

UNITED

UNTIL THERE'S A CURE

INSIDE THIS ISSUE

NEW RESEARCH
PROJECT
AWARDED

FIRST
OSTEOSARCOMA
METASTASIS
NETWORK

NEW RESOURCE
FOR HEALTHCARE
PROFESSIONALS
RAISES AWARENESS

PLUS MUCH
MORE...

**BONE CANCER SURVIVOR
GOES FOR GOLD AT THE
2020 PARALYMPIC GAMES**

PAGE 4



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

WELCOME TO UNITED - YOUR FIRST ISSUE OF THE DECADE!

We start this issue of United with Laurence's inspirational story following a diagnosis of osteosarcoma when he was 14 years old. Laurence is one of our ambassadors and will be going for **gold** at the 2020 Paralympic Games in Tokyo! You can read Laurence's story on page 4 – I'm sure you will join us in wishing him the best of luck!

We started the decade with the news of awarding all five NHS bone cancer surgical centres in England with our award-winning Infrastructure Grants. The grants enable the centres to continue collecting patient samples for use in life-saving research. Turn over to page 9 to read an interview with Mr Rankin, Consultant Orthopaedic Surgeon from the Freeman Hospital in Newcastle, who has received one of our grants. He explains more about the difference the funding will make to patients.

One of our amazing supporters Liz Clarke-Saul set up a Special Fund with the Bone Cancer Research Trust in 2019, to change the landscape of adamantinoma research and thanks to the efforts of Liz's family and friends, we are delighted to announce the opening of our first research grant call dedicated to adamantinoma research. Find out more on page 12.

On page 14, you can read more about an exciting new research finding from Professor Heymann, where he has identified immune cells as potential new treatment targets for osteosarcoma.

We are delighted to share with you that we have awarded a new research project to Professor Mitnacht from University College London, Cancer Institute. We interviewed her on page 18 and she explains more about the project, which aims to use a bone model outside of the body to study how osteosarcoma develops and test potential new treatments.

Helping us raise vital awareness among healthcare professionals are students from the University of Sheffield. They've created a new flashcard highlighting the red flag symptoms of primary bone cancer. Find out more from the students on page 15.

We've added a new feature to United on page 16 'Inspiration after bone cancer'. Three amazing individuals share with us their new inspirations after a diagnosis of primary bone cancer. If you would like to share your new inspiration after bone cancer in the next issue of United, we would love to hear from you.

Finally, we were wondering **What have you done today to make you feel proud?** If you're still deciding, we can help you... Bone Cancer Ball tickets are now on sale **Movin' On Up** to page 19 to find out which chart legend will be joining us, and for more information about the night.

We would like to thank everyone who has contributed to this issue of United.

Deborah Flyde
Communications Manager



NEWS IN BRIEF

BONE CANCER CONFERENCE WINS AWARD

We are proud to announce that we have been awarded a Sarcoma Patients EuroNet (SPAEN) Advocacy in Action Award at the SPAEN annual conference! Our **Bone Cancer Conference** was recognised as an outstanding initiative, highlighting the importance of patient advocacy in sarcoma, how action can be taken to improve situations, achieve changes and help to fulfil unmet patient needs.

Our award-winning Bone Cancer Conference will be held in Manchester, 17th October 2020. Book your place today at bcrt.org.uk/conference.



NEW SKILLS DEVELOPMENT GRANTS

Skills Development Grants will enable researchers to come together and develop essential new skills to enhance their research into this brutal form of cancer, whilst establishing networks of collaboration. The grants will be available to UK based primary bone cancer researchers, at all levels in their careers and will fund travel both nationally and internationally.

If you're a researcher and want to find out more or apply visit bcrt.org.uk/researchgrants.

**Skills
Development
Grants**

BONE CANCER AWARENESS WEEK - SAVE THE DATE!

During Bone Cancer Awareness Week 2019 vital awareness and funds were raised all over the UK! You shared, liked, tweeted, loved and posted on social media. You took to the streets, supermarkets and train stations with your collection buckets, banners and microphones! And you baked for our first ever Bake it for Bone Cancer Day! Once again, our community didn't let us down, thank you for helping us raise crucial awareness.

Bone Cancer Awareness Week 2020 will be 5th – 11th October. Visit bcrt.org.uk/bcaw for updates and all the ways you can get involved.



Photo credit Nick Middleton

Photo credit Nick Middleton

LAURENCE'S STORY

In June 2006, 14 year old Laurence was diagnosed with osteosarcoma below his right knee. 14 years later, Laurence Whiteley MBE will be going for his second paralympic gold medal at the 2020 Paralympic Games in Tokyo. Laurence shares his inspirational story.



I first noticed symptoms during a PE lesson at school; it felt like pins and needles around my knee. It progressed for about a week or two and running became more and more difficult, even walking began to be a problem. I visited my GP, but it was put down to growing pains and I was told to keep off it, to rest and that it would go away in time, which is difficult when you're a 14-year-old lad. Trying to stop me at that age was borderline impossible.

I persevered, but it was getting worse. Then a lump appeared just below my right knee, along with night sweats from the pain it was causing me, so again we went back to the GP, and I was told 'We'll keep an eye on it.'

One night I accidentally banged my leg just below my right knee, I was in absolute agony and floods of tears. It was one of the most painful things to this day that I can still recall. That was the tipping point for my parents, and they took me back to my GP again.

Everything moved quickly then. I had an X-ray on the Thursday and then on the following Monday we got an unexpected knock at the door. It was the GP, he sat down and said, 'We think it's bone cancer.'

On the Wednesday of the same week I had a biopsy, and on the Friday, we had the results back confirming it was osteosarcoma. I started treatment the following week.

My symptoms started 4-5 months before my diagnosis. In my case, I was lucky. I know a few individuals who would probably still be around if their diagnosis came sooner.

My treatment was at the Royal Victoria Infirmary in Newcastle. I had chemotherapy and extensive limb salvage surgery to remove the tumour on September 6th, 2006.

I will never forget that when I was diagnosed and going through treatment, there was no one sharing their positive stories or similar circumstances.

“

I want patients and their families to know there are survivors and you can go on to make the most incredible memories, whether that's winning a gold medal or taking your first steps after surgery.

”

Good luck Laurence!

There were no stories about patients who had come through the other side, not necessarily gone on to sporting success but just gone on to live. I share my story and I visit the hospital where I was treated because I want patients and their families to know there are survivors and you can go on to make the most incredible memories, whether that's winning a gold medal or taking your first steps after surgery. That's still a win and was for me.

In 2011 I was in the gym with my dad when we got talking to a lady about my story, and she invited me to Tees Rowing Club. I thought I would give it a try. Over time I started to row more and more, I was then invited for the trials at Team GB and that's where my journey started as part of Team GB.

I was paired with Lauren. We have an unspoken communication which makes us so successful as a team.

I know what she's doing almost before she's doing it, we have that synergy. **After rowing together for a short period of time, we went on to win a silver medal at the 2015 World Championship. We then won gold at the 2016 Paralympics, I was awarded an MBE in 2017 and the same year became an Ambassador for the Bone Cancer Research Trust. In 2019 we won gold at the World Championships.**

We'll be going to the Tokyo 2020 Paralympic Games as gold medalists and current World Champions, so we are very driven to win again. This will be the first games with a new distance of 2,000 metres, and we want to go and show how strong we can be. As a whole team we want to do phenomenally well.

To read Laurence's full story visit bcrt.org.uk/Laurence

INTRODUCING THE FIRST OSTEOSARCOMA METASTASIS NETWORK



Researchers working in isolation will inevitably delay progress in addressing the issues of metastasis in osteosarcoma. Therefore, there is an urgent need to adopt a collaborative approach for osteosarcoma research. With our support this innovative research network has come together.

OMeNet is a pre-clinical research collaboration, focused on understanding and developing treatments for osteosarcoma metastasis. In order for any of the outcomes from clinical research projects to be translated for patient benefit and treatments, early pre-clinical research is inevitably needed.

OMeNet will pave the way for faster and more accurate translation of findings from current research projects, as well as setting the standard for future pre-clinical research into osteosarcoma and other primary bone cancer metastasis.

MEET THE TEAM



DR HELEN ROBERTS



PROF ALISON GARTLAND



DR DARRELL GREEN



DR KATIE FINEGAN

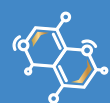


PROF AGI GRIGORIADIS



MR KENNY RANKIN

THE RESEARCH PROCESS



DISCOVERY AND TARGET VALIDATION

Primary bone cancer research starts in the lab where researchers investigate the way primary bone cancer develops and grows. They identify and select biological targets for treatment as well as drug molecules that can activate or deactivate them.



PRE-CLINICAL RESEARCH

Researchers start to test new treatments for primary bone cancer and determine safety and effectiveness before testing on patients.



CLINICAL RESEARCH

New treatments are tested on primary bone cancer patients. Also known as a clinical trial. During a clinical trial, patients' samples are analysed in the lab to monitor their response to treatment and to inform further research.



ANALYSIS

Research is an iterative process, where outcomes inform the next steps. Even after a clinical trial, the results may indicate that more investigations are needed; sometimes even going back to stage one!

PETE'S PUSHING FOR A CURE

In 2011 Pete was diagnosed with osteosarcoma, which later led to him having a full leg amputation in October 2017. Last year, Pete set up a Special Fund with the Bone Cancer Research Trust called Pushing For A Cure.

In April 2019 Pete decided to take on the incredible challenge of the Manchester Marathon for the Bone Cancer Research Trust and that's where his wheelchair racing started.

Worried he wouldn't be able to complete the marathon, Pete had a discussion with his friend who put him in touch with Stockport Wheelchair Racing, and in Pete's words, 'The rest is history'.

With lots of hard work and persevering, Pete completed the Manchester Marathon and raised over £2,000 for our life-saving work.

After even more hard work, on the 7th September 2019, **Pete classified as a T54 wheelchair athlete at Stoke Mandeville.** Pete has since been training with Stockport Wheelchair Racing and his aim is to take on the wheelchair racing world and raise awareness through road and track events.



"Life after bone cancer will never be 'normal' but we have found our new normal. I want more bone cancer patients and their families to find their new normal. To try new challenges and not feel like they're unable to do things. To #PushForACure and join in being out of their comfort zones, to help raise as much awareness and funding as possible."



Pete hasn't stopped there either... This year he chose to do the Arctic One Challenge to keep up his training and motivation throughout the winter when the weather is awful, and the track is closed due to poor conditions. Pete was delighted to receive an Arctic One Forward Motion Grant, which supports disabled athletes.

"Becoming a Special Fund with the Bone Cancer Research Trust is hugely important to me, as they are the only charity dedicated to finding a cure for primary bone cancer."

To find out more about Pete's Special Fund and all of his sporting updates head over to bcrt.org.uk/PeteLloyd





Q&A

AN INTERVIEW WITH
MR KENNY RANKIN



PROF TIM THEOLOGIS, DEPARTMENT OF CHILDREN'S ORTHOPAEDIC SURGERY, NUFFIELD ORTHOPAEDIC CENTRE, OXFORD.

CO- APPLICANTS: MR MAX GIBBONS, PROF NICK ATHANASOU

Research confirms that it is essential to use surgery guiding scans taken before chemotherapy rather than those taken after chemotherapy to plan surgery for Ewing sarcoma patients.

RESEARCH FINDING



Treatment for Ewing sarcoma includes an intensive regime of chemotherapy, usually combined with surgery and radiotherapy. There is often a balance, in bone sarcoma surgery, between ensuring the tumour is safely and fully removed to limit the chances of recurrence but not removing normal bone and tissue unnecessarily. Patients receive an MRI before they start chemotherapy and again after chemotherapy.

KEY FINDINGS OF THIS RESEARCH

Irrespective of response to chemotherapy, surgery is currently planned using the scans done prior to chemotherapy, even if this suggests removing tissue that now has no evidence of tumour.

Professor Theologis and his team investigated whether it would be more beneficial to plan surgery based on scans done after chemotherapy, therefore, performing less radical surgery, preserving more bone and tissue, while still maintaining a clear margin and not leaving tumour behind.

They completed a retrospective study on a small number of patients, looking at their clinical, and surgical history, as well as analysing the available tissue samples for the presence of tumour versus healthy bone.

The researchers concluded that if they were to have based their surgical margins on scans done after chemotherapy, in the hope of preserving more healthy bone and/or joint, they would have left tumour behind in a third of cases. Therefore, the current practice of planning the surgical approach based on the MRI scans done before chemotherapy remains the safest approach and do not recommend the use of post- chemotherapy MRI to guide surgery.

We started 2020 by awarding five new Infrastructure Grants to the NHS bone cancer surgical centres in England. The grants enable them to continue collecting patient samples for use in research. We interviewed Mr Kenny Rankin, Consultant Orthopaedic Surgeon from the Freeman Hospital in Newcastle, who has received one of our grants.

CAN YOU TELL US ABOUT YOUR ROLE AND YOUR INVOLVEMENT IN THE INFRASTRUCTURE GRANTS?

I am an orthopaedic surgeon but spend half my time in the lab doing research, including projects using patient samples. When the Bone Cancer Research Trust were considering setting up these grants, I had some input into what would be helpful to researchers doing this sort of work.

WHY DO YOU THINK IT'S SO IMPORTANT TO FUND TISSUE SAMPLE COLLECTIONS?

It is important because it provides each centre with support to routinely collect samples, which are used locally or sent elsewhere in the country to researchers.

WHAT DIFFERENCE HAS THE GRANT MADE AT THE FREEMAN HOSPITAL?

The main difference has been the increase in the number of samples collected. This has happened because the support is flexible. The Bone Cancer Research Trust have allowed each centre to adjust the funds to suit their local needs. At the Freeman Hospital, funds are used to cover 'per patient costs' for the research team to consent to sample donation. This means fewer patients are missed. On the university side, we have a part-time technician in place who has been trained to collect and receive the samples. They log and process them, either for experiments locally or send on to other centres as required.

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

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. A good example is one of our osteosarcoma patients who helped me to validate a protein named MT1-MMP as a therapeutic option. I have now referred two bone sarcoma patients to the Christie for consideration in an early phase clinical trial of a novel drug which targets this protein.

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

Donating tissue and blood samples makes a difference. The Infrastructure Grants have boosted our ability as researchers to collect more samples and to collaborate. Long may it continue!

The Infrastructure Grants were awarded to the Royal Orthopaedic Hospital NHS Foundation Trust, Royal National Orthopaedic Hospital, Freeman Hospital, Nuffield Orthopaedic Centre and Robert Jones & Agnes Hunt Orthopaedic Hospital. We would like to thank them for their ongoing commitment to the project.

For more information about this pioneering project visit bcrt.org.uk/Infrastructure



BCRT.ORG.UK/TEAMBONESTREK

28th June 2020

The **Taster 10K** is perfect for those wanting a flavour of the Yorkshire Three Peaks experience, including capable children. Starting in Horton-in-Ribblesdale you will ascend Pen-y-Ghent taking in the stunning views of the National Park before looping back to the finish line in Horton-in-Ribblesdale to receive your well-earned medal!



BCRT.ORG.UK/TEAMBONESTREK

28th June 2020

An **X-Trail** distance designed for the experienced hiker or trail runner. Trek or run the Classic route until you reach the summit of Ingleborough where you will break away down to the village of Clapham and on to Feizor and Dry Rigg Quarry before returning to Horton-in-Ribblesdale. This is a challenge of epic proportions as you must complete the 33 miles in 12 hours.



BCRT.ORG.UK/TEAMBONESTREK

28th June 2020

The **Classic 24.5 mile Yorkshire Three Peaks** route. Starting bright and early in Horton-in-Ribblesdale you'll follow our guides up Pen-Y-Ghent, past Ribbleshead Viaduct to ascend Wharfedale and finally tackle Ingleborough before heading back into Horton-in-Ribblesdale and across the finish line!

"I loved taking part in the Yorkshire Three Peaks last year. I completed it with a team from work. It was great for morale and helps spread the awareness of bone cancer. I would thoroughly recommend this event to anyone. Although a challenge, it can be achieved with a bit of training, determination and the cause at the forefront of your mind."

Helen Anderton, mum of Jude who passed away from osteosarcoma

TREKKING WITH #TEAMBONES...

...Takes us one step closer to finding a cure!

This year we have something for everyone! For the first time ever, the whole family can be part of a #TeamBonesTrek. You can take it steady or push yourself to the limit! Want to see your options? Then STEP this way...



'I want to help the poorly boys and girls.'
Bradley, Age 5

BCRT.ORG.UK/DERWENTDAMS

4th July 2020

Trek the stunning **Derwent Dams** this July with #TeamBones and visit the site where 617 Squadron prepared for the Dambuster raids of WW2. This moderate to leisurely trek provides breath-taking views of Derwent, Howden and Ladybower reservoirs, and with 10 and 15-mile routes to choose from, the Derwent Dams #TeamBonesTrek is a perfect challenge for individuals, families, beginners and keen walkers alike.

CAN'T MAKE ONE OF OUR #TEAMBONESTREKS BUT STILL WANT TO STEP UP FOR BONE CANCER?



BCRT.ORG.UK/STEPUP

Step Up For Bone Cancer is back! And it's so easy to get involved. Decide how far you would like to walk, choose your location and set the date. It could be a walk in the park with your friends or a hike in the hills with your colleagues... There are so many ways to get involved!

"We chose to Step Up For Bone Cancer to raise awareness and funds. After coming to the conference we were extremely touched and saddened by the stories of the families who had lost loved ones and those who had endured horrific treatment because of the lack of research, so as a family we wanted to help raise vital funds to ensure others in the future could have a more positive outcome."

Sarah, Giant Cell Tumour of the Bone patient



ADAMANTINOMA PATIENT RAISES FUNDS

FOR THE UK'S FIRST EVER RESEARCH PROGRAMME

Liz Clarke-Saul was diagnosed with adamantinoma in 2001 at the age of 12. Following multiple surgeries, Liz had her leg amputated in 2003, when she was just 14 years old. In 2018, Liz's cancer returned and spread to her lungs. She was then told that it was incurable.

Liz decided to set up a Special Fund with the Bone Cancer Research Trust in 2019, called The Liz Clarke-Saul Fund, to change the landscape of adamantinoma research.

Adamantinoma is a rare form of bone cancer, amounting to less than 1% of all bone cancer diagnoses. There is currently no research into new treatments for the disease, due to the lack of research funding and availability of patient tumour samples. The Bone Cancer Research Trust is now supporting the five NHS bone cancer surgical centres in England to enable collection of adamantinoma samples to support future research projects. However, we know more needs to be done.

The Liz Clarke-Saul Fund has already raised over £25,000, beating their initial target of £20,000! Thanks to the efforts of Liz's family

and friends we are delighted to announce the opening of our first ever research grant call dedicated to adamantinoma research.

This grant will fund UK scientists to carry out pioneering research, with the ultimate objective of identifying new treatments for adamantinoma. This will be the first grant in our future adamantinoma research programme, starting with a grant of £25,000.

Liz, her family and her friends have been incredibly dedicated to fundraising. There has been pub quizzes, half marathons, bake sales, carolling, school fairs, bucket collections and even a dog show! They have lots more exciting things planned for 2020, to reach their new target of £90,000.

"I would like to say a huge thank you to everyone who has helped us to reach this point as it would not have been possible without them. It was a real ambition of mine to be able to fund the first ever research project into adamantinoma and I am delighted that we have been able to do this within 7 months of starting our fundraising. I really hope this is the start of transforming the landscape of the disease and we look forward to continuing our fundraising to support the next stage." - Liz

On behalf of everyone at the Bone Cancer Research Trust, we would like to thank Liz, and all of her family and friends for their continued support.

To read more about The Liz Clarke-Saul Fund, visit bcr.org.uk/LizClarkeSaul

To find out more about setting up a Special Fund, visit bcr.org.uk/Funds



Bake
it for
BONE
CANCER

LET'S MAKE IT PERSONAL

Bake it for Bone Cancer is a fun way to raise funds and get together with your friends, family or colleagues any time of the year.

NEW FOR 2020 - YOU CAN MAKE IT PERSONAL!

Bake it for Mummy, Bake it for your Friends or Bake it for a Cure! You can now personalise your very own Bake it for Bone Cancer to show the ones you love the most how much they mean to you. Plus, what's better than enjoying some tasty treats, whilst helping to raise life-saving funds and awareness!

Our vital work is only possible with your support, so please join in and help 'bake' a difference for bone cancer patients everywhere.

We're Baking it for Sarcoma Awareness Month on Friday 3rd July 2020. Why not host your very own Bake It on the day or during the month and help us raise vital funds.

Visit www.bcr.org.uk/Bake to request your free fun-filled fundraising pack, which is bursting with materials and ideas.



PROFESSOR DOMINIQUE HEYMANN,
UNIVERSITY OF SHEFFIELD (UK) AND
UNIVERSITÉ DE NANTES (FRANCE)

In 2016 the Bone Cancer Research Trust funded a study by Professor Dominique Heymann to investigate early events of recurrent disease and metastatic dissemination in osteosarcoma. This study has recently completed, and we are delighted to be able to share with you some findings.



RESEARCH FINDING



Bone Cancer Research Trust project identifies immune cells as new potential treatment targets for osteosarcoma.

KEY FINDINGS OF THIS RESEARCH

Osteosarcoma tumours develop in a favourable “microenvironment” (like seeds growing in a well composted soil) which is composed of bone cells, blood vessels, and immune cells; these cells co-operate with each other and facilitate cancer growth and spread.

Macrophages are large white blood cells that play an important role in our immune system by engulfing unwanted particles. Osteosarcoma tissues are invaded by macrophages called “Tumour-Associated Macrophages” (TAMs).

TAMs can adopt two forms M1 or M2. M1-macrophages function as anti-tumour cells and M2 macrophages are pro-tumour regulators.

Professor Heymann studied samples of pre-chemotherapy osteosarcoma biopsies from patients with localised osteosarcoma and from patients with metastatic osteosarcoma.

The results indicate that M1-macrophages are present in non-metastatic patients; whereas M2 macrophages are predominant in metastatic osteosarcoma patients. This change of balance increases the formation of blood vessels around the tumour and facilitates the metastatic process.

The results from this study indicate that the presence of M1/M2 macrophages can be used as a marker for early metastasis from osteosarcoma biopsies and therefore identify patients at greater risk of disease spread.

It also emphasises the potential for treatment targets in osteosarcoma, which aim to increase M1 and/or reduce M2 macrophage production.



‘The flashcard is an excellent resource, which is eye catching and informative without being too wordy.’
DAN NICHOLLS, ADVANCED PRACTICE PHYSIOTHERAPIST

NEW RESOURCE FOR HEALTHCARE PROFESSIONALS

Amy, Dhruv, Emma and Pallavi are in their third year of their medical degree at the University of Sheffield. They have been working on how we can increase awareness of primary bone cancer among healthcare professionals. They produced a fantastic flashcard that includes the red flag symptoms and investigations needed to achieve a faster diagnosis.

CAN YOU TELL US ABOUT THE SOCIAL ACCOUNTABILITY INITIATIVE?

The Social Accountability initiative is a placement designed for medical students. It aims to help future doctors gain insight into the social issues that can affect patients and their families. The objective is to help us see how different organisations/charities, can support and improve people’s health and wellbeing, by providing holistic healthcare outside formal healthcare.

WHAT MADE YOU CHOOSE THIS PROJECT?

Primary bone cancer is a very small part of the curriculum in medical schools. We were aware of it, but we knew little about it. The placement allowed us to learn more. We now know that primary bone cancer is an understudied field and that there is a fundamental lack of awareness. We felt that by increasing awareness, we could really make a difference to patient lives.

WHY IS INCREASING AWARENESS AMONG HEALTHCARE PROFESSIONALS IMPORTANT?

Often primary bone cancer patients are misdiagnosed with growing pains or a sports injury. Yet, early diagnosis is essential to improving patients’ outcomes and experiences.

By being aware of primary bone cancer, healthcare professionals will be more likely to consider it as a possible diagnosis and consequently, will enable patients to start a referral pathway sooner.

WHAT DIFFERENCE COULD THIS WORK MAKE FOR PATIENTS IN THE FUTURE?

We hope that our work increasing awareness of primary bone cancer will improve diagnosis times for patients and consequently achieve better prognosis and survival, as well as improve their quality of life. We also hope that our contribution will help those suffering from primary bone cancer feel acknowledged. And, although it is a rare cancer, they are not being ignored and that people, such as those at the Bone Cancer Research Trust are working hard to bring improvements to primary bone cancer care and support.

WOULD YOU LIKE TO SAY ANYTHING TO OUR SUPPORTERS?

We are truly grateful to each supporter of BCRT, as it is their support which makes research to improve outcomes for bone cancer patients possible.

Request your free flashcard today at
bcrt.org.uk/Flashcard

FINDING INSPIRATION AFTER BONE CANCER

Below we share with you three amazing individuals who have all found new inspirations after a diagnosis of primary bone cancer.



ALEXANDER GOODWIN

In 2015 at just eight years old Alex was diagnosed with Ewing sarcoma. Alex has turned his attention to not only recovering but to enjoying new things in life like Archery.

"Today I was practicing my archery. I love this ancient art and noble sport. Three years ago, the doctors said I wouldn't survive. Last year I was in a wheelchair. Now I'm walking with help."



MATTHEW WOOLLIAS

Matt was diagnosed with Ewing sarcoma at the age of 20. Matt made the decision to have his leg amputated below the knee in order to beat the disease.

"I went along to a Paralympic potential day in 2011 and I was talent spotted for Para-Ice Hockey. I've since represented GB at 5 major championships. I now play for Sheffield Steelings, the current League and Playoff Champions."



MARSHA DANZIG

In 1967, at just five years old, Marsha was diagnosed with Ewing sarcoma. 53 years later, she is a Yoga Therapist and Author.

"My close brushes with death offered me a fierce determination to let nothing stand in the way of my passions and joy. As prosthetics improved, I was able to get back to dance once again. Eventually that led to yoga."

Would you like to share your new inspiration? If so, contact our communications team at info@bcrt.org.uk



INTERVIEW WITH
CLINICAL NURSE
SPECIALIST
MILLI LIPSHAW



“ The Bone Cancer Research Trust booklets are extremely helpful as they have clear and concise information. They allow families to read information that they can trust is factually correct.

We interviewed Milli Lipshaw, Paediatric and Adolescent Sarcoma Clinical Nurse Specialist from the Royal National Orthopaedic Hospital about our information resources.

CAN YOU PLEASE TELL US A BIT ABOUT YOURSELF AND YOUR ROLE?

I work as part of the London Sarcoma Service and we care for children and adolescents aged 0-19 years old. We meet families at the start of their cancer journey and support families by answering any queries or concerns they have. Also, part of our role is to raise awareness of sarcomas and the help and support available to benefit families going through this journey.

WHY DO YOU THINK OUR CHILDREN'S RESOURCES ARE SO IMPORTANT?



'Harry has an Operation' and 'Abbie has Osteosarcoma' are fantastic resources which explain in simple terms and pictures the processes and treatment plan ahead. They are written like story books, which helps to engage children and allows them to ask questions.

HOW DO OUR RESOURCES SUPPORT A CHILD AND THEIR FAMILY GOING THROUGH A DIAGNOSIS?

When people have a question these days, they tend to go straight to the internet to find out the answer. We all know how easy it is to end up scrolling through internet sites and finding information that may not be relevant. The BCRT booklets are extremely helpful as they have clear and concise information. They allow families to read information that they can trust is factually correct. They are worded in nice, simple terminology and include a glossary of medical words that you might not understand yet. We always advise our families to stick to trusted websites rather than typing search terms into a web browser, but often the information in the BCRT's guides is enough for families. I also recommend the **'Step-by-Step Guide for Patients'** as it is useful to jot down your treatment details and contacts in one place.

HOW DO OUR RESOURCES SUPPORT YOU IN YOUR ROLE?

We understand that a cancer diagnosis is a very difficult thing to hear. Most of the time people hear the word 'cancer' and everything else is a blur. Part of our role is to ensure the family understand what is going on and guide them to the next steps. The BCRT booklets are incredibly helpful as they contain information we will have discussed with families. We can highlight sections for them to refer back to.

To read Milli's full interview and for more information about the research project visit bcrt.org.uk/Milli



Q&A

INTERVIEW WITH
PROFESSOR
SIBYLLE MITTNACHT



We spoke to Professor Mittnacht from University College London, Cancer Institute about our newly awarded research project. The project aims to use a bone model outside of the body to study how osteosarcoma develops and test potential new treatment options.

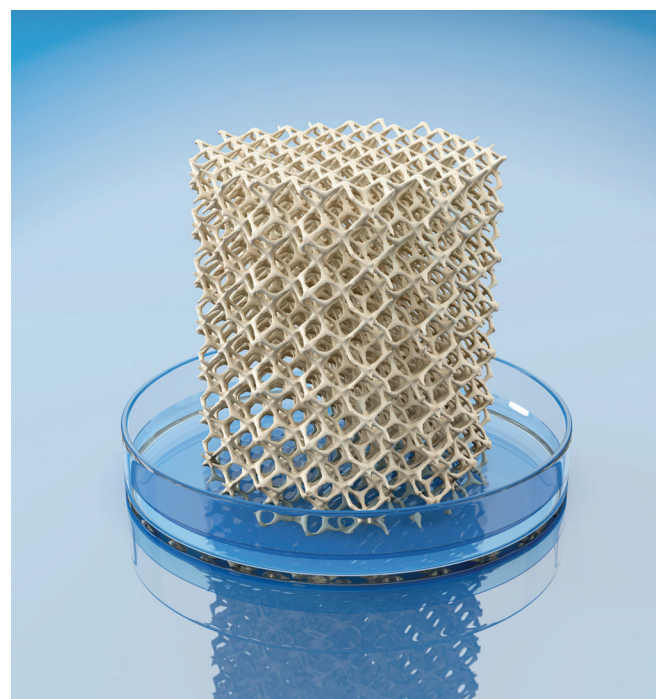
CAN YOU TELL US ABOUT THE PROJECT?

The project funded by Bone Cancer Research Trust aims to develop methodology through which it will be possible to study osteosarcoma within its natural environment, but outside the patient. The programme of work involves close collaboration with a tissue engineering team lead by Professor Wenhui Song. The Song team has world-recognised expertise in developing bone tissue outside of the body.

WHAT ARE THE AIMS OF THE PROJECT?

The project will make use of this technology to enable the growth of osteosarcoma tumours from patients in their natural context, yet outside the patient's body. A further partner is Dr Sandra Strauss, a clinical oncologist who treats patients with osteosarcoma, who will provide her expertise on how these tumours mirror those inside the body. In addition, this way of collaborating will allow potential treatments to be tested and determine their effectiveness before they are given to the patient.

The overarching goal of this project is to generate a realistic model for the study of osteosarcoma. If successful, it could be extended to other forms of primary bone cancer as the search continues for new and more effective medicines.



WHAT DIFFERENCE COULD THIS PROJECT MAKE FOR FUTURE PATIENTS?

As with all rare cancers, there are great difficulties to conduct robust clinical trials that could help improve treatment and there is recognised need for the development of models that faithfully replicates the way osteosarcoma develops and grow in patients.

If successful, this approach will allow researchers to gain a deeper understanding of how osteosarcoma tumours develop and grow and importantly, how they respond to potentially personalised treatment options.

To read Sibylle's full interview visit
bcrt.org.uk/bonemodel

THE BONE CANCER WINTER BALL

SATURDAY 7th NOVEMBER 2020
ROYAL ARMOURIES, LEEDS

The Bone Cancer Ball is coming back and it's bigger and better than ever. If you've been before you'll know it's a night to remember; if not - allow us to tempt you...!

With thanks to our friends at Capstone and RNB, plans for this year's Winter Ball are well underway, bringing you the best night Yorkshire has to offer whilst raising thousands for our life-saving work. Expect a whole host of crowd favourites - from fabulous auction prizes to our no-losers balloon raffle, and the brilliant Nightjars, back by popular demand. We also have a few new treats in store, including our first Bone Cancer Ball awards - more details coming soon on our website.

So whether you've got £1 in your pocket or thousands to play with - there's something for you. But that's not all.

From London 2012 anthem *Proud*, to *Search for the Hero* and *Movin' On Up*, her songs are a soundtrack to our lives, seeing us through the good and the bad, the glorious and the sad. We're delighted to bring chart legend **Heather Small**, up close and personal, to this year's Bone Cancer Winter Ball with her live, intimate set.

YOU DON'T WANT TO MISS IT!

It's our Winter Ball so SNOW tables are on sale NOW at £600 per table of ten, or £60 per ticket, including a sparkling drinks reception, three-course dinner, two bottles of wine per table and a fabulous night's entertainment. A limited number of SNOW tables seating 12 are available at £720.



FANCY PUSHING THE BOAT OUT...?

In prime position with uninterrupted stage views, a limited number of ICE tables are now on sale at £1000 per table of ten (£1200 per table of 12) - the best seats in the house. Four bottles of wine plus two bottles of Prosecco per table alongside your sparkling drinks reception and three course dinner will help make sure your evening goes with a swing. Businesses taking an ICE table will get a mention on our 'Wall of Fame', featured both in our souvenir programme and on the night.

See you there!

Book now at bcrt.org.uk/ball or by calling us on 0113 258 5934.

WE ARE HERE FOR YOU

YOU ARE NOT ALONE. IF YOU NEED SUPPORT, OUR SUPPORT AND INFORMATION TEAM ARE ON HAND AND HERE FOR YOU.

We provide a dedicated Support & Information Service which is available to anyone affected by primary bone cancer or bone tumour. Our approach to the service is dynamic and patient-led in a bid to provide all-round holistic help to all of those who access our service.



THE DIFFERENCE OUR SUPPORT AND INFORMATION SERVICE MADE IN 2019...



WE RESPONDED TO 324 SUPPORT REQUESTS



457 PEOPLE JOINED OUR ONLINE SUPPORT GROUPS



250 PEOPLE ATTENDED SUPPORT EVENTS



429,035 VISITS TO OUR SUPPORT & INFORMATION WEBPAGES

"I would encourage all bone cancer patients or survivors to attend one of the Bone Cancer Research Trust support events, whether you've just been diagnosed, going through treatment or life beyond cancer." - Former patient



bcrt.org.uk/support



0800 111 48 55



support@bcrt.org.uk

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.

Editorial: Deborah Flyde, Mat Cottle-Shaw, Francesca Haigh Design: Romana Carter



©Bone Cancer Research Trust 2020
10 Feast Field, Horsforth Leeds LS18 4TJ | bcrt.org.uk | 0113 258 5934
@BCRT BoneCancerResearchTrust @bonecancerresearch



**INSTITUTE OF FUNDRAISING
YORKSHIRE & HUMBER AWARDS**
Fundraising Team and Campaign of the Year



THE NATIONAL CHARITY AWARDS
National Healthcare & Medical Research
Charity of the Year

Charitable Incorporated Organisation (CIO) Number - 1159590