

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

**MORE
PATIENTS
SURVIVING.
MORE
PATIENTS
THRIVING.**

**OUR 2022-2032
STRATEGY**

CONTENTS.

- 03. OUR VISION, OUR MISSION, OUR VALUES
- 05. INTRODUCTION
- 06. UP TO NOW
- 10. WHERE WE ARE
- 11. PRIMARY BONE CANCER IN NUMBERS
- 12. WHERE WE WANT TO BE
- 13. WHAT WE NEED TO DO TO GET THERE
- 14. WHY IS OUR PLAN SO IMPORTANT
- 16. PATIENT STORIES
- 20. OUR AIMS & OBJECTIVES
- 22. RESEARCH
- 24. OUR 2022-2032 GRANT PROGRAMME
- 25. GRANT DESCRIPTIONS
- 26. AWARENESS
- 27. SUPPORT & INFORMATION

MORE PATIENTS SURVIVING. MORE PATIENTS THRIVING. OUR 2022-2032 STRATEGY



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.

OUR VALUES.

PIONEERING. We lead the way, we leave no stone unturned, we are prepared to take risks.

DYNAMIC. We don't stand still, we innovate, we celebrate every success.

SUPPORTIVE. We listen, we understand, we care.

KNOWLEDGEABLE. We know our stuff; we are eager to know more.

TRUSTWORTHY. We do what we say we're going to do; we do the things that matter.



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INTRODUCTION

Since 2006, the Bone Cancer Research Trust has remained the leading charity dedicated to saving lives and improving outcomes for primary bone cancer patients. In 2017, we launched The Biggest Ever Commitment to Primary Bone Cancer, our most ambitious strategic plan to date outlining our ambitions between 2017 and 2022.

As we began to plan our future, we asked you, our community, and stakeholders, to help shape our charitable objectives. 1,471 of you shared your feedback in our 2020 Patient Survey and 2021 Help Shape Our Future Survey.

Your views and those from interviews and focus groups helped us identify the priorities that matter to you, and we have put these at the heart of our plans.

UP TO NOW.

Thanks to your unwavering support, we have grown our income, allowing us to achieve all the objectives we set out in our 2017-2022 strategy.

**£2.8
MILLION**

COMMITMENT TO
NEW RESEARCH

**4600
SAMPLES**

COLLECTED FOR USE
IN RESEARCH

**3
PHD**

STUDENTSHIPS
FUNDED

ALL

GP PRACTICES IN
THE UK PROVIDED
WITH EDUCATIONAL
PACKS

**STEP-
BY-STEP**

GUIDE FOR PATIENTS
LAUNCHED

2000

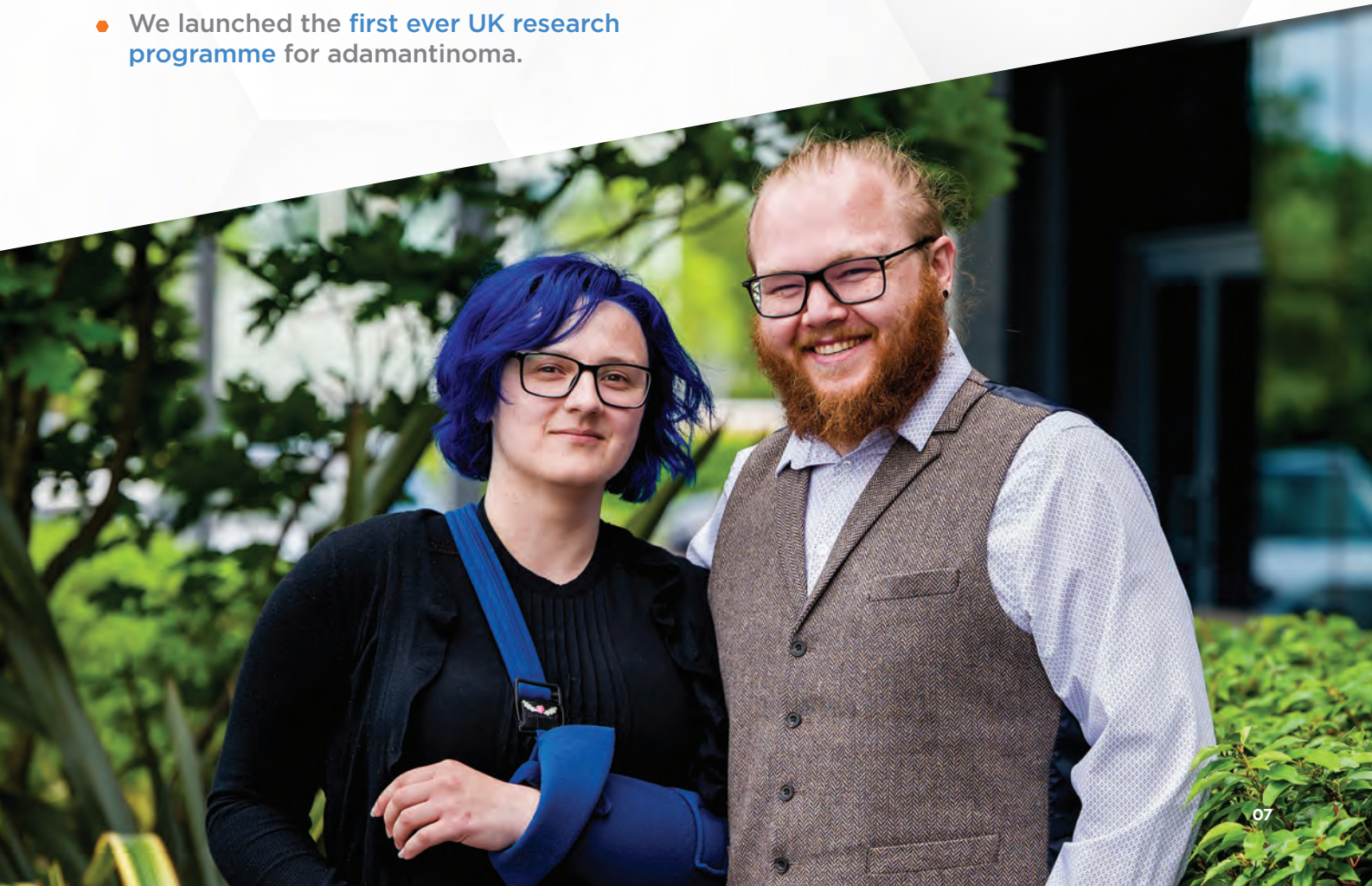
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HERE ARE JUST SOME OF THE HIGHLIGHTS, YOU HAVE MADE POSSIBLE SINCE 2017:

