

UNITED

UNTIL THERE'S A CURE

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AWARDED

HIGHLIGHTS
FROM THE
BONE CANCER
CONFERENCE

DEDICATED
SUPPORT AND
INFORMATION
SERVICE MAKES
AN IMPACT

NEW RESEARCH
UPDATES

PLUS MUCH MORE...



“ MAXI MAKES EVERYONE
SMILE! HE HAS THE
BIGGEST PERSONALITY AND
LIGHTS UP A ROOM.

JULIE SHARES HER SON'S
INSPIRATIONAL STORY



WELCOME TO A VERY FESTIVE ISSUE OF UNITED!

You'll notice this issue of United looks a little bit different as we enter the festive period and launch our Christmas Shine A Star Appeal. In this edition we've got lots of sparkling updates, twinkling interviews and bright research discoveries.

Let's start with our little superstar Maxi! At just 15 months old Maxi underwent major surgery and months of treatment, he is now four years old and his mum, Julie, has shared their inspirational story with us on page 6.

We've recently awarded two new pioneering research projects. The first aims to develop a new blood-based test for detection of small tumour-derived DNA fragments in the blood from osteosarcoma and chordoma patients. You can find this on page 8 where we interviewed the lead researcher Dr Lyskjaer. The second was awarded to Professor Burchill who is investigating a novel gene implicated in treatment-resistant Ewing sarcoma. Read Professor Burchill's interview on page 12.

This year we received an unprecedented number of requests to attend the Bone Cancer Conference so in response we've decided to hold two conferences in 2020. On page 4 you can read a few highlights from our 2019 conference and see how you can sign up for one of the 2020 Bone Cancer Conferences. We can't wait to see you all in London and Manchester!

You'll find new research discoveries on pages 9 and 14, which are shining examples of the progress our researchers have made thanks to your continued support and donations.

Since the launch of our new Support and Information Service in May, the service has gone from strength to strength. Our Support Manager, Louise, has been holding Support Groups across the UK as well as launching other aspects of our service. On page 10 you can find out more about the service and how to contact us, if you ever need us.

As 2019 draws to a close, we would like to say a huge thank you to the bone cancer community who have continued to support our vital work; you are all stars! On behalf of everyone at the Bone Cancer Research Trust we would like to send you our very best wishes this festive season.

We're going to be shining stars all Christmas, but did you know you can shine your very own? Follow this shooting star all the way to page 7 to find out how.

Deborah Flyde
Communications Manager



NEWS IN BRIEF

RESEARCH SYMPOSIA

This year we held an Osteosarcoma Symposium in collaboration with Children with Cancer UK, which brought together researchers and medical professionals from across the globe to identify progress, challenges that need to be overcome and opportunities to move research forward. The symposium made a huge impact and following its success we are holding our first Chondrosarcoma Symposium in November and are delighted to announce we will be holding a Ewing Sarcoma Symposium in 2020, which also marks 100 years since Professor James Ewing first identified Ewing sarcoma as a form of cancer. In 2020 a second Osteosarcoma Symposium will be held to progress our international collaboration and work established at the 2019 symposium.

BONE CANCER AWARENESS WEEK

During Bone Cancer Awareness Week 2019 we were #HereForYou and launched our first ever Digital Support Groups for each primary bone cancer and tumour. During the week over 300 people joined the groups, with many more joining the groups since their launch. You can join a group at bcrt.org.uk/digitalsupportgroups. Your support during the week was incredible, with many 'bun-derful' cakes baked for our first ever Bake it for Bone Cancer Day! Vital awareness and funds were raised as you took to the streets, supermarkets and train stations with your buckets, banners and our stand-out #TeamBones t-shirts! For the week our reach was over four million and we couldn't have done it without you! Thank you.

BONE CANCER BALL

Once again, the Bone Cancer Ball was a HUGE success! Over 500 people attended the ball and helped us raise life-saving funds. Thank you to everyone who attended and supported the event. **Tickets for our 2020 Bone Cancer Ball will be going on sale soon - watch this space!**



BONE CANCER CONFERENCE

Following the incredible success and dramatically increased guest numbers at the Bone Cancer Conference 2019, we are delighted to be holding two Bone Cancer Conferences in 2020, one in London and one in Manchester.

Below are just some of the highlights from this year and more information about how you can register for one of our 2020 conferences.



Patients being filmed and sharing their journeys to help increase awareness and offer support.

It feels like a family

Relative of a Patient

CONFERENCE



Medical students from the University of Sheffield explain why awareness amongst medical students is so important.



Interactive session, extracting DNA from strawberries.

"Makes you know you are not alone"

Relative of a Patient

"The talks were so good, I didn't want to miss anything"

Relative of a Patient



A relaxed environment and opportunities to meet other patients and families.



A supportive and friendly community.



A welcoming environment for all the family.



News of the latest developments in bone cancer research.



Stick your tongue out to bone cancer and #takeasophie.

100% of guests want to attend again

"Reassuring to know I am not alone feeling the way I do"

Former Patient



Patients during the day kindly shared their stories.

"Informative and thought provoking"

Former Patient

92% reduction in feelings of very high or extreme anxiety

Whether you're a patient, former patient, family member, supporter, researcher or medical professional - everyone is welcome to join us at the Bone Cancer Conference for a day of inspiration and support.

Visit bcrf.org.uk/Conference or call us on 0113 258 5934 to register for one of our 2020 Bone Cancer Conferences now.

MAXI'S STORY

This Christmas we are shining a very special star for Maxi and his family, who have kindly shared their inspirational story all the way from Australia.

In November 2016 at just 15 months old, Maxi was diagnosed with osteosarcoma. Maxi underwent weeks of chemotherapy and rotationplasty surgery. Maxi's mum, Julie has shared her son's story and how, despite everything he has been through, he always makes everyone smile and lights up a room.

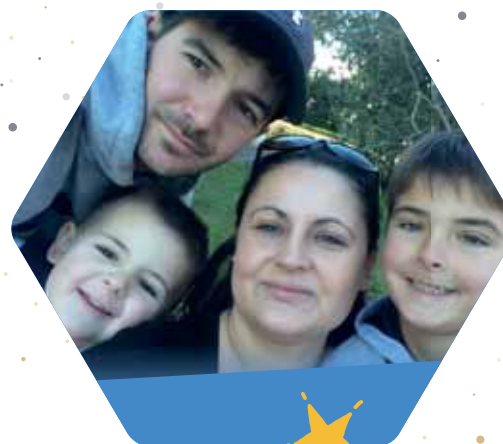
On the 26th October 2016, we noticed Maxi's foot was turning outwards as he walked, he was struggling to put any weight on his leg, so we took him to see the doctor. There we were told he had a temperature and a virus in his knee. Over the next seven days he got worse, not wanting to bear any weight, Maxi reverted back to crawling. We returned to the doctor only to be told that it was just the way a baby walks. We pushed for an X-ray, and on the same day we got a phone call to be told that there was a shadowing on his right knee and to go straight to A&E.

Maxi had a full body X-ray and we were told it could either be a childhood cancer, a cyst or a low-grade tumour. We didn't believe it could be cancer and we held on to the hope of it being the other alternatives.

We went back to hospital the next day for an MRI scan, this was followed by a biopsy and then Maxi was sent home with a cast on his leg. 14 days after his biopsy we received a call and we were told we had to fly to Melbourne for more scans.

I begged on the phone to find out what was going on and that's when we were told Maxi had osteosarcoma in his right knee.

Three days later we were in Melbourne and Maxi had PET scans and a Hickman line to receive chemotherapy through. It was then it was then confirmed it was a high-grade malignant tumour - osteosarcoma. Thankfully his tumour was isolated bringing Maxi's chances of survival up to 75%, from around 35% if it had spread.



We were to spend the next 9 months in Melbourne.

Maxi's treatment regime was 11 weeks of chemotherapy followed by surgery and then another 18 weeks of chemotherapy following his surgery.

Nothing could have prepared us for how sick Maxi was about to get. We were told there was a risk Maxi would lose his leg, but we never thought that it might actually happen. We were so hopeful right up until the decision by surgeons was revealed.



Maxi was very ill during his chemotherapy and as a result had bad mouth sores from the Methotrexate. He also needed blood and platelet transfusions throughout. He lost his hair, eyelashes, eyebrows and had really bad bruising. He fell very ill between his chemo sessions and we would often spend around 7 days back in hospital. An MRI and a PET scan showed that after his first two blocks of chemotherapy, the tumour had thankfully reduced in size.



We were then given two options for Maxi; an above the knee amputation or a rotationplasty. We were told limb salvage surgery was not an option because of Maxi's age.



We were just in shock and disbelief. With the help of a lot of people, we decided on a rotationplasty.

Maxi's surgery was on the 23rd February 2017 and lasted for nine hours. It was excruciating waiting, with all our hope that the surgery would run smoothly.

After surgery Maxi wasn't himself. He didn't smile and that showed us he was in a lot of pain.

15th March, Maxi started his post-surgery chemotherapy and fell very sick again.

Maxi started his physio while still having his chemotherapy and had an outer metal brace on his leg which was screwed into his bone. On 22nd June the metal work was removed, and Maxi could get around well. He loved having the brace off.

His last chemotherapy was on the 1st August 2017, four days before his 2nd birthday. We had a celebration for Maxi on the hospital ward and a birthday party at the apartment.

We went back home to Tasmania on the 8th of August, which was very long awaited.

We had to go back to Melbourne in September for the fitting of his prosthetic leg. Maxi tried it on for the first time



and looked like a baby lamb walking for the first time, very unsteady.

6th September 2017, Maxi's MRI, PET and CT scans came back clear and he also took his first steps with his new leg.

Maxi had physiotherapy and hydrotherapy over a short period of time when we arrived back home however, it did take two years to start intensive physiotherapy and hydrotherapy due to medical teams from Tasmania and Melbourne trying to communicate and be on the same page. Maxi continues to have around 15 appointments a month.

Maxi, now four years old, makes everyone smile! He has the biggest personality and blows people away with his knowledge of his favourite animals and dinosaurs. Maxi is always happy and he's always asking if you're happy too.

We think Maxi is an absolute star!

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

Shine a Star

YOU CAN SHINE A STAR FOR ABSOLUTELY ANYONE WHO IS SPECIAL TO YOU THIS CHRISTMAS!

SHINE A STAR TODAY AT SHINEASTAR.ORG



DID YOU KNOW?

ROTATIONPLASTY IS WHERE THE BOTTOM OF THE FEMUR, KNEE AND THE UPPER TIBIA ARE SURGICALLY REMOVED. THE LOWER LEG IS THEN ROTATED 180 DEGREES AND ATTACHED TO THE FEMUR. RESULTING IN A BACKWARD FACING FOOT TO REPLACE AND ACT AS THE KNEE.

Q&A

AN INTERVIEW WITH
DR IBEN LYSKJAER

We spoke to Dr Lyskjaer about our new research project which aims to develop a new blood-based test for detection of small tumour-derived DNA fragments in the blood from osteosarcoma and chordoma patients.

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

I am a postdoctoral researcher at the University College London Cancer Institute. I finished my PhD in Health Sciences from Aarhus University, Denmark, last year, where I focused on designing a blood-based test for the detection of tumour DNA in colorectal cancer. After my PhD, I moved to London in order for me to investigate the complex characteristics of sarcoma tumours.

TELL US ABOUT THE PROJECT AND ITS AIMS?

This project aims at developing a new blood-based test for detection of small tumour-derived fragments (known as circulating tumour DNA or ctDNA) in the blood from osteosarcoma and chordoma patients. Tumours shed small pieces of DNA into the blood stream, and by looking for osteosarcoma and chordoma tumour-specific markers/tags we can measure the levels of tumour DNA in the body. So far, we have identified tumour-specific markers for a variety of tumours and with the funding awarded from the Bone Cancer Research Trust we are now able to test our markers in both tumour and blood DNA from patients with osteosarcoma and chordoma.

We will be able to use these markers to measure the level of tumour DNA in the blood and determine whether the test can be used to monitor patients post treatment for residual disease and early disease relapse.

WHAT DIFFERENCE COULD THIS PROJECT MAKE FOR PATIENTS WITH CHORDOMA AND OSTEOSARCOMA IN THE FUTURE?

This pilot-study will be the first step towards applying circulating tumour DNA analysis to monitor disease status, response to treatment before and after surgery, and to detect residual disease in patients with osteosarcoma and chordoma. Ultimately, this will provide a more personalised treatment for patients, detect relapse early using a non-invasive simple blood test and provide more accurate prognoses. An added benefit of such tests would subsequently result in a reduction in the schedule of often inconvenient and expensive medical imaging that patients undergo for surveillance.

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

We are grateful to all Bone Cancer Research Trust supporters that continue to raise money and make projects like ours possible.

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



RESEARCH FINDING



Bone Cancer Research Trust project finds protein that promotes osteosarcoma lung metastasis and an inhibitor that could prevent it.

KEY FINDINGS OF THIS RESEARCH

A protein called FGFR1 was found to have a key role in controlling the communications within osteosarcoma cells that result in the formation of lung metastases. When FGFR1 was stopped from functioning by using an inhibitor, which is currently in clinical trials for other cancers, the spread of cancer cells to the lungs was reduced.

Since this finding we have awarded further funding to Professor Grigoriadis and he is now investigating the possibility of inhibiting other signalling proteins at the same time as FGFR1, in order to achieve a greater reduction in metastatic spread.

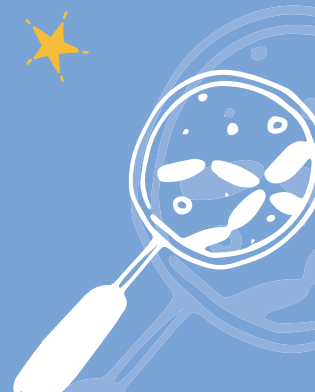
A complementary piece of research also funded by the Bone Cancer Research Trust, discovered that osteosarcoma patients with high levels of FGFR1 had poorer responses to chemotherapy. This study was carried out by Professor Adrienne Flanagan OBE and Dr Sandra Strauss from University College London, and provided a rationale for inclusion of patients with osteosarcoma in clinical trials using FGFR inhibitors.

We hope that further investigations in this area would arrive at the development of new treatments for metastatic disease, to benefit patients in whom the presence of these proteins is confirmed.



PROFESSOR AGAMEMNON GRIGORIADIS
KING'S COLLEGE LONDON

Funding was awarded to Professor Agamemnon Grigoriadis who is based at King's College London, to investigate novel approaches to reduce the spread, resistance to treatment and recurrence of osteosarcoma.



SUPPORT AND INFORMATION SERVICE

Making a Difference

BONE CANCER AND BONE TUMOUR SUPPORT GROUPS

Our Support Groups provide you with dedicated information and emotional support whether you're a patient, family member or friend who has been affected by primary bone cancer.

We launched our support groups during Sarcoma Awareness Month in July. Since then our Support Manager, Louise, has supported over 120 people at the groups, across 12 locations.

For more information on our planned support groups please visit Bcrt.org.uk/SupportGroups

GLASGOW

NEWCASTLE

SKIPTON

LIVERPOOL

SHEFFIELD

MANCHESTER

BIRMINGHAM

OSWESTRY

LEICESTER

UCLH

OXFORD

LONDON

What is the impact?

Since the launch of our Support and Information Service in May, we have provided support to over 400 people

75% of people who came to one of our support groups felt less anxious afterwards

Over 350 people have joined our Digital Support Groups since they launched in October, during Bone Cancer Awareness Week



“ It gave me a chance to speak openly knowing that the group fully understood what I went through. Hearing everyone's stories I realised that I'm not alone in facing a disease so very rare. I found it has helped towards my healing process and I'm hoping these support groups will be beneficial to other patients too.

“ I enjoyed listening to the Q&A with another patient as it sparked conversation afterwards.



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



*This year we awarded a research grant to **Professor Sue Burchill from Leeds University**. Professor Burchill explains more about the new Ewing sarcoma research project and the difference it will make for future patients.*



CAN YOU TELL US ABOUT THE PROJECT AND ITS AIMS?

We have recently shown that Ewing sarcoma is driven by a sub-population of cells that divide and are resistant to current treatments, so-called Ewing sarcoma cancer stem-like cells (ES-CSCs). Improved outcome for some patients will only be achieved when drugs to target these cells have been identified and incorporated into treatment. We have identified a lead protein that drives the growth and renewal of ES-CSCs. This protein is therefore an attractive target for the design of new treatments. However, the protein exists in two different forms called A and B. With funding from the Bone Cancer Research Trust we will determine whether A and B, just A or just B are expressed in Ewing sarcoma and ES-CSCs.

HOW IS THE PROJECT A CONTINUATION OF RESEARCH PREVIOUSLY FUNDED BY THE BONE CANCER RESEARCH TRUST?

With support from the Bone Cancer Research Trust and Ewing's Sarcoma Research Trust we have been able to collect and characterise patient-derived Ewing sarcoma cells. These cells provide a unique and precious resource to test treatments that might be used to improve outcomes and identify targets like protein A and B that could then be exploited to eradicate the cells responsible for progression and relapse.

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

Confirmation of the driver protein in ES-CSCs and subsequent identification of drugs to target this protein will allow us to fast-track targeted treatment to eradicate

ES-CSCs, with the goal of accelerating new treatments into early phase clinical trials to improve outcomes. The combination of targeted treatment to kill ES-CSCs with chemotherapy is predicted to improve outcomes and minimise treatment-induced side effects.

HOW IMPORTANT IS THE FUNDING PROVIDED BY THE BONE CANCER RESEARCH TRUST?

Without the support of the Bone Cancer Research Trust it would not be possible to undertake our research in Ewing sarcoma or attract and train future research scientists in the field.

YOU'VE BEEN SUCCESSFUL IN RECEIVING GRANTS FROM US IN THE PAST, DO YOU THINK WE ARE STIMULATING THE BONE CANCER RESEARCH COMMUNITY?

Yes. It's a wonderful charity to work with as they are committed to promoting and sustaining the best research for patient benefit.

WHAT WOULD YOU SAY TO BONE CANCER RESEARCH TRUST SUPPORTERS WHO ARE RAISING FUNDS FOR RESEARCH?

A huge thank you. Your commitment and enthusiasm to raise funds for the Bone Cancer Research Trust is essential for the continuation and expansion of research into bone cancers, to improve outcomes and minimise treatment induced side-effects for everyone. Together we can beat bone cancer.

To read the full interview and find out more about the project visit bcrt.org.uk/SueBurchill

SPECIAL FUNDS

We have over 40 Special Funds across the UK. They all have one thing in common, they want to raise funds and awareness to change the outcomes for those affected by primary bone cancer, both now and in the future.

WHAT IS A SPECIAL FUND?

Our Special Funds are usually set up in memory of a loved one, inspired by someone who has survived primary bone cancer or set up by a person living with primary bone cancer.

By setting up a Special Fund you create a dedicated fund in your name or the name of your loved one. It is a wonderful way for friends, family and colleagues to join together to do something that really matters to them.

WHAT DO THE SPECIAL FUNDS DO?

Those running Special Funds have complete control over their fundraising, you can choose how you wish to raise funds and when. This could be anything from bake sales and bucket collections, to skydives and marathons or organising events such as golf days, cinema nights or music festivals! Nothing is too big or too small, as every penny really does count in our fight against primary bone cancer.

WHAT HELP DO YOU RECEIVE?

Our Special Funds team are on hand to support you every step of the way. We look after all your admin tasks such as the legal stuff, thanking supporters and Gift Aid so that you can concentrate solely on raising much needed funds and awareness.

We provide you with your own Special Fund logo, a page on our website and all the materials you need to fundraise; including personalised banners, collection tins and buckets, wristbands, leaflets and even balloons to promote your fund! We are also on the other end of the phone to help with fundraising advice and ideas or just for a chat.

To find out more and to meet some of our special funds, visit bcrt.org.uk/Funds. Or call our friendly Special Funds team, Kate and Lauren on 0113 258 5934.





PROFESSOR JOHN ANDERSON,
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH,
UNIVERSITY COLLEGE LONDON

The Bone Cancer Research Trust funded a study by Professor John Anderson from the Great Ormond Street Institute of Child Health, University College London, that aimed to identify a new biological target for the treatment of Ewing sarcoma.

RESEARCH FINDING



Research project identifies a protein that enables cancer cell growth.

KEY FINDINGS OF THIS RESEARCH

Transcription factors are proteins that help turn specific genes “on” by binding to DNA. Once the genes are turned on, other proteins are produced that promote cancer growth.

Professor Anderson’s research revealed that a transcription factor named STAT3 is present and active in 58% of the Ewing sarcoma tissues he studied, and that Ewing sarcoma cells containing active STAT3 grow faster than those in which STAT3 is absent.

STAT3 was inactivated using an inhibitor named S3i-201, and by doing so, the growth of Ewing sarcoma cells was reduced.

A second part of the research discovered that inactivation of STAT3 also affected the ability of Ewing sarcoma cells to release proteins named chemokines that activate the body’s immune response against cancer cells.

Further studies need to be performed and this is an ongoing area of interest for the Bone Cancer Research Trust and researchers.



Q&A

WITH OUR PHD
RESEARCH STUDENT
TYLER BARR



“I am truly grateful to each supporter of the Bone Cancer Research Trust, as it is their support which makes research to improve outcomes for bone cancer patients possible.”

After losing her friend to Ewing sarcoma, Tyler tells us more about her drive to succeed and the difference our PhD research project ‘Oncolytic virus therapy for Ewing sarcoma’ could make to patients.

CAN YOU TELL US ABOUT YOURSELF AND HOW YOU GOT INVOLVED WITH EWING SARCOMA RESEARCH?

I completed a First-Class Honours degree in Biomedical Science in 2017. It inspired me to do a Masters degree in Molecular Medicine at the University of Leeds. I completed a research project investigating the use of Oncolytic Virus therapy for colorectal cancer. While working on the project, Professor Graham Cook was awarded a PhD Studentship Grant from BCRT, I applied and was successful.

I lost a friend, Will, to Ewing Sarcoma in 2015, and while I always knew I wanted to undertake a PhD in cancer immunotherapy, when this project came up it was very close to my heart and gave me a personal drive to succeed.

WHAT IS A DAY IN THE LAB LIKE?

A day in the lab consists of culturing Ewing sarcoma cell lines, which I use to screen Oncolytic Viruses, to determine if these agents can kill Ewing sarcoma cells. Oncolytic Viruses are an immunotherapy, so their effect on immune cells is also investigated. I obtain immune cells from blood samples and assess the ability of Oncolytic Viruses to activate ‘killer’ cells of the immune system. I also work on developing a more representative 3D model of Ewing sarcoma, which we can use in the lab to screen Oncolytic Viruses.

WHY IS FUNDING FOR A PHD STUDENTSHIP GRANT IMPORTANT?

Funding for PhD studentships is so important. It allows research to be carried out to investigate new treatment options for bone cancer patients. The length of this project, which is four years, allows time to learn more and for the research to progress. BCRT have been able to offer many opportunities for studentships over recent years which is amazing.

WHAT DIFFERENCE DO YOU THINK YOUR WORK COULD MAKE TO EWING SARCOMA PATIENTS IN THE FUTURE?

Current treatment options for Ewing Sarcoma are very limited, and new treatment options are vital to improve patient outcomes. The Oncolytic Viruses being investigated in the lab have shown positive results in other cancers, and importantly, have demonstrated safety in patients. This has important implications for Ewing sarcoma patients, as it reduces the time between lab-based research and clinical trials. Promising results in the lab could be quickly taken to the clinic for trials in Ewing sarcoma patients.

WOULD YOU LIKE TO SAY ANYTHING TO OUR SUPPORTERS?

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

To read Tyler’s full interview and for more information about the research project visit bcrt.org.uk/TylerBarr

HOW YOU CAN HELP OUR COMMUNITY DURING THE FESTIVE SEASON

Show your support

Jingle Bones CHRISTMAS JUMPER DAY

JINGLE BONES - CHRISTMAS JUMPER DAY!

"By taking part in Jingle Bones, we feel like we are making a difference and that something positive can come from losing Jude." Helen Anderton, Jude's Mum.

Join us on Friday 13th December (or whenever is best for you) and don your favourite winter woollies to help raise festive funds for our vital work!



SUPPORT THE...



HELP STAMP OUT PRIMARY BONE CANCER THIS CHRISTMAS!

Over the festive period join our dedicated team of Stamp Champs and save your used postage stamps. **1kg of stamps helps pay for 1 hour of life-saving research**, so please encourage your friends, family, workplaces, schools and clubs to get on board this Christmas and start saving stamps!



Find out more at bcrt.org.uk/JingleBones

Start collecting now and request a Stamp Appeal pack at bcrt.org.uk/Stamps

ABOUT UNITED

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