

# DRIVING CHANGE DELIVERING HOPE

OUR RESEARCH  
IMPACT REPORT 2025



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

# BONE CANCER RESEARCH TRUST

In 2004, a group of families who had lost children and young people to primary bone cancer united. At that time, there was a severe lack of accessible information and almost no funding for research into this disease. With the guidance of Professor Ian Lewis, a consultant paediatrician and adolescent oncologist at St James's University Hospital in Leeds, these families established the Bone Cancer Research Trust as a charity in 2006.

Today, the Bone Cancer Research Trust stands as the leading charity dedicated to saving lives and combating primary bone cancer.

## OUR VISION

A world where primary bone cancer is cured.

## OUR MISSION

To save lives and improve outcomes for people affected by primary bone cancer through research, information, awareness, and support.

### RESEARCH

As of March 2025, the Bone Cancer Research Trust has committed over £11 million towards primary bone cancer research. Our goals include gaining a deeper understanding of the disease, enhancing diagnostic methods, developing gentler and more effective treatments, and ultimately discovering a cure.

### INFORMATION

Our portfolio of accredited information assists healthcare professionals, patients, their families, friends, and the general public in understanding primary bone cancer, including its diagnosis and treatment.

### AWARENESS

We represent the primary bone cancer community, advocating for increased awareness among the public, healthcare professionals, researchers, and policymakers.

### SUPPORT

We offer a dedicated Support & Information Service, freely accessible to anyone impacted by primary bone cancer and tumours.

**PRIMARY BONE CANCER  
ACCOUNTS FOR APPROXIMATELY  
0.2% OF ALL CANCER DIAGNOSES  
IN THE UK.**

**ALTHOUGH IT CAN AFFECT  
PATIENTS AT ANY AGE, WHEN  
COMPARED TO OTHER CANCERS,  
PRIMARY BONE CANCER SHOWS  
A MARKED PREDILECTION  
FOR OLDER CHILDREN AND  
TEENAGERS, ACCOUNTING FOR  
4% OF ALL CANCER DIAGNOSES  
IN CHILDREN AND 4% OF  
ALL CANCER DIAGNOSES IN  
TEENAGERS AND YOUNG ADULTS  
IN THE UK.**



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# WELCOME FROM THE RESEARCH TEAM

Since our charity was founded in 2006, we have remained committed to funding pioneering collaborative research focused on improving outcomes for primary bone cancer patients.

This report outlines the progress we have made up to March 2025, since our previous edition was published in 2023.

Now, fully embarked on our 2022-2032 strategic period, we reflect and benchmark ourselves against the objectives we set out to accomplish and look towards the 20<sup>th</sup> anniversary of the Bone Cancer Research Trust, that we will celebrate with our community in 2026.

The views of patients and their families are at the heart of our research funding process. In the summer of 2021, we introduced our Patient and Public Involvement Panel (PPIP) and now, they have helped us explore the concept of research impact. Together, we set out to understand what 'impact' means to those affected by primary bone cancer and how it can be most meaningfully and effectively shared. When constructing this report, we have incorporated their views, and we thank them as always for their dedication and support.

We recognise the importance of partnering with like-minded organisations and have strengthened our collaborative efforts to fund research in critical areas. These include improving diagnosis, identifying prognostic and treatment response biomarkers, discovering novel therapeutic targets and gentler, more effective drugs, leveraging the immune system against cancer, enhancing surgical techniques, and studying cancer cells in detail to better understand the behaviour of all types of

primary bone cancer, including rarer forms.

These collaborative efforts extend to researchers, and in this report, we illustrate how different areas of research are coming together in a coordinated network of initiatives aimed at achieving progress for Ewing sarcoma patients.

As we celebrate some successes and mark the difference we have made **TOGETHER** for primary bone cancer patients, we acknowledge the challenges we face and how we are responding to them through our funded research, but we know that there is much more that needs to be done.

We fully appreciate that none of this would be possible without the steadfast support of our amazing community.

**THANK YOU** to all our supporters for being an integral part of this journey. Your efforts and generosity enable researchers, clinicians, surgeons, and healthcare professionals to continue their tireless work in improving the lives of primary bone cancer patients and their families.



**Dr Zoe Davison,**  
Director of Research & Information  
and Deputy CEO



**Dr Kathleen Kane,**  
Research & Engagement Officer



**Dr Victoria Vinader,**  
Head of Research



**Jade Bradley,**  
Research Support Assistant

# A GLANCE AT WHAT WE HAVE ACHIEVED TOGETHER

Since our last impact report and up to March 2025...



We have **committed £3.2 million** to research, taking our total since 2006 to over **£11 million**.



We are already **59%** of the way towards achieving our **strategic goal of investing £10m** in research between 2022-2032.



We have funded **95** research grants, **20** research projects, **62** skills development grants, **4** research meetings, **4** research consortia, **5** infrastructure - sample collection grants.



Since their start in 2017, the **infrastructure grants** have facilitated the collection of over **14,000** patient samples.



**67** of these research grants support **early career researchers**.



Since 2006, research funded by the bone cancer research trust has resulted in **125 scientific publications<sup>1</sup>** which have been **cited in the scientific literature over 5,000 times**.

The frequency with which other researchers cite this work strongly indicates the significance and impact of the knowledge and precedents established through this funding.



**219 grants since 2006 support 141 Principal Investigators** with some receiving funding on several occasions (141 unique /78 repeat funding).



Supported by **482 Co-Applicants and Collaborators** with some doing so on multiple occasions (275 unique/207 repeat collaborations).



Our **Clinical Trial Support Grants** support the **rEECur** trial for recurrent and refractory Ewing sarcoma.



Following **ICONIC<sup>2</sup>**, our clinical study **Ad-ICONIC** has completed its first year, continuing as the largest osteosarcoma collaboration in the UK.



**130 Academic institutions** funded supported by multiple Co-Applicants and Collaborators on numerous occasions.

# FLEXIBILITY IN FUNDING

As funders, we have learned to adapt and pivot when necessary to address emerging needs and trends in research, enabling us to effectively support the community and respond to evolving challenges.

## WHY IS THIS IMPORTANT?

### ENHANCED RELEVANCE

Consulting with clinicians, researchers, and patient communities ensures the research we fund addresses pressing needs and is both relevant and impactful.

### INCREASED TRUST & COLLABORATION

Building strong relationships with clinicians and researchers fosters a collaborative environment, encouraging innovation and shared goals.

### ADAPTIVE FUNDING SCHEMES

Introducing new funding schemes that are responsive to feedback ensures that resources are allocated effectively and can adapt to emerging needs and challenges.

## SPOTLIGHT ON INNOVATIVE FUNDING SCHEMES

### CLINICAL TRIAL SUPPORT GRANTS

Our first clinical trial support grant was awarded to **Professor Martin McCabe**. The project started in March 2023 to support the introduction of Lenvatinib in combination with high dose Ifosfamide as part of the rEECur clinical trial, which aims to define a standard of care for patients with Ewing sarcoma which has returned or those for which the initial treatment did not work.

### THIS FUNDING HELPS:

- Evaluate the amount of Lenvatinib in the blood of patients, ensuring sufficient levels are present to cause an effect.
- Search for markers in either the blood or tissues of patients to predict which patients will respond to Lenvatinib.
- Construct a collection of tumour samples from multiple patients, to identify markers for relapse in Ewing sarcoma.

### TO DATE:

**26 patients recruited to be treated with high dose Ifosfamide and Lenvatinib**

**25 recruited to be treated with high dose Ifosfamide without Lenvatinib**

of a planned total of 60 patients to each arm.

## SPOTLIGHT ON EMERGING AREAS OF RESEARCH

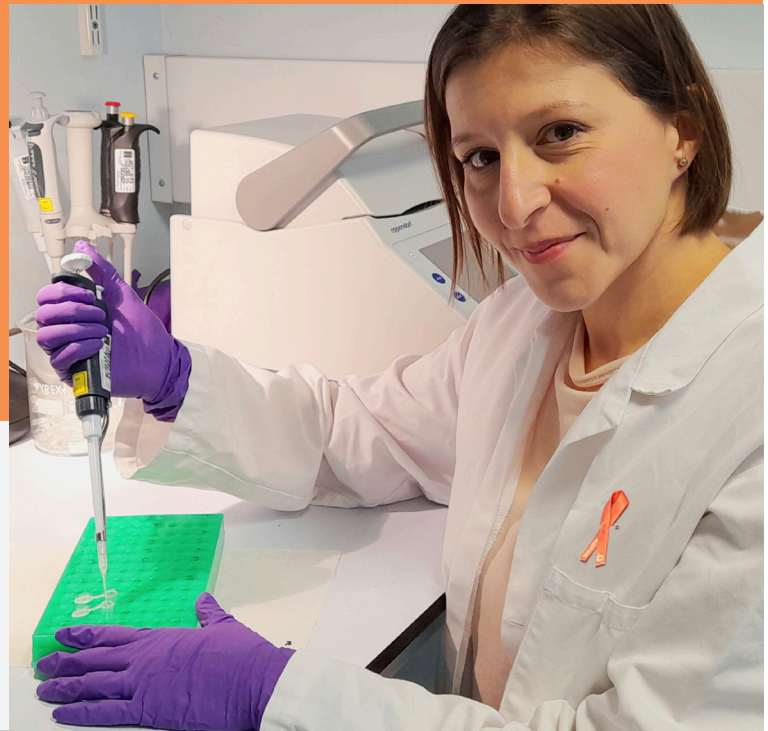
Research into **chemoresistance** is vital for enhancing treatment outcomes for patients. By uncovering the mechanisms behind chemoresistance, researchers can devise new therapeutic strategies to make tumours more responsive to therapy, potentially resulting in improved patient outcomes.

In 2023, we awarded our first Early Career Fellowship, enabling **Dr Lucia Cottone** to focus exclusively on primary bone cancer research.

Now in the second year of her 5-year fellowship, she is making significant strides in understanding the mechanisms that cause osteosarcoma cells to become “dormant” and evade the effects of chemotherapy

*“By understanding how this occurs, we hope to be able to develop ways of making cells re-gain sensitivity to chemotherapy.”*

**Dr Lucia Cottone**, University College London



**Immunotherapy** is a dynamic and swiftly advancing area of research. While the early successes observed in other cancers have not yet been realised for primary bone cancer patients, BCRT-funded researchers are exploring innovative methods to harness the patient’s immune system to target and destroy bone cancer cells.

Co-funded with Hannah’s Willberry Wonder Pony Charity, **Dr Jun Ishihara** is investigating a new immunotherapy approach for osteosarcoma.

The protein interleukin-12 (IL12) is known to successfully activate anti-tumour immune cells. This award allows him to explore ways to direct IL12 to the tumour, hence avoiding its otherwise induced toxicity towards healthy cells.

*“There remains huge room for improvement for immunotherapy in osteosarcoma. We hope that this innovative approach will result in a kinder and more effective therapeutic approach for patients”*

**Dr Jun Ishihara**, Imperial College London





*“After such brutal first line treatment for this awful disease, I would give anything for Freddie to remain cancer free as the terror of what he’s been through stays with you forever.*

*Sadly, relapse is always a worry on our mind due to Ewing sarcoma’s high relapse rate. This worry is amplified by the fact there is no official second line treatment should the relapse nightmare come true. We are lucky we have not had to go down this road, but from what I understand it is a case of*

*picking the best option out of a very limited set of options with poor statistics attached to them. Every day I hope and pray there is a treatment to give us more hope and for someone to take our worries away.*

*This is why research for relapse patients is so important to families like ours. The continued worry about what happens if it comes back is so real, and such a truly helpless feeling as the options for us are so uncertain.”*

**Nicole**, mother of Freddie and member of PPIP

## OVERVIEW: THE CHALLENGING ENVIRONMENT OF RESEARCH FUNDING

### WE HAVE

Adopted a flexible and innovative approach, introduced new funding schemes, responded to change and supported emerging areas of research.

### IMPACT

Enduring collaborations with other funders have been forged. Regular review of our funding streams ensures we are aligned with current needs and support key areas of research.

# PATIENT & PUBLIC INVOLVEMENT PANEL:

## OUR GUIDING VOICE IN RESEARCH FUNDING & BEYOND

The Bone Cancer Research Trust's Patient & Public Involvement Panel (PPIP) was established in 2021, bringing together members of the primary bone cancer community with diverse lived experiences and a shared goal to drive forwards research advancements.

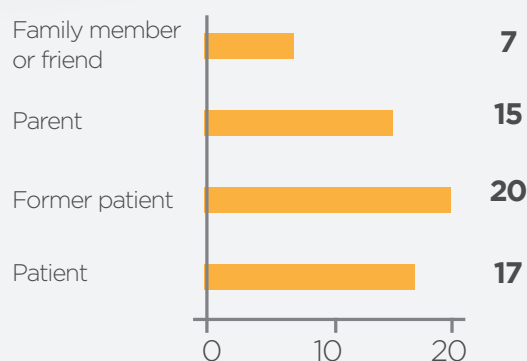
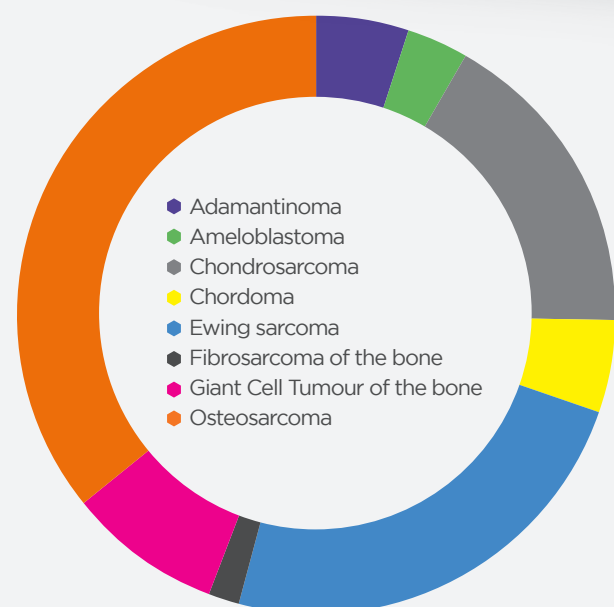
### WHAT IS PATIENT & PUBLIC INVOLVEMENT AND WHY IS THIS IMPORTANT?

**Patient & Public Involvement (PPI)** refers to the active involvement of people with lived experience in shaping and guiding research that matters to them.

According to the National Institute of Health Research (NIHR), the aim of PPI is to ensure that research is carried out **with** patients and members of the public, rather than 'to', 'about' or 'for' them.

For BCRT, this means ensuring that the voices of the primary bone cancer community are at the heart of everything we do, not only guiding the research we fund, but also the awareness we raise and the support & information we deliver.

Over the past three years, our Patient & Public Involvement Panel has gone from strength to strength, growing in **size and representation**, with members bringing diverse lived experiences as patients, parents, family members and friends, across a wide range of primary bone cancers and tumours.



ENSURING PATIENT AND PUBLIC NEEDS ARE AT THE HEART OF OUR RESEARCH

We have achieved a significant milestone in **welcoming our 50<sup>th</sup> member** and have continued to expand, with a total of 59 members past and present. We continue to remember the contributions of three valued members who have sadly died during this time, but whose involvement has left a lasting legacy.

Overall, our members have ensured that the patient voice remains at the heart of BCRT, across research and beyond, supporting us in moving forwards with our **research** strategy, guiding us in shaping future plans and priorities for raising **awareness**, reviewing a breadth of resources as part of our ongoing **information** review, and inputting into our work to understand the long-term **support** needs for those living with & beyond primary bone cancer.



To date, our panel members have been involved in the development and review of more than **75 proposals** submitted to BCRT's funding calls.



This equates to over **£5.9 million** of primary bone cancer research investment which has been guided by the perspectives and priorities of patients & families.

Since our last impact report, the **reputation and influence** of our PPIP has also grown, with their expertise sought by researchers and clinicians from right across the primary bone cancer research community. Our members have been consulted in the development of proposals submitted to a host of **other funding bodies**, shaping and influencing the direction of research across the field more widely and allowing more researchers to learn from lived experience. They have also had the opportunity to consult with **major pharmaceutical companies** and with **NHS England**, providing vital contributions in conversations around clinical trial design and standards of care.

## SPOTLIGHT ON PPI IN RESEARCH: FROM THE LABORATORY TO CLINICAL TRIALS

Laboratory research can feel far-moved from the clinical setting, for both researchers and patients alike.

For Research Associate and Research Laboratory Manager, **Dr Lucas Souza**, consultations with PPIP members introduced him to the real-life experiences behind the primary bone cancers which he has been studying so closely in the lab.



*“Consultation meetings with PPIP were essential to improve my applications, but also, they’ve provided me with the opportunity to get closer to the patients, which is something I’ve always wanted but didn’t know how, and never had the opportunity to do. These meetings significantly increased the relevance and impact of my research projects.”*

**Dr Lucas Souza**, Royal Orthopaedic Hospital and Aston University



Jacky Harding is one of the panel's longest-serving members, having joined with her husband, Andy, in the early days of PPIP, bringing their lived experiences of Andy's journey through chondrosarcoma treatment. Together, they were involved in shaping and reviewing many proposals for **laboratory based research** guiding vital **early steps towards treatment advancements**. Sadly, Andy passed away in 2023. His memory lives on in the research which is underway thanks to his input and insights.

More recently, Jacky had the opportunity to share their experiences to shape research much **closer to patients**, joining other PPIP members in a focus group with a pharmaceutical company leading a chondrosarcoma clinical trial. Their input has been crucial to informing elements of the trial itself, as well as the information shared with participants.

This demonstrates the potential for meaningful involvement of those with lived experience in all manner of research, guiding impact **from the lab right through to the patient**.

*"I like being able to contribute something to the research being carried out into bone cancer. It is something that makes me feel that I can help towards finding a cure even if it is in a tiny way by passing on our lived experiences."*

**Jacky & Andy**, PPIP members

## SPOTLIGHT ON PPI BEYOND RESEARCH: REVIEWING & SHAPING EXPERIENCES OF CARE

Moving beyond the research context, our members have also championed **PPI in the clinical setting**, with several joining forces with clinicians to undertake a **peer review of the care pathways** delivered across the five **bone cancer specialist surgical centres** in England. Their insights and lived experiences of treatment and care were vital to ensuring a **patient-centred approach** when identifying areas of good practice, and recommendations for improvement.

Tracey, our 50<sup>th</sup> PPIP member, brought her own experiences of undergoing treatment for osteosarcoma. Guided by these insights, she **advocated** for the primary bone cancer community and ensured that their **needs & priorities** were captured in the review of care.

*“BCRT helped me so much during my recovery from osteosarcoma during the Covid pandemic. The Virtual Cuppas were a lifeline during that very frightening time as a cancer patient; they continue to support me and I now have friends within the BCRT community.*

*I wanted to give something back to this amazing charity and I was honoured to become the 50th PPIP Member. I was excited and delighted to support NHS England’s review of one of the specialist bone cancer centres from a patient perspective at a different hospital to where I was treated. After weeks as an in-patient and many*

*out-patient appointments, I felt equipped to offer my input and opinions and although I was the only patient amongst clinicians, I was listened to and supported.*

*I have reviewed research grant applications and been part of an awareness focus group. I am looking forward to many more exciting projects to help shape primary bone cancer research and care through PPIP.”*

**Tracey**, PPIP member



## OVERVIEW: PUTTING THE PATIENT FIRST

### WE HAVE

Honoured our commitment to ensuring that the patient’s perspective is at the forefront of the research we fund.

### IMPACT

Together, we are steadily shifting the dynamic to a more **equitable and collaborative partnership** between researchers and experts through lived experience, facilitating **meaningful discussions and connections** between those carrying out the research, and those central to it.

We have also harnessed the expertise and vital lived experiences of our PPIP across our **Support, Information and Awareness** activities, and have established our PPIP as an **expert voice for the primary bone cancer community** across **research** and **clinical** settings.

# PATIENTS CONTRIBUTING TO PRIMARY BONE CANCER RESEARCH

Patients play a crucial role in advancing research by donating samples. These donations enable researchers to gain a deeper understanding of primary bone cancer, develop new treatments, and enhance diagnostic methods. By analysing patient samples, scientists can uncover insights into the development and progression of primary bone cancer, which is crucial for creating targeted therapies.

## HOW WE FACILITATE SAMPLE COLLECTION:

To collect these sample donations and for these invaluable resources to drive progress and improve outcomes, we need to support the framework existing at the bone cancer **specialist surgical centres**, where biopsies are taken, and patients undergo surgery.

Since 2017 our **Infrastructure Grants** have supported centres with the equipment and materials needed to prepare and store these samples. They have allowed them to employ staff that help patients consent to donations, receive, log and process samples, manage biological studies, process tissue requests from researchers and ensure all operational, ethical and legal requirements are met.

Since then, over **14,000 have been gathered**.

Samples collected through the Infrastructure Grants have contributed to **41 research projects**, evidenced by **32 publications** in high impact factor scientific journals<sup>3</sup>.

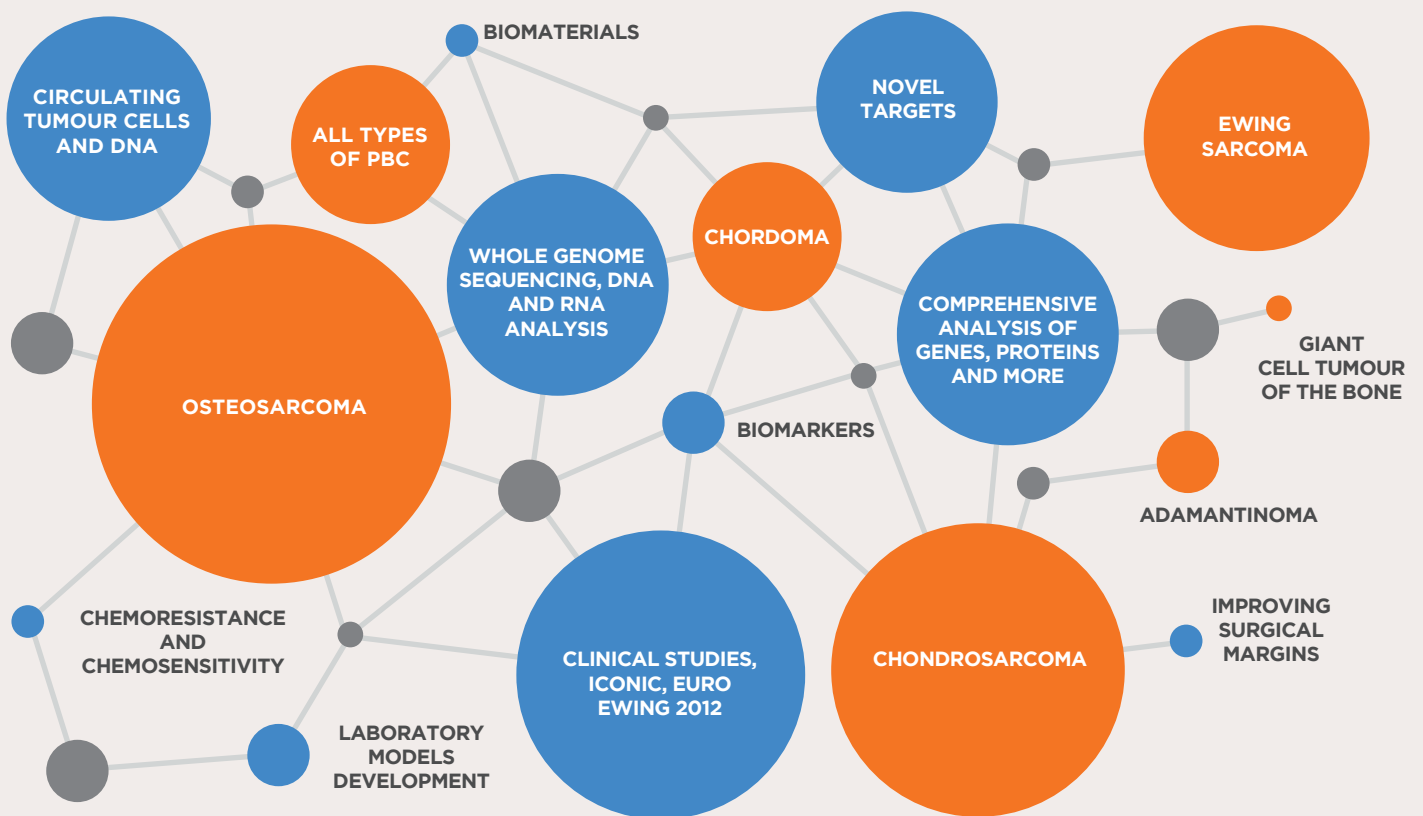
Common themes representing the research projects supported by the Infrastructure Grants since 2017 to date are summarised in the diagram on page 18, as well as their connection to the type of primary bone cancer they are intended for.

In this scheme, the size of each circle is proportional to the commitment the specialist centres have dedicated to these themes.

The larger number of projects have supported osteosarcoma studies, followed by chondrosarcoma, Ewing sarcoma and chordoma. Other research projects target all types of primary bone cancer, as well as rarer forms like adamantinoma and giant cell tumour of the bone.

# THE INFRASTRUCTURE GRANTS EFFECT

■ Research projects ■ Primary bone cancer





## SPOTLIGHT ON THE COMPLEX CHANGES THAT FUEL THE DEVELOPMENT AND PROGRESSION OF PRIMARY BONE CANCER

Much remains to be understood about the genetic changes that drive the malignant (cancerous) transformation of cells, the factors that contribute to disease progression, the mechanisms behind some tumours' resistance to treatment, and those that facilitate their invasive behaviour and eventual metastatic spread.

Patient samples collected at the Royal National Orthopaedic Hospital in London contributed to the discovery of a crucial mechanism (loss-translocation-amplification chromothripsis) which is responsible for genetic changes, leading to the development and progression of osteosarcoma.

Researchers led by **Dr Isidro Cortés Ciriano** and **Professor Adrienne Flanagan** also identified a potential biomarker which may be used to predict the course of the disease<sup>4</sup>.



*“The BCRT funded Infrastructure Grant at RNOH has been pivotal in maintaining the Sarcoma Biobank. The patient samples collected have led to numerous discoveries in osteosarcoma, chondrosarcoma, chordoma and more besides, contributing to patients receiving more accurate diagnoses and tailored treatments.”*

**Professor Adrienne Flanagan,**  
University College London

**Dr Katie Finegan** at the University of Manchester is investigating the potential of signalling proteins MEK5 and ERK5 to monitor and treat adamantinoma relapse and spread.

Patient samples collected at the Royal Orthopaedic Hospital (ROH) in Birmingham from adamantinoma patients are allowing her research team to determine if these proteins are “switched on” and driving adamantinoma and whether by inhibiting them we can slow down their growth and reduce their metastatic potential.



**Dr Katherine Finegan,**  
University of Manchester

*“With BCRT’s grant support and essential samples provided by ROH, we were able to develop the first cell models from adamantinoma (AM) patients and used them to show that blocking the MEK5-ERK5 pathway could be a promising new treatment approach. We also conducted the first-ever study of AM’s immune environment, finding that high levels of ERK5 or certain immune cells (called T cells and macrophages) were linked to worse outcomes. These discoveries could lead to both new targeted therapies for adamantinoma and new biomarkers to better identify high-risk patients.”*

*“This project would not have been possible without BCRT’s funding into rare cancers, which is vitally important to find new treatments and improve outcomes for patients with rare cancers.*”

*Samples donated from patients with rare cancers are essential to successful research and are the only way we can find both new treatment options and ways to identify high-risk patients. Samples from ROH, donated by patients with adamantinoma are the reason this work was possible.”*

## **OVERVIEW: DISCOVERIES ARE FUELLED BY ACCESS TO PATIENT SAMPLES**

### **WE HAVE**

Supported the specialist centres to help patients donate tissue and blood samples that are processed, stored and made available for research.

### **IMPACT**

Discoveries are being made that are helping us better understand the disease and pave the way for more accurate diagnosis, disease monitoring and potential new treatments.



# COLLABORATIVE EFFORTS TO ACCELERATE PROGRESS

Collaboration is key to achieving success in primary bone cancer research, as it allows researchers to combine their diverse expertise, share valuable resources, and work together towards common goals, ultimately accelerating progress and driving innovative solutions that can improve patient outcomes.

## THE BENEFITS OF COLLABORATION:

### COMBINING RESOURCES:

Primary bone cancer lacks the funding that more common cancers receive. Researchers, institutions, and organisations join forces and pool their resources to support research.

### SHARING DATA AND KNOWLEDGE:

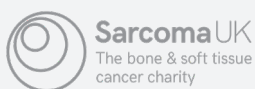
Sharing valuable data and insights can accelerate our understanding of primary bone cancer and the development of more effective treatments.

### PATIENT INVOLVEMENT:

Collaboration includes those with a lived experience of primary bone cancer. Our Patient & Public Involvement Panel helps bridge the gap between researchers and patients, ensuring our funded research is patient centred and aligned with the needs and priorities of the primary bone cancer community.

Since 2023 we have joined forces with Sarcoma UK, Children with Cancer UK, Hannah's Willberry Wonder Pony Charity, CCLG: The Children & Young People's Cancer Association and Great Ormond Street Hospital Charity.

By partnering with these charities, we have successfully **co-funded 12 research grants** amounting to **£2.7m** that would not have been feasible otherwise.



## SPOTLIGHT ON BRINGING THE PATIENT AND RESEARCH COMMUNITIES TOGETHER TO IMPROVE DIAGNOSIS

When developing our research strategy in 2022, **improving diagnosis** was highlighted by our community as one of their priority areas. In January 2024, in partnership with Sarcoma UK, we convened researchers, clinicians, patient advocates, and allied healthcare professionals with a shared interest in diagnostics, sarcoma research, and clinical management. The goal of this meeting was to unite these stakeholders to identify the key barriers and opportunities for advancing research aimed at improving sarcoma diagnosis.

Discussions highlighted key challenges in the **diagnosis of sarcoma** and helped us identify areas of focus to shape a joint research funding call, with two projects eventually funded in early 2025.

### IMPORTANT THEMES:

- Challenges to early diagnosis posed by the heterogeneity of sarcoma
- Identifying higher-risk groups for sarcoma
- The potential for developing new biomarker tests for sarcoma
- Genomics and pathology
- Accessing and making use of data
- Issues and solutions around primary care
- Exploring patient empowerment and communication gaps when patients present with symptoms

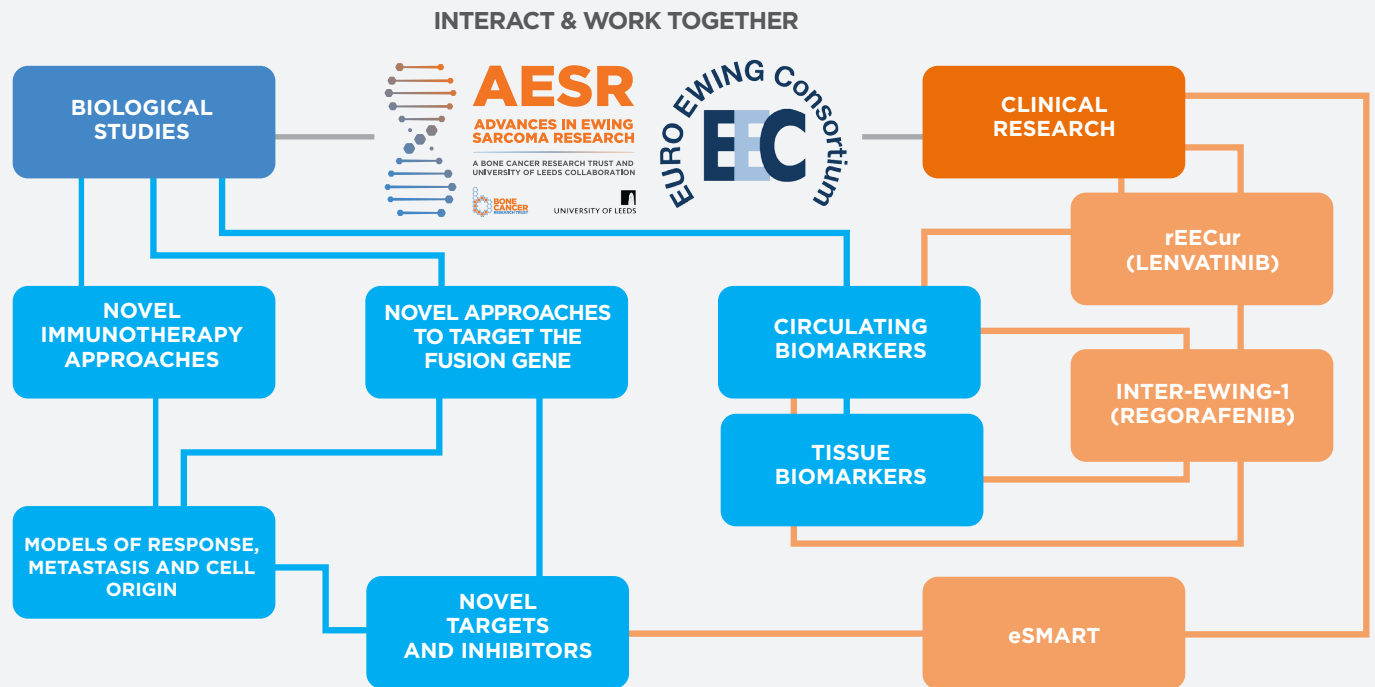


# SPOTLIGHT ON BRINGING CLINICAL AND LABORATORY RESEARCHERS TOGETHER TO FACILITATE PROGRESS IN EWING SARCOMA

By funding the **Euro Ewing Consortium**, the Bone Cancer Research Trust ensures that efforts concentrate on setting up larger, more reliable clinical trials. Through the **Advances in Ewing sarcoma Research** meetings, researchers share progress, identify opportunities for collaboration and define priorities for subsequent research.

The consortium and annual research symposium act as hubs, ensuring different projects funded by the charity for **Ewing sarcoma** are connected as part of a **network of collaborations** that are linked to ongoing international clinical trials for patients who are first diagnosed or are facing recurrent disease.

## COLLABORATIVE NETWORK FOR EWING SARCOMA SUPPORTED BY BONE CANCER RESEARCH TRUST FUNDING



**Andy Westwood,**  
Patient Advocate,  
the Euro Ewing Consortium

*“As both a Patient Advocate with the Euro Ewing Consortium and a BCRT supporter, I’m delighted by their effective collaboration.”*

*BCRT’s fundraising strengthens the EEC while bringing crucial patient perspectives into research forums. They’ve fostered important initiatives like AESR and support emerging researchers through their grant awards - essential for future progress in Ewings. The EEC leverages international collaboration to unite top researchers, clinicians, and investigators across Europe. Together, these organizations create a powerful alliance that advances Ewing sarcoma research and improves patient outcomes through shared expertise and resources.”*

## OVERVIEW: TOGETHER WE ARE ACHIEVING MORE

### WE HAVE

Reached out to other charities to co-fund projects and fostered collaboration among researchers.

### IMPACT

More projects have been funded.

Some of these collaborative projects have a real potential for delivering novel therapeutic options, others are enabling ongoing clinical trials.



# ENSURING SUSTAINABILITY IN RESEARCH

The Bone Cancer Research Trust supports the growth of the primary bone cancer research community by nurturing new talent. Our goal is to retain top scientists and clinicians, expanding research efforts in the UK and globally, to move closer to finding a cure.

Transitioning from research student to early career researcher and to independent researcher can be very challenging. We are committed to supporting researchers to navigate these steps, ensuring they remain in the field.

## KEY STEPS IN AN EARLY CAREER RESEARCHER'S PROGRESSION

### SECURING FUNDING:

Obtaining research grants is crucial for supporting researchers with fresh ideas that can develop into independent research projects.

### PUBLISHING AND ESTABLISHING EXPERTISE:

Publishing research findings helps researchers to establish themselves as experts in the field, gaining recognition and further opportunities.

### BUILDING A NETWORK:

Forming connections with mentors and peers provides valuable guidance and collaboration opportunities.

Since 2006 we have funded **24 projects** amounting to **over £2.6m** for which an early career researcher was either the principal applicant or a co-applicant.

In addition, **10 studentships** have supported the training of PhD students, helping them gain the skills they require to embark on their research journey.

Over 50 publications acknowledging BCRT funding include early career researchers among their authors.

In 2022, we introduced our Skills Development Grants. Since then, we have helped **65 early career researchers** to attend national and international conferences where they have presented their results, a fantastic opportunity to receive feedback from peers and mentors and build a network of future collaborations.

**10 early career researchers** have benefited from laboratory stays, gaining new skills in specific laboratory techniques or valuable experience in primary bone cancer genetics, pathology or surgical techniques.

## SPOTLIGHT ON GAINING EXPERIENCE IN SARCOMA GENETICS AND PATHOLOGY

**Dr Vanghelita Andrei**, a pathology clinical fellow from the Royal National Orthopaedic Hospital spent 3 months at the North Thames Genomic Laboratory Hub, assessing the impact of Next Generation Sequencing on sarcoma diagnosis and gained additional experience in molecular analysis techniques.

She was involved in building the library of cases for AI-SCOPE: Artificial Intelligence for Sarcoma Outcome, an observational clinical study aiming to determine if artificial intelligence (AI) can help support pathologists in the diagnosis of sarcoma<sup>5</sup>.

*“I am committed to specialising in sarcoma pathology; BCRT’s Skills Development Grant enabled me to develop my knowledge of sarcoma genetics and meet others working in the sarcoma field in the UK.”*

**Dr Vanghelita Andrei**, Royal National Orthopaedic Hospital, London



## SPOTLIGHT ON GAINING EXPERIENCE IN ADVANCED ORTHOPAEDIC ONCOLOGY SURGERY TECHNIQUES

**Dr Sonia Ubong** from the University of Cambridge, Addenbrookes Hospital attended Massachusetts General Hospital’s Orthopaedic Oncology Department, observing the clinical application of Photodynamic Nail Stabilisation (PDN), a minimally invasive approach for securing pathological and impending pathological fractures.

She gained an insight into the implementation of PDN as part of a personalised treatment plan that considers the complex nature of primary bone tumours.



*“My time at MGH has confirmed my passion for orthopaedic oncology and solidified my desire to pursue research in surgical technologies. The mentorship I received has been instrumental in shaping this decision, and for that, I am profoundly grateful.”*

**Dr Sonia Ubong**, Department of Surgery, University of Cambridge

## OVERVIEW: THE NEXT GENERATION OF RESEARCHERS

### WE HAVE

Made it possible for early career researchers to apply for research funding and supported them with their development.

### IMPACT

A new generation of primary bone cancer researchers is being built.

They are bringing new ideas and collaborating to maintain and accelerate progress.

# DEDICATED TO EVERY BONE CANCER PATIENT

Up until now, funded projects by the Bone Cancer Research Trust have largely targeted osteosarcoma and Ewing sarcoma.

Currently, approximately 40% of our awarded grants focus on all types of primary bone cancer. However, in terms of expenditure, they constitute a relatively small portion of our overall investment. For instance, our Infrastructure Grants gather samples from patients with all types of bone cancer, including the rarer forms.



While our commitment to osteosarcoma and Ewing sarcoma remains steadfast, we recognise that our community encompasses a diverse range of primary bone cancer tumours. Therefore, we must ensure that **all patients** have access to improved treatments.

The reality is that the majority of funding applications we receive focus on osteosarcoma and Ewing sarcoma. With the support of the patient and research community, we are implementing various strategies to boost funding for rarer types of primary bone cancer.

## WE ARE:

### RAISING AWARENESS AMONG RESEARCHERS:

Engaging with scientists and providing support with available patient samples helps them extend their ideas, broadening their field to include rarer types of primary bone cancer.

### HOSTING CONFERENCES AND WORKSHOPS:

Organising events that bring together researchers, clinicians, and stakeholders to discuss advances and challenges in rare primary bone cancer research. These forums foster collaboration and innovation.

### OFFERING DEDICATED, COMPETITIVE FUNDING SCHEMES:

Providing research grants focused on rare forms of primary cancer, or unmet needs that may be applicable to all. This can attract and incentivise researchers to focus on these areas.

Despite **chondrosarcoma** being the most common type of primary bone cancer, research in this field is insufficient. Approximately 30 researchers, clinicians, and surgeons attended our chondrosarcoma conference in 2022. The meeting aimed to identify challenges, set priorities, and foster collaborations for research. This effort led to the creation of a significant multidisciplinary funding call launched in 2024, with outcomes to be announced later in 2025.

Our commitment to chondrosarcoma, was further emphasised with a research meeting grant contributing to the organisation of the Birmingham Orthopaedic Oncology Meeting (BOOM), held in January 2024. It convened

309 delegates from 53 countries to discuss and refine 21 consensus statements on the optimal management of chondrosarcoma<sup>6</sup>.

In October 2024, in collaboration with the Chordoma Foundation and Chordoma UK, we hosted a chordoma research symposium. Over 50 leading **chordoma** researchers from around the world shared their progress and identified priorities for future research. Emphasising the importance of our role in uniting the research community, our Skills Development Grants enabled some emerging chordoma researchers to attend this pivotal meeting.



## SPOTLIGHT ON ADAMANTINOMA RESEARCH

**Adamantinoma**, an ultra-rare bone cancer, is very difficult to differentiate from the less aggressive osteofibrous dysplasia and osteofibrous dysplasia like adamantinoma tumours. In contrast to adamantinoma, these two lesions contain much less epithelium, and do not behave as a cancer.

**Professor Judith Bovée** is investigating the differences between these tumours at the molecular and microscopic level, looking at the interaction between epithelium and bone with the aim of developing more robust criteria that can be used by pathologists at diagnosis.

By improving diagnostic accuracy, we hope that both outcome prediction and treatment planning will be improved.



*“Treatment planning can be improved if we become better at diagnosing and predicting the behaviour of these tumours. By unravelling the differences between adamantinoma and similar less aggressive tumours, we can design new ways to treat patients with adamantinoma that cannot be operated on or who develop metastases.”*

**Professor Judith Bovée**, Leiden University Medical Center (The Netherlands)

## OVERVIEW: RESEARCH INTO ALL FORMS OF PRIMARY BONE CANCER

### WE HAVE:

Organised research meetings for specific tumour types and encouraged researchers to collaborate and develop innovative research guided by the needs voiced by patients & families and, with input from the research community, we have designed dedicated funding calls for specific types of primary bone cancer.

### IMPACT:

Research grants are awarded for adamantinoma, chondrosarcoma, mesenchymal chondrosarcoma and Ewing-like sarcomas.

These projects are helping us to better understand their biology, with the hope of developing novel therapeutic options for patients diagnosed with these tumours.



*“Elizabeth’s first diagnosis when she was 13 was fibrous dysplasia. It was only after undergoing two invasive surgeries that Elizabeth finally received a correct diagnosis of adamantinoma. It is incredibly painful for us as a family to think that it was almost certainly the first, incorrect diagnosis and consequent inappropriate treatment that led to Elizabeth’s death nearly 20 years later.*

*It is our hope that this work will mean that in the future accurate diagnosis of adamantinoma will give patients facing this awful disease the best possible chance of a positive outcome.”*

**Lesley, Jeremy and Jack**, parents and husband of Liz Clarke-Saul



# WE ARE TACKLING THE PROBLEMS FACED BY PRIMARY BONE CANCER PATIENTS

## CHALLENGES AND BONE CANCER RESEARCH TRUST RESPONSE THROUGH FUNDED RESEARCH

◆ challenges
 ◆ response





**SARCOMA SURGERY IS DIFFICULT**

**WE FUND RESEARCH TO IMPROVE SURGICAL MARGINS**

The **Surgical Consortium** brings together surgeons from across the world to investigate whether fluorescence technology can improve technique in image guided sarcoma surgery, potentially leading to better outcomes and quality of life for patients.

Understanding the needs of **spinal sarcoma** patients before, during and after treatment and surgery to provide better care for these patients.

**IMMUNOTHERAPY HAS PROVEN INEFFECTIVE IN PRIMARY BONE CANCER**

**WE FUND RESEARCH INTO NOVEL IMMUNOTHERAPY APPROACHES**

Highly multidisciplinary projects are funded to:

Design engineered patients' T cells with specific **T-cell receptors** to recognise and destroy **Ewing sarcoma** cells.

Investigate **gamma-delta T cells** that target Ewing sarcoma cells in the lungs.

Evaluate the potential for **CAR-T cells** and **oncolytic viruses** for the treatment of osteosarcoma.

Develop tumour targeted **interleukin-12** immunotherapy approaches for **osteosarcoma**.

**WE LACK MARKERS OF RESPONSE OR PROGNOSIS**

**WE FUND RESEARCH INTO BIOMARKERS**

Funded research is looking for protein signatures that can be used to predict response to **Regorafenib** or **Lenvatinib** in **Ewing sarcoma** patients enrolled in the **rEECur** and **INTER-EWING-1** clinical trials.

Biomarker analysis from the rEECur trial is being used to determine the prognostic value of **circulating tumour DNA and RNA and circulating proteins** present in the blood in recurrent and refractory **Ewing sarcoma**.

**FEW CLINICAL TRIALS FOR PRIMARY BONE CANCER**

**WE FUND CLINICAL RESEARCH**

**Ad-ICONIC** continues the follow up of osteosarcoma patients recruited during **ICONIC**, increasing our understanding of **osteosarcoma** and collecting evidence for a future interventional trial.

The **Clinical Trial Support** grant scheme is well established.

Additional support is provided for the inclusion of **Lenvatinib** to the high dose Ifosfamide arm of **rEECur**, an international trial for recurrent **Ewing sarcoma** patients.

# REFLECTING ON PROGRESS, PLANNING FOR THE FUTURE

In 2022, we launched our ambitious 10-year research strategy, **Accelerating Research to Help More Patients Survive and Thrive**, which outlines a clear set of research objectives aiming to bring us closer towards the commitment of **More patients surviving. More patients thriving.**

We measure our progress against these objectives. While we are extremely proud of the progress we have made TOGETHER, we recognise that there is still a long way to go before that commitment becomes a reality.

An open dialogue with researchers, clinicians, surgeons, healthcare professionals and the primary bone cancer community allows us to ensure our strategic plans respond to changes in priorities and support emerging technologies and discoveries.

The generosity of patients who donate samples for research underpins pioneering research. Our PPI Panel continues to grow and guide us, guaranteeing the research we fund remains patient centred.

With your support, we remain committed to improving diagnosis and finding better, kinder treatments that ultimately will improve outcomes and the quality of life of primary bone cancer patients.

As always, we thank...

...all the researchers, clinicians, surgeons, and healthcare professionals. We deeply appreciate your hard work and dedication. **THANK YOU!**

...the bone cancer community. With your unwavering support, we strive to continue working on your behalf, forging collaborations and funding pioneering research, so groundbreaking discoveries can be made. **THANK YOU!**



Abby brings her breadth of lived experience as a chondrosarcoma patient to her role on the Patient & Public Involvement Panel, advocating for the primary bone cancer community by helping to shape and drive forwards impactful research.

*“You hear so much about other types of cancer that get more funding and support. Impact is knowing that stuff is happening, and no one is giving up on primary bone cancer.”*

*Research impact is like a marriage! It's important to celebrate the milestones, 5 years, 10 years, but also the everyday. Research isn't just about the milestone moments. It's the fact that it's continually happening, and that takes a lot of work, a lot of small day to day wins...For example, hearing about medical students choosing to take in a project in PBC, that's impact and that's exciting for us as patients to hear. Thank you to the researchers and to our community for the progress they are making, collectively, towards improved outcomes for patients.”*

**Abby**, PPIP member



*“The Bone Cancer Research Trust is instrumental for researchers like us working in the field of primary bone cancer. They provide vital funding for pioneering, patient-centred research. What sets BCRT apart is its strong sense of community and its commitment to fostering regular interactions between researchers and patients through conferences and fundraising events. These opportunities not only allow for the sharing of knowledge and research updates but also serve as powerful reminders of the urgent need to improve current treatments for primary bone cancer.”*

**Dr Karan Shah**, University of Sheffield

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# DRIVING CHANGE DELIVERING HOPE

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