- We exceeded our **£2.8million** commitment to new research, totalling **41 grants** overall.
- Through our Infrastructure Grants, **89% of patients** are now consenting to sample donation. Over **4,600 samples** have been collected for use in research, supporting over **21 research projects** to date.
- We launched **ICONIC**, the UK's first age-inclusive observational clinical trial for osteosarcoma.
- We funded **3 PhD Studentships**, supporting researchers at the start of their career.
- We launched the **first ever UK research programme** for adamantinoma.
- We launched a **dedicated Support & Information Service** which has supported over **2,000 patients** and their families.
- We reached all GP practices, radiology departments, musculoskeletal physiotherapy practices and dental practices in the UK, providing them with educational packs on the signs, symptoms and referral pathways for primary bone cancers and tumours.
- We have ensured dedicated information resources for each primary bone cancer and tumour are readily available and accessible for all patients and we **launched our Step-By-Step Guide For Patients** which takes patients and their loved ones through diagnosis, treatment and recovery.



MORE PATIENTS SURVIVING. MORE PATIENTS THRIVING.

Our 2022-2032 strategy places our patients upfront and central across three strategic foundations:

- 1. RESEARCH**
- 2. AWARENESS**
- 3. SUPPORT & INFORMATION**

Our plan encapsulates our values and sets a framework for change that will drive significant improvements for patients and their families, ultimately resulting in more patients surviving and more patients thriving.



WHERE WE ARE.

Since 2006, much progress has been made and the Bone Cancer Research Trust has spearheaded the transformation of the primary bone cancer landscape.

From a time when primary bone cancer research was not being considered, to today where the Bone Cancer Research Trust is ensuring regular and reliable funding is available to support research idea development through to patient benefit.

Our Support & Information Service now ensures that no patient or family member has to face primary bone cancer alone. Our dedicated information and specialist knowledge for every form of primary bone cancer and tumour has made us the go to organisation for bone cancer and bone tumour patients.

Through our public and healthcare awareness campaigns, we have reached national and international audiences, making hundreds of thousands of individuals more aware of primary bone cancer and how to spot the presenting symptoms.

However, patients are still being diagnosed late and those that start treatment, are being treated with toxic drugs that were developed over 40 years ago.

Access to new treatments is still elusive for bone cancer patients and is simply a situation that cannot continue. Patients are still facing terrible side effects and desperately need new, kinder and more effective treatments to improve their chances of survival. And whilst the volume and scope of primary bone cancer research has increased, this has focused on more common forms, with rarer forms falling behind.

For those that do survive, the post-treatment impact can be life-long, limiting their ability to find a 'new normal' when they are cancer free. Dedicated support is needed for our patients to help them return to a full life and thrive once again.



PRIMARY BONE CANCER IN NUMBERS.



