMS

Download and complete our symptoms awareness poster and share with others on social media **#BoneCancerAwareness**

### HELP PROMOTE AWARENESS

Request an Awareness Pack which contains posters, leaflets and everything you need to raise awareness in your community

### BE AWARE OF THE SYMPTOMS

Watch and share our symptoms video

### FUNDRAISE

Take part in **#TeamBones Takeover** and hold a bucket collection or **Bake it for Bone Cancer** and raise vital funds



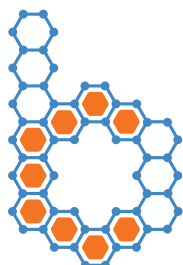
Photo credit: RANKIN

**EVERYTHING YOU NEED TO GET INVOLVED DURING BONE CANCER AWARENESS WEEK 2018 CAN BE FOUND AT [BCRT.ORG.UK/BCAW](http://BCRT.ORG.UK/BCAW)**

## ABOUT UNITED

United is a free magazine for supporters of the Bone Cancer Research Trust. The Bone Cancer Research Trust is the leading charity dedicated to fighting primary bone cancer. The contents of United are the copyright of the publishers. Articles may be reprinted without charge provided that credit is given to United magazine. A copy of any reprinted article should be sent to the address below. Please let us know your thoughts and feedback about United by emailing [info@bcrt.org.uk](mailto:info@bcrt.org.uk).

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



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

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