

UNITED

UNTIL THERE'S A CURE

**BONE CANCER PATIENT,
ABIGAIL JOINS US IN
OUR 15TH ANNIVERSARY
CELEBRATIONS AND
SHARES HER STORY**

PAGE 12

15 YEARS OF
RESEARCH IMPACT

FIRST INTERNATIONAL
RESEARCH GRANT
AWARDED

UK'S BIGGEST PRIMARY
BONE CANCER AND
BONE TUMOUR
AWARENESS CAMPAIGN

PLUS MUCH
MORE...



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





EDITOR'S NOTE

Welcome to a special 15th anniversary edition of United.

Packed full of news, updates, stories and interviews this celebratory edition of United includes so many proud moments and achievements from the past 15 years!

We start by going all the way back to the beginning with an exclusive interview with Professor Lewis, one of our founding trustees, on page 4. Read all about our 15 years of research impact on pages 5, 6 and 7, where you can find out about what has been made possible because of the vital funds you, our supporters, have raised over the years. You can also see how innovative our fundraisers have been over the years in raising those life-saving funds on page 8.

Find out more about our Support & Information Service on page 10 and how we've adapted because of COVID-19. We also share Abigail's inspirational story on page 12.

In the midst of the pandemic, we also delivered the biggest primary bone cancer and bone tumour awareness campaign ever undertaken in the UK! Find out more on page 16.

We would love to hear from our readers. If you would like to share any ideas or topics for us to cover, please let us know by emailing info@bcrt.org.uk.

Deborah Flyde
Communications Manager



FOREWORD FROM CHAIRMAN

In 2006, the Bone Cancer Research Trust was registered as a charity, and over the past 15 years we have achieved so much because of the support of the bone cancer community.

I've been the Chairman of the charity for 5 years now and I'm honoured to have witnessed so many amazing achievements with my own eyes. The Bone Cancer Research Trust remains the only charity dedicated to finding a cure for primary bone cancer, and the vital work we deliver is made possible because of the funds raised from supporters like you.

Over the past 15 years we've seen exponential growth in our research community, and we've funded over 300 researchers from 187 academic institutions and hospitals around the UK, and more recently internationally, equating to 88 pioneering projects totalling a research investment of over £4.1 million. This also included investing over £1.2 million to nurture the next generation of bone cancer researchers by supporting the training of 9 PhD Students.

In addition to investing in research, we listened to the needs of our community and responded by launching a dedicated Support & Information Service. Our wonderful team are now supporting hundreds of patients and their loved ones.

More recently we delivered the UK's biggest primary bone cancer and tumour awareness campaign ever undertaken in the UK! Over 368,000 educational resources on the signs and symptoms of primary bone cancer were delivered to all GP surgeries, musculoskeletal physiotherapists, radiology departments, medical schools and pharmacy practices across the UK.

This is all truly remarkable, and I would like to take this opportunity to say thank you to our incredible supporters and our amazingly dedicated team for making all this happen!

We are a small charity, with an incredibly supportive community, which means together, we will continue to make a difference for all those affected by this brutal disease, until there's a cure.

Andy Lewis
Chairman

NEWS IN BRIEF

FIRST INTERNATIONAL EWING SARCOMA SYMPOSIUM

During Bone Cancer Awareness Week 2020, we held our first ever International Ewing Sarcoma Symposium, hosted by Professor Sue Burchill, from the University of Leeds, to encourage further international collaboration, align strategic approaches and stimulate new research. The symposium included talks and pioneering updates from 14 speakers and brought together 120 researchers from across the globe. **The day was a huge success and it concluded with the opening of a new Ewing sarcoma research grant call, funded in collaboration with the Ewing's Sarcoma Research Trust.**



THE 2.6 CHALLENGE

The Virgin Money London Marathon was unfortunately cancelled due to COVID-19 and in its place the organisers launched the 2.6 Challenge! We were incredibly overwhelmed by the support we received from the bone cancer community. **You completed everything 2.6 related from a 26 mile bike ride, walking 26,000 steps to 26 cartwheels and a 26 hours of silence! Thanks to your amazing efforts, together you raised a phenomenal £31,178 for bone cancer patients!**

COLLABORATING WITH EWING'S SARCOMA RESEARCH TRUST

In 2013, we started to work in collaboration with the Ewing's Sarcoma Research Trust. Together our aim is to revolutionise treatments and improve outcomes for Ewing sarcoma patients and their families. **To date, the Ewing's Sarcoma Research Trust have contributed £230,000 towards four pioneering research projects.** Through continued collaboration, we are delighted to share that in 2021 we are coming together again to fund even more large-scale Ewing sarcoma research projects.





INTERVIEW
WITH...
**PROFESSOR
IAN LEWIS**



We interviewed Professor Ian Lewis, one of the founding trustees of the Bone Cancer Research Trust. Now retired, Professor Lewis reflects on some of the challenges the charity faced back in 2006 and why the success of the Bone Cancer Research Trust is built on trust, collaboration and putting patients and their families at the centre of the charity's existence.

WHAT WERE THE CHALLENGES THE CHARITY FACED IN THE EARLY DAYS?

There were lots of challenges; becoming recognised as a reliable source of research funding and accurate and trusted information, being accessible to patients and families and developing a national (and then hopefully international) community who shared the overall aims of improving outcomes for primary bone cancer through research and collaboration.

WHEN YOU BECAME A TRUSTEE OF THE CHARITY WHAT WERE SOME OF THE GOALS YOU WANTED THE ORGANISATION TO ACHIEVE?

What we really wanted to see was more patients surviving bone cancer with less disability. There were some factors that we identified at a very early stage that would be key to improving survival and treatment, such as to try and lessen the time it takes to diagnose bone cancer. There have now been many initiatives and campaigns over the last 15 years trying to improve awareness of bone cancer with professionals and the public with the aim of enabling earlier diagnosis. Also, the need for scientists to have access to bone cancer tissue from patients if we were to improve our understanding of the different forms of bone cancer and to test out possible new treatment approaches. Before the Bone Cancer Research Trust was formed there was no clear path or system for clinical teams to ask patients if they would agree for their bone tumours to be used in research. The Bone Cancer Research Trust's Infrastructure Grants are a game changer and the work to link clinical centres with researchers will continue to be key to achieving the charity's aims.

THE BONE CANCER RESEARCH TRUST IS NOW THE LEADING CHARITY DEDICATED TO FIGHTING PRIMARY BONE CANCER, HOW DOES THAT MAKE YOU FEEL?

I have enormous pride that I was able to contribute to the Bone Cancer Research Trust and by what was achieved as we took off and started to fly. We only did that because the charity was built on collaboration, trust, and holding fast to a set of values that puts patients and their families at the centre of our existence. I look at the range and scope of the research the charity is now funding and how far the Bone Cancer Research Trust has come. I look at the information and various campaigns and how many desperate people are now being helped – it is wonderful!

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

Everyone's contribution is really valued and important but there is still much to do before every person who is newly diagnosed with bone cancer is treated successfully. Until that happens the need for the Bone Cancer Research Trust to exist continues and so the work must go on.

To read the
full interview with
Professor Lewis, visit
[bcrt.org.uk/
IanLewis](http://bcrt.org.uk/IanLewis)

15 YEARS OF RESEARCH IMPACT

To mark our 15th anniversary we look back and celebrate key research achievements that are helping scientists, clinicians, and surgeons to gain a better understanding of the causes of primary bone cancer and to find more effective treatments.

PATIENT SAMPLE COLLECTION

Patient samples are an invaluable resource for researchers. Our Infrastructure Grants have enabled the five bone cancer surgical centres in England to approach patients, obtain consent and collect primary bone cancer specimens for research.

WHOLE GENOME SEQUENCING

The 100,000 genomes project aimed to gain a better understanding of rare diseases and cancers, to potentially identify their cause and find new treatments. Our Infrastructure Grants made possible the inclusion of primary bone cancer patient samples in the study. All sarcoma tumour samples can now be submitted to NHS England for whole genome sequencing.

COMPUTER NAVIGATION ASSISTED SURGERY

We funded the initial investigations to assess the efficacy of computer-guided pelvic surgery. The results have now confirmed significantly better outcomes in local control and progression-free survival for chondrosarcoma patients.

PROTON BEAM THERAPY PROTOCOLS

We funded a clinical fellowship to establish the protocols and assess intensity modulated radiotherapy and proton beam radiotherapy for bone cancer patients. Proton beam therapy is now available for bone cancer patients at the Christie NHS Foundation Trust.

COMBINATION OF DNA REPAIR INHIBITORS WITH RADIOTHERAPY AND CHEMOTHERAPY

PARP inhibitors increase the DNA damage in cancer cells caused by chemotherapy and radiotherapy. We funded research projects that collected preclinical evidence for the inclusion of Ewing sarcoma patients into current clinical trials investigating the efficacy of PARP inhibitors in combination with other chemotherapies.

NOVEL BIOMARKERS FOR DIAGNOSIS AND MONITORING

We have funded researchers investigating novel markers for better diagnosis, monitoring progression and response to treatment. Analysis of gene and protein expression, circulating tumour DNA and circulating tumour cells is now becoming a reality for bone cancer patients.

ICONIC

ICONIC aims to recruit every newly diagnosed patient with osteosarcoma, to build the UK's first ever age-inclusive osteosarcoma clinical trial – combining clinical data with tissue collection and analysis. ICONIC brings together patients, health professionals, clinical and scientific experts, with the aim of achieving better treatments and outcomes for osteosarcoma patients. It has now become a model to follow for setting up observational clinical trials.



RESEARCH TIMELINE

Below, we are delighted to share more of our research achievements from the past 15 years.



First two pioneering research grants awarded. One to study potential risk factors for bone cancer and the second to investigate ways to utilise the body's immune responses against Ewing sarcoma.

2006

2006-2021

- We have provided funding for 88 research projects totaling over £4.1 million
- We have supported:
 - 88 Principal investigators
 - 224 Co-applicants and collaborators
 - From 187 academic institutions and hospitals around the UK, and more recently internationally
- We have invested over £1.2 million to nurture the next generation of bone cancer researchers by supporting the training of 9 PhD students
- Our Infrastructure Grants have facilitated the collection of 4458 patient samples for specific research projects and have collected and stored 4666 samples for future research
- We have facilitated and supported 6 international research conferences, bringing together the best researchers in the field, to promote collaboration and exchange of ideas



Research grant awarded investigating if PARP inhibitors increase the effectiveness of chemotherapy in Ewing sarcoma. This research has provided evidence to include Ewing sarcoma patients in a 2014 clinical trial.

2009



Research to assess the efficacy of computer-guided pelvic sarcoma surgery commences. This has led to significant improvement for chondrosarcoma patients in survival and quality of life.

2010



Following our campaign to reverse the refusal by NICE to include Mepact as treatment for osteosarcoma, approval was granted.

2011

2012



Research started to develop protocols for intensity-modulated radiotherapy and proton beam radiotherapy for bone cancer patients. Proton beam is now available to patients at The Christie.



Our funded research finds a potential biomarker to predict poor response for patients with localised Ewing sarcoma.



Held the first International Osteosarcoma Symposium bringing together researchers from across the world.



Awarded Healthcare and Medical Research Charity of the Year in recognition of our Infrastructure Grants.

2019



Funded a ground-breaking project to reduce side effects of methotrexate for osteosarcoma patients.

2018



Funded the UK's first age-inclusive osteosarcoma clinical trial, ICONIC. This is our largest ever research grant and is a UK-wide collaboration between all new patients diagnosed with osteosarcoma, the medical professionals involved in treating them and scientists trying to understand the disease and find more effective treatments.



Research commenced on blood test biomarkers to detect primary bone cancer cells and tumour DNA fragments in the blood.

2013



Launch of the UK's first adamantinoma research programme.



We award our first cancer evolution research project, trying to understand how chondrosarcoma develops and changes over time.



First international research grant awarded in the USA for Ewing sarcoma.

2020



We co-hosted the first International Ewing Sarcoma Research symposium to stimulate international collaboration resulting in our largest grant call for Ewing sarcoma.



In response to being eligible for the 100,000 Genome Project, our patient sample collection Infrastructure Grants are launched.

2017

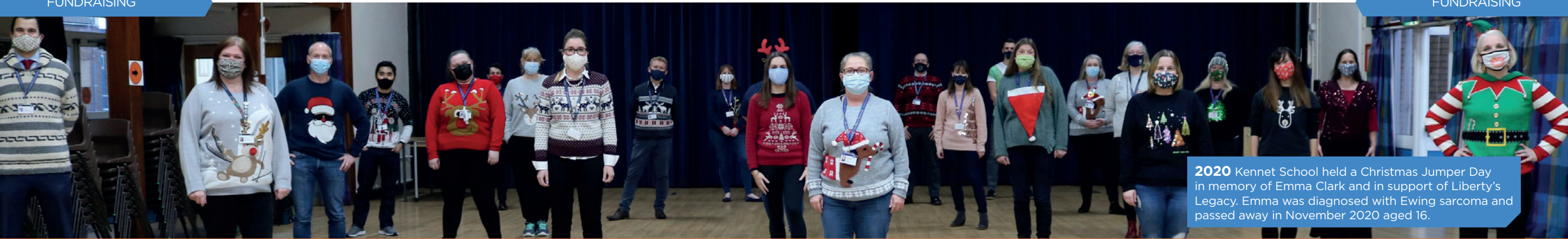


Supported three international primary bone cancer meetings, including the 2nd Ewing Sarcoma Consensus Meeting to harmonise approaches to the treatment of Ewing sarcoma.



Launch of the 'LIVING WITH, AND BEYOND, PRIMARY BONE CANCER' report, which became the foundation of our 2017-2022 strategy.

2015



2020 Kennet School held a Christmas Jumper Day in memory of Emma Clark and in support of Liberty's Legacy. Emma was diagnosed with Ewing sarcoma and passed away in November 2020 aged 16.

15 YEARS OF FUNDRAISING... EVEN DURING A PANDEMIC!

Our wonderful Team Bones supporters never fail to amaze us with their passion for and dedication to raising life-saving funds. Thank you to every single person who has supported our vital work over the last 15 years. We wish we could include everyone, you are all truly awesome! But we hope you enjoy seeing a snapshot of '15 years of Team Bones'.



2007 Fourteen firemen from Bradford Fire Station Green Watch climbed the Yorkshire Three Peaks, inspired by Francesca Haigh who was diagnosed with osteosarcoma.



2008 Sydenham High Junior School's football team raised funds and awareness in support of Rose Allocca who had osteosarcoma and passed away in 2010 aged 8.



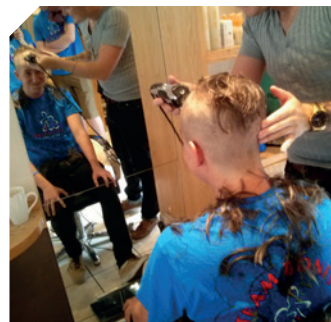
2012 Ellie and Abbie Roberts had a charity stall at Melton Mowbray Christmas lights switch-on in memory of their friend Abbie Freeman who they lost to osteosarcoma in 2010.



2018 The epic 13-day Tri-Nations Challenge was organised by Dai Gallivan in memory of his daughter Tasha who passed away in 2016 aged 34.



2020 Blessed Thomas Holford Catholic College remembered Jude Anderton on his 15th birthday with a Wear Orange Day #bemoreJude.



2014 David Nagaj swapped his 60s quiff for the cropped look at the same place his Mum did when she was preparing for chemotherapy.



2014 The 3rd annual Pink Party took place in memory of Alexander Albiston who was diagnosed with osteosarcoma and passed away in 2010 aged 18.



2014 Kira Hagan and students at Tuxford Academy held a bake sale and non-uniform day, as well as a week of awareness-raising assemblies, led by Kira, in memory of her son Zack.



2019 Pannal Primary School made and sold friendship bracelets in memory of former pupil Frank Ashton who passed away in 2019 aged 14.



2020 Wendy Price designed and sold Christmas cards inspired by 7 year old Freddie Croft who was diagnosed with Ewing sarcoma in 2019.



2020 Catriona McNabb held weekly Zoom yoga classes. Her daughter was diagnosed with adamantinoma in 2012 aged 7.



2020 Four year old Teddy took on the 2.6 Challenge with his stuffed dog Merida. Together they cycled 2.6 miles in memory of Al Dawson.



2015 Sarah Weare held a non-stop 6 hour Aerobathon in memory of Mary Collard who was diagnosed with osteosarcoma and passed away in 2012 aged 11.

The Bone Cancer Research Trust is dedicated to fighting primary bone cancer, but we can't do it without the support of people like you. Whether it's a bake sale at school, a cycling challenge with friends or a black-tie gala event, your support makes our work possible. If you would like to get involved, we'd love to hear from you. **We're a friendly bunch, so do give us a call on 0113 258 5934 or email fundraising@bcrt.org.uk.**

KATE & SIOBHAN, COMMUNITY FUNDRAISING TEAM

SUPPORT AND INFORMATION

In 2019 we launched our dedicated Support & Information Service. The service has been a huge success and we have supported hundreds of primary bone cancer and bone tumour patients and their families.

Due to the COVID-19 pandemic, our Support & Information Service has had to change. We quickly moved from face-to-face support events in hospitals to virtual support groups. We adapted and we did it quickly, to ensure the bone cancer community continued to get the support they needed, when they needed it. As a result, we are supporting more people than ever before.

When the national lockdown was announced, our Support & Information Service experienced an increase of 64% and we have gone on to see a further 82% increase in the level of enquiries from the bone cancer community at certain times throughout the pandemic.

WHAT DOES THE SUPPORT & INFORMATION SERVICE OFFER?

We can't wait to start meeting bone cancer and bone tumour patients and their families again face-to-face, but at the moment this is still not possible. As we continue to face uncertain times, we are still here for our community in many ways. Our service currently offers:

VIRTUAL CUPPA AND EVENING CUPPA

Our Virtual Cuppas and Evening Cuppas are friendly and informal virtual support groups, held every Tuesday from 1-2pm (Virtual Cuppa) and on the last Tuesday of every month from 7:30-8:30pm (Evening Cuppa) via Zoom.

To find out more contact our Support & Information Team

Visit: bcrt.org.uk/support
Call: 0800 111 4855
Email: support@bcrt.org.uk

VIRTUAL SOCIAL

Our Teenage Young Adult meet-up is for 16-30 years-old who have experienced a primary bone cancer or bone tumour diagnosis. It is held quarterly on the first Tuesday of the month from 7:30-8:30pm.

VIRTUAL STORYTIME

Virtual Storytime is held in collaboration with Henry Dancer Days, bringing children between 5 and 11-years-old a world of imagination as part of our friendly community. Henry Dancer Days' hugely successful, 'Storytelling Project' which usually takes place in 7 children's cancer hospitals in the UK, has gone virtual with us.

“ They were so happy after the stories. They loved it so much especially the funny books and my son keeps asking when he's having another story. ”

“ My family is experiencing the worst nightmare imaginable, but Joanne and Louise have been lifesavers with their support. We are far from through this dreadful experience, but I know that they are there for us no matter what. We shall be forever grateful. Thank you. ”

SUPPORT AND INFORMATION WEBINARS

We have a collection of support and information webinars available to view at any time via our website. They are designed to inform and provide help to those facing a primary bone cancer and bone tumour journey and beyond. Each virtual webinar has a different theme and cover topics from late effects and fertility to nutrition and proton beam therapy.

DIGITAL SUPPORT GROUPS

Our Digital Support Groups on Facebook offer a safe online place where people affected by primary bone cancer can connect. Our Groups enable you to share your experiences, access support and connect with the bone cancer community. We have created nine groups for each primary bone cancer and bone tumour.

FINANCIAL ASSISTANCE GRANTS

Here at the Bone Cancer Research Trust, we know that a cancer diagnosis costs from the point of diagnosis onwards. To help with the immediate costs of cancer, we provide a Financial Support Grant of £50 to all primary bone cancer and bone tumour patients (UK and Republic of Ireland only) currently in active treatment.

We also offer a Travel Assistance Grant of £120 to all primary bone cancer patients to help with the cost of travel for Proton Beam Therapy at the Christie Hospital, Manchester and will be available soon for treatment at the University College London Hospital.

“ I cannot express how fantastic this support is. The team were extremely knowledgeable and supportive and could not have been more helpful. ”



ABIGAIL'S STORY

Abigail Frechou was diagnosed with metastatic Ewing sarcoma 18th June 2019 when she was nine years old. Abigail's Mum, Ellie shares her daughter's inspirational story.

In June 2018, 12 months prior to Abigail's diagnosis, I took Abigail to see her GP because she was having a lot of pain in her legs. Sometimes the pain would make her cry. The GP dismissed it as growing pains and waved us out of the room.

Abigail's sister, Annabel had some special insoles fitted and they had helped her. So, we thought that insoles might help with Abigail's pain. We saw a podiatrist and Abigail had insoles fitted and they did help for a while.

She started to get really upset at the beginning of May and she cried to her teacher, which was most unlike her, as she was generally a well child and didn't easily complain or get upset. So, we knew something really wasn't right. I tried to get a GP appointment, but I was told it wasn't an emergency and would have to wait until the end of the week.

I turned to my fellow paediatric nurses and they suggested going to A&E and she had an X-ray and was diagnosed with an irritable hip and sent home. Abigail cried all night with tremendous pain, we gave her pain relief, but it did not ease the pain.

The A&E department we took Abigail to, did a second review of her X-ray and we received a call from a consultant radiologist who said we needed to come to the hospital immediately.

He took my husband and I into a side room and told us he had seen something on the X-ray. At that time, we were told it was either a lesion or bone cancer and I said 'osteosarcoma' and he nodded. Abigail's diagnosis then took 6 weeks. The first biopsy only got necrotic tissue (dead cells), so she had to have a second one. Both biopsies were done at the Royal Orthopaedic Hospital in Birmingham.

Abigail was diagnosed with metastatic Ewing sarcoma in her right pelvis, the tumour was approximately 7-10cms and it had metastasised under her clavicle (collarbone) to her left supraclavicular node, but it was too dangerous to take a biopsy.

Abigail had 14 rounds of 5 different types of chemotherapy at the Royal Manchester Children's Hospital, she was diagnosed on the 18th June 2019 and chemotherapy started on the same day. Abigail's oncologist Dr Anthony Penn and the team were fantastic.

Abigail also had 58 sessions of radiotherapy at The Christie in Manchester and their team were amazing. Due to receiving chemotherapy and radiotherapy at the same time, Abigail was very poorly and spent most of the summer in hospital.

November 2019, Abigail had major surgery at the Royal National Orthopaedic Hospital, which involved removing the right side of her pelvis. Before being discharged, Abigail had to learn to walk again using mobility aids with the help of the physiotherapy team. Her treatment finished on the 1st of March 2020.

Because of the COVID-19 pandemic, Abigail went straight from treatment into shielding and because of lockdown she couldn't have physiotherapy or hydrotherapy, which was essential to help her rehabilitate from the surgery to her pelvis. Abigail has been really upset about the pandemic because she was looking forward to normality and getting her life back and the virus has stopped that. If she had one wish it would be there was no virus.

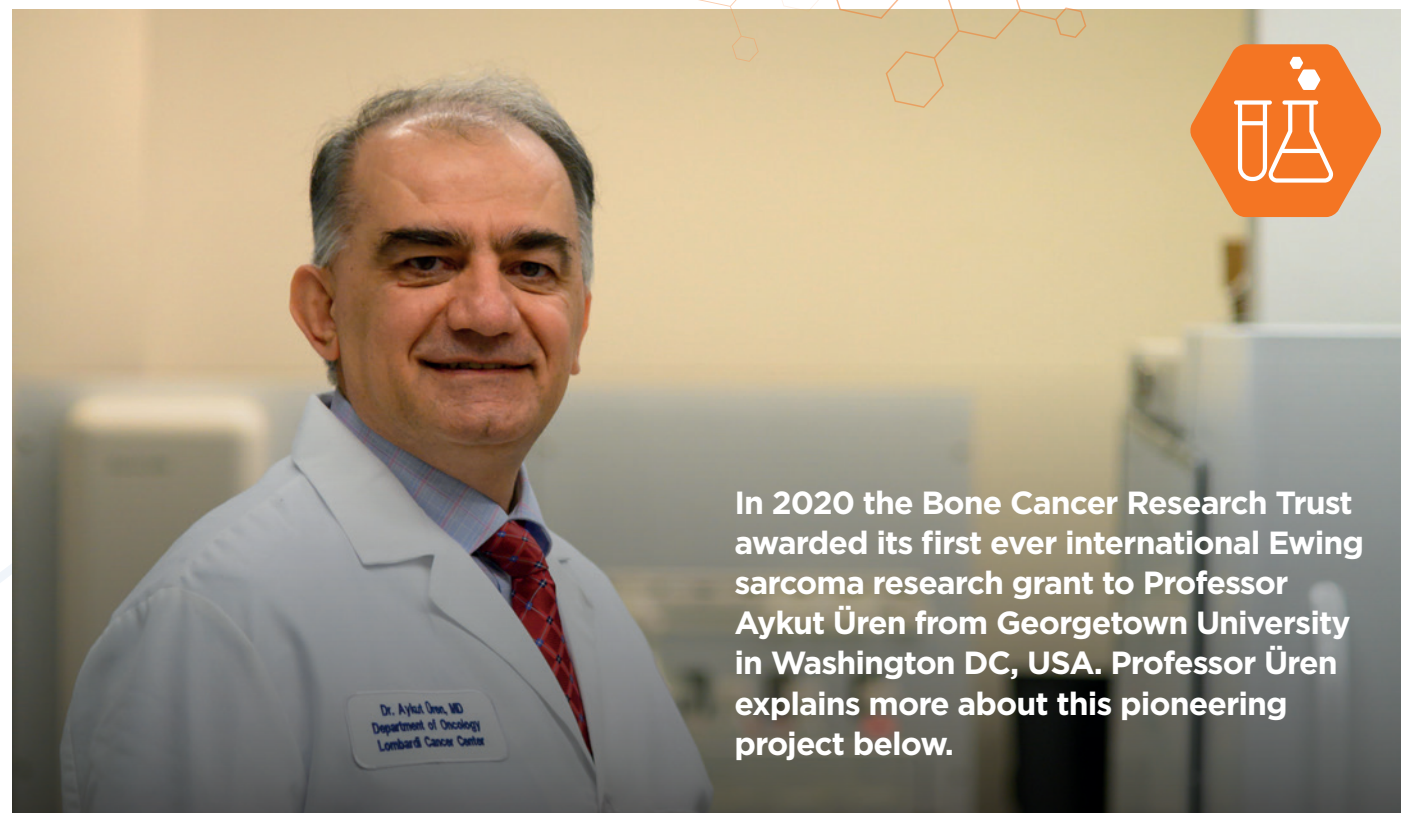
There are lots of physical activities Abigail is unable to do and is now classed as disabled. However, she is so determined, and she tries to not let this stop her, she is always looking forward and her latest scan results were all-clear.

“Annabel, Abigail's little sister, has supported Abigail and all the family throughout. Coming home from very difficult days and getting cuddles from Annabel was an incredible feeling.”



Abigail's family have set up a Special Fund with the Bone Cancer Research Trust called Abigail's Ambition to help find kinder treatments.

To find out more about Abigail's Ambition visit bcrt.org.uk/abigailsambition



In 2020 the Bone Cancer Research Trust awarded its first ever international Ewing sarcoma research grant to Professor Aykut Üren from Georgetown University in Washington DC, USA. Professor Üren explains more about this pioneering project below.

CAN YOU TELL US ABOUT YOURSELF?

I grew up in Ankara, Turkey. When I was a medical student at Hacettepe University, I came to the USA, National Cancer Institute in Bethesda Maryland, and worked as a volunteer in research laboratories. When I finished medical school, I was offered a postdoctoral fellowship at the same institute, that is when I moved to the USA. I joined the faculty at Georgetown University in Washington DC and I have been involved in cancer research for more than 25 years. My research lab focuses on discovering new drugs for paediatric sarcomas.

CAN YOU TELL US ABOUT THE PROJECT AND ITS AIMS?

The project is trying to improve an existing drug so that it can become a targeted therapy option for Ewing sarcoma patients. Ewing sarcoma cells have a common feature on their surface. Presence of a protein called CD99 separates Ewing sarcoma from many similar tumours. More importantly, CD99 appears to be critical for the growth and aggressiveness of Ewing sarcoma cells. Therefore, we have been trying to develop drugs to target CD99 on the Ewing sarcoma cell surface and kill the tumour cells. We discovered that two FDA approved drugs can directly bind to CD99 and kill Ewing sarcoma cells. These drugs are currently used for treating some types of leukaemias by a different mechanism inside the cell.

Our discovery of them binding to CD99 on the cell surface of Ewing sarcoma creates new opportunities for targeted therapy. In this project we aim to make modifications in the structure of these existing drugs so that they can still bind to CD99 on the surface of Ewing sarcoma cells, but lose their ability to enter the cells. If our experiments can successfully create such a molecule, it will become a Ewing sarcoma specific drug and since it can not enter the cell, we will be eliminating many of the side effects related to these agents, including bone marrow suppression.

WHAT DIFFERENCE COULD THIS PROJECT MAKE TO FUTURE PATIENTS?

Our studies have the potential to create a novel therapeutic option that will be specific to Ewing sarcoma with reduced side effects, which can both improve overall survival and quality of life for patients suffering from this disease.

HOW DOES IT FEEL TO RECEIVE FUNDING FOR OUR FIRST INTERNATIONAL GRANT AND WHAT WOULD YOU LIKE TO SAY TO OUR SUPPORTERS?

That is a great honour. Our team will work on this important project tirelessly and try to come up with new promising drug candidates.

COLLABORATION RESULTS IN A NEW BREAKTHROUGH

An important research outcome has resulted from a collaboration between researchers at the Universities of Manchester and East Anglia. They were supported by the Royal Orthopaedic Hospital, that is funded by our Infrastructure Grants.

The research was led by Dr Katie Finegan (University of Manchester) and Dr Darrell Green (UEA), both founding members of OMeNet (Osteosarcoma Metastasis Network), a group of current and past Bone Cancer Research Trust funded academics working together, to share knowledge, develop ideas and obtain further funding to advance pre-clinical research into osteosarcoma and other primary bone cancer metastasis. Dr Green is also a Trustee of the Bone Cancer Research Trust.

The team compared primary with metastatic tumours and circulating tumour cells from osteosarcoma patients, and identified high levels of the MMP9 protein, a known controller of metastasis in several solid cancers.

This points towards using drugs that inactivate MMP9 as a treatment option to reduce the spread of osteosarcoma. Unfortunately, MMP9 inhibitor drugs have had limited success in clinical trials for other cancers. Facing this dilemma, the researchers adopted another approach.

The MAPK7 gene is responsible for the production of MMP9 and other proteins. Using gene editing techniques, they silenced the MAPK7 gene in osteosarcoma cells, and saw a strong reduction in their potential to grow and spread. When these altered cells were explored further, tumours grew much more slowly and did not spread to the lungs.

Dr Finegan is now developing drugs against the MAPK7 protein that will hopefully benefit primary bone cancer patients in the future.

The Royal Orthopaedic Hospital supported this research through the identification and consenting of 50 patients between 2017 and 2020, meticulously collecting tissue samples and associated clinical data for the project, which was made possible by our Infrastructure Grants.

“The Infrastructure Grants ensure that the essential research staff and processes are in place within the Royal Orthopaedic Hospital to provide high quality research specimens to projects such as Dr Finegan’s and Dr Green’s.

Carolyn Langford, Head of Research, Audit and Development, Royal Orthopaedic Hospital

“We are indebted to the Bone Cancer Research Trust for their new initiative: OMeNet. This new co-operative has already yielded great results with mine and Dr Green’s team, working together to make the first big breakthrough in osteosarcoma in nearly 40 years, by together identifying new treatment possibilities for osteosarcoma. This work would not have been possible without the research vision and support of the Bone Cancer Research Trust.

Dr Katie Finegan

“Teams of experts and institutions operating within individual niche expertise must work together to put together the pieces of nature’s broken puzzle. Only then we will see the ‘big picture’ in order to correct the broken pieces, develop novel treatments and significantly improve survival rates for patients like Sophie, pictured below.

Dr Darrell Green



AWARENESS

In 2020 we produced a Patient Survey report, which is the most comprehensive analysis of presenting symptoms and routes to diagnosis for primary bone cancers and bone tumours in the UK. It has formed the foundation for the UK's first and largest awareness campaign aimed at healthcare professionals.

The survey consultation focused on the signs, symptoms, and referral pathways for primary bone cancers in the UK. We received 739 responses from across the world, 312 were from the UK. The primary objective of this report, and the research contained within, is to improve outcomes for patients and ultimately save lives through earlier diagnosis. It is our hope that this data will also help to inform future clinical guidelines to ensure diagnostic targets are met and allow patients to have an improved diagnostic experience.

Our findings suggest that there are significant omissions in the training of a wide range of healthcare professionals. We have identified GPs, physiotherapists, radiologists, A&E doctors, medical students, and dentists as the key healthcare professionals that patients encounter in their diagnostic journey. We are committed to provide them with the tools and resources needed to increase their understanding of and enable them to recognise primary bone cancers and bone tumours.

FROM THE FINDINGS OF THIS RESEARCH, WE...

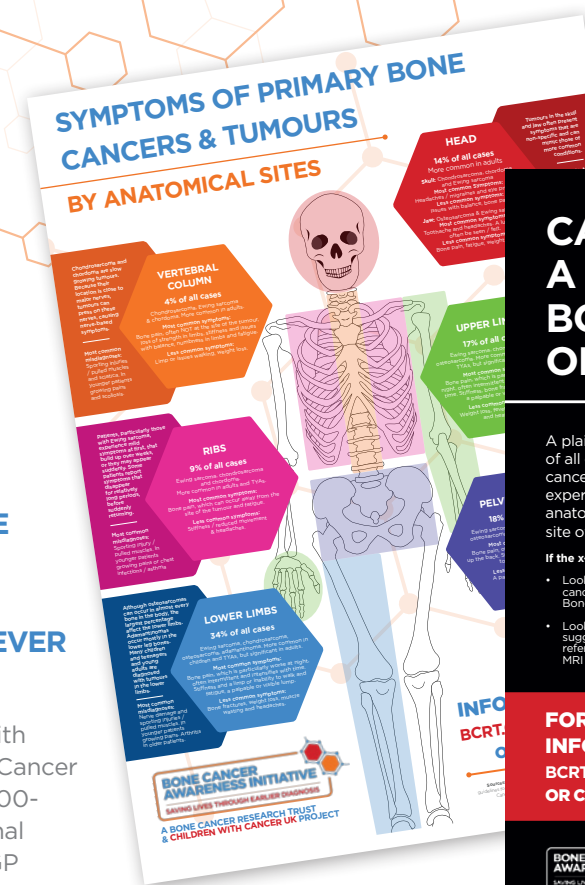
- Assembled an expert task force to develop training resources and peer-to-peer training opportunities to educate key healthcare professionals
- Produced bespoke educational tools tailored to each specialism, enabling each to recognise presenting symptoms and understand onward referral pathways
- Launched public and healthcare professional targeted campaigns to increase awareness and engagement with our new education resources

USING OUR FINDINGS, WE DELIVERED THE BIGGEST PRIMARY BONE CANCER AND BONE TUMOUR AWARENESS CAMPAIGN EVER UNDERTAKEN IN THE UK!

We teamed up with Children with Cancer UK to deliver the Bone Cancer Awareness Week Initiative – a 100-day ground-breaking educational campaign, aiming to reach all GP practices, medical students, radiology departments, musculoskeletal physiotherapists and pharmacies in the UK, with bespoke information materials describing the symptoms of primary bone cancers and bone tumours, and containing guidance on how to confirm or rule out a diagnosis of primary bone cancer.

Our expert task force of medical professionals supported our campaign and during Bone Cancer Awareness Week 2020, they delivered a series of webinars targeted to each of the key specialties that patients encounter during their diagnostic journeys, as well as medical students, the healthcare professionals of the future. The webinars were attended by over 700 GPs, physiotherapists, radiologists, pharmacists, medical students, and the general public; with 100s more registered to receive a recording of the webinars, which are now available via our website.

“ I thought it was excellent. I have never received training in the area in 20 years of practice. I think your resources are very helpful and will be sharing with management. ”
Physiotherapist



CAN YOU SPOT A PRIMARY BONE CANCER OR TUMOUR?

A plain x-ray may miss a third of all cases of primary bone cancers. 32% of patients experience pain in a different anatomical location to the site of their tumour.

If the x-ray results:

- Look suspicious for primary bone cancer, refer directly to a specialist Bone Cancer Centre
- Look negative or clear, refer back to GP suggesting that if symptoms persist a referral for further imaging including MRI should be made

FOR MORE INFORMATION VISIT:
BCRT.ORG.UK/AWARENESS
OR CALL 0800 111 4855



368,642

EDUCATION RESOURCES WERE SENT TO:

10,771

GP SURGERIES

1,542

RADIOLOGY DEPARTMENTS

44

MEDICAL SCHOOLS

586

MUSCULOSKELETAL PHYSIOTHERAPISTS

12,811

PHARMACY PRACTICES

To access the 2020 Patient Survey report and free educational resources, visit bcrt.org.uk/awareness



INTERVIEW
WITH...
**DR KATIE
FINEGAN**



We interviewed Dr Katie Finegan from the University of Manchester, to find out more about the aims and objectives of her newly awarded adamantinoma research grant.

WHAT DO YOU ALREADY KNOW ABOUT ADAMANTINOMA?

We started our research by reviewing what is already known about adamantinoma from a biological point of view, what drives the behaviour of these cancer cells, why does it spread and become unresponsive to treatment, which is unfortunately often the case.

We then focused on the processes that take place inside cancer cells. We found that several of them are controlled by a pathway we have already researched in my group called MEK5-ERK5. This pathway is important in other cancers; clinical studies have shown that its excessive activation leads to a lack of response to treatment, progression and spread. We have demonstrated that in osteosarcoma, this signalling pathway is key for the development and spread of tumours.

WHAT IS THE AIM OF THE PROJECT?

Our aim is to validate if the MEK5-ERK5 pathway also drives the progression of adamantinoma and then test if MEK5-ERK5 inhibitor drugs which we are currently studying and are effective in osteosarcoma, could also work in adamantinoma.

Initially we will use 20 patient specimen samples, made available by the Infrastructure Grants, funded by the Bone Cancer Research Trust; cancer cells will be extracted and grown in the laboratory, to test if these drugs can successfully kill them.

In osteosarcoma, the quantity of MEK5-ERK5 proteins in the tumour cells correlates to how well patients respond to treatment and indicates if they would require more aggressive treatments. Therefore, a second aim of the project is to evaluate MEK5-ERK5 as a novel prognostic biomarker in adamantinoma.

Professor Gartland, from the University of Sheffield, will assist in extracting the cells from the patient samples. We are also collaborating with Dr Green from the University of East Anglia to extract and analyse RNA from the adamantinoma samples, to identify genetic differences between the samples of patients at different stages of the disease.

WHAT COULD THIS MEAN FOR ADAMANTINOMA PATIENTS?

We aim to validate the MEK5-ERK5 pathway as a new therapeutic target. A drug that inactivates this pathway is already in phase two clinical trials and we are also making new inhibitors of the MEK5-ERK5 proteins that are at the in vivo stage of research in the laboratory

Our novel inhibitors completely block all the cellular signals mediated by MEK5-ERK5. When osteosarcoma cells are treated with them, they die within a week. This research project will provide the evidence base needed to determine if they could also be used for adamantinoma.

We have already demonstrated in laboratory models that targeting MEK5-ERK5 reduces the spread of osteosarcoma to the lungs, we now want to extend this to adamantinoma.

Funding for this pioneering research into adamantinoma has been made possible by **The Liz Clarke-Saul Fund, a Special Fund of the Bone Cancer Research Trust**

NEW INSPIRATION AFTER BONE CANCER

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



Nikita was ready to start her professional dancing job when she was diagnosed with osteosarcoma at the age of 23. After months of treatment, surgery, and recovery, she strived to get back on the stage. Two years on, she hit her milestone.

“ If you put your mind to it, you can do anything. Like Walt Disney says, ‘All our dreams can come true, if we have the courage to pursue them.’ ”

From breaking his toe, to being diagnosed with Ewing sarcoma, which led to an amputation, Nik did not let bone cancer stop him. He opened, with three other friends, a personal training gym, The Fitness Collective, with plans to help other cancer sufferers who have lost their limbs.

“ I’m a firm believer in focusing your efforts on the things you can control and spending less time on worrying about the things you can’t. It’s amazing what you can achieve with a positive mindset and a belief in your own capabilities. ”



Cerys was diagnosed with osteosarcoma in 2019. Due to liver failure she had to have an amputation to save her life. Cerys now shares her amazing journey through YouTube and shares her incredible make-up skills on Instagram.

“ The strongest people always get the hardest battle. ”

Euan was 4 years old when he was diagnosed with Ewing sarcoma. Since then, Euan won the 2018 Jones – Fenleigh award for Vertebrate Palaeontology and Comparative Anatomy. He is the only undergraduate ever to win the award. Beyond Euan’s studies, he has been chosen for the Paralympic Great Britain pistol event.

“ Always believe in you. Believe you can get through this; believe you can recover. Believe in your dreams because what you dream about, can come about. So, believe and never stop. No matter the troubles, no matter the trials, Believe, and your battle is already won. ”



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

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Help save lives for years to come by taking advantage of our Free Will Writing Service and remembering the Bone Cancer Research Trust in your will. Our partnership with Farewill means you can write your single or joint will online or over the phone in less than half an hour.

Writing your will can help give you peace of mind for the future – knowing that your loved ones will be provided for and your affairs will be taken care of. Most of our supporters who use our Free Will Writing Service choose to include a gift to the Bone Cancer Research Trust, however there's no obligation to do so.

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