EVERY 10 MINUTES ANOTHER CHILD, TEENAGER OR ADULT IS DIAGNOSED SOMEWHERE IN THE WORLD



560 PEOPLE ARE DIAGNOSED EACH YEAR IN THE UK



INCIDENCE HAS **REMAINED STATIC** IN THE UK SINCE 1996



EVERY DAY, AT LEAST ONE MORE PERSON LOSES THEIR LIFE TO THIS DISEASE IN THE UK



THE CURRENT OVERALL 5-YEAR SURVIVAL RATE IN THE UK IS **APPROXIMATELY 61%**



THERE ARE OVER **6,000 PEOPLE** LIVING WITH OR BEYOND PRIMARY BONE CANCER RIGHT NOW IN THE UK



PRIMARY BONE CANCER REPRESENTS **0.2% OF ALL CANCERS** AND **4% OF ALL CHILDHOOD CANCERS** DIAGNOSED EACH YEAR IN THE UK

THERE ARE ALSO A FURTHER 102 NON-CANCEROUS PRIMARY BONE TUMOURS DIAGNOSED EACH YEAR IN THE UK THAT CAN BE HIGHLY INVASIVE, DESTRUCTIVE AND LIFE-CHANGING FOR PATIENTS

WHERE WE WANT TO BE.

Through our our new objectives, we will continue to transform the research landscape. We will encourage and facilitate the development of new and more effective treatments for patients, recognising the importance of a personalised approach, capitalising on wider work being undertaken and harnessing the potential of new technologies.

All patients deserve a timely and accurate diagnosis. By delivering our objectives, we will reduce the time between symptom onset and referral, allowing treatment to start sooner, ensuring the best outcomes for patients, improving their chances of survival.

Additionally, patients and families deserve access to the right support and information at the right time. By reaching all patients at diagnosis, we will be there for our patients throughout their journey, providing dedicated support and information to them and their loved ones. No patient will feel alone or isolated and every patient will be supported so that they can once again thrive after primary bone cancer.



WHAT WE NEED TO DO TO GET THERE.

To deliver our plans we must ensure our charity is robustly prepared, structured and financed. We will do this by:

- Investing in our people and infrastructure, ensuring we have appropriate talent and skills within our team that utilise appropriate technologies to deliver our objectives.
- Diversifying our research and working to a specific research strategy, designed to provide a framework and focus for our research that will result in the greatest benefit for primary bone cancer patients.
- Delivering a multi-year supporter-centric fundraising strategy that will facilitate continued growth and provide the financial resources to deliver our plans.
- Championing the collection and reporting of primary bone cancer data throughout the UK, improving detail, quality and accessibility.



WHY IS OUR PLAN SO IMPORTANT?

The following two stories are those of patients at very different stages of their primary bone cancer journey. They represent the two key aspects of our strategy and demonstrate just how essential our work is to the primary bone cancer community.

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MORE PATIENTS SURVIVING.



Meet Lucy, all patients like Lucy should have a timely diagnosis and be given access to effective and kind treatments that will ensure the best chance of survival. This is her story...

Lucy McGeehan was 5 years old when she was diagnosed with Ewing sarcoma in her upper thoracic spine in 2018. She endured 3 invasive surgeries, 14 rounds of chemotherapy and 27 proton beam therapy treatments.

From what started as constipation on a family holiday in July 2018, Lucy had weeks of discomfort and was losing use of her legs, she visited her doctor, was given treatment for constipation and had blood tests that showed nothing. Lucy eventually had to be hospitalised at Altnagelvin Hospital, Derry, as she became paralysed from the waist down.

Concerned for her health, Lucy was sent by ambulance to Royal Belfast Hospital for Sick Children where she eventually had an MRI scan. Before the scan had finished, the medical team informed Lucy's parents that they had found a tumour.

"We were totally shocked"

Lucy was kept at the hospital for 4 weeks whilst they carried out scans and tests. Initially, the medical team were unable to extract enough of the tumour to carry out a biopsy. They decided to give Lucy an open biopsy and at the same time, remove as much of the tumour as they could. They had realised that part of the tumour was pressing on Lucy's spinal column which was causing her paralysis.

"After that first surgery we were told that the damage was done, and that Lucy might never walk again, or it would take her a long time to regain any movement. Lucy was having none of it and just a few nights later, she started moving her legs."

It was confirmed that Lucy had a Ewing sarcoma. Lucy started treatment two weeks later with vincristine, doxorubicin, cyclophosphamide, ifosfamide and etoposide.

"The doxorubicin was terrible, and after every round Lucy would develop terrible mucositis."

Lucy underwent 10 cycles at Royal Belfast Hospital for Sick Children before being transferred to the Birmingham Children's Hospital, in England for further surgery.

Lucy had surgery to remove the residual tumour and to remove three of her vertebrae, which were replaced by two of her ribs and held together with carbon fibre rods and Jazz Bands. Lucy's surgeon had to keep the use of titanium to a minimum as she was due to have proton beam therapy later as part of her treatment. The surgery was a success and all of Lucy's tumour was removed.

Unfortunately, within weeks, Lucy had to undergo further surgery as her carbon rods did not hold. These were replaced with longer carbon rods that had to be held with titanium screws.

It was intended that Lucy would return to Belfast Children's Hospital for more chemotherapy and then to Germany for her proton beam therapy. However, Lucy was in so much pain from her surgeries, her medical team changed plans and arranged for her to have the rest of her chemotherapy at Birmingham Children's Hospital and for her to receive proton beam therapy at The Christie Hospital.

Lucy's last four rounds of chemotherapy left her so poorly, and she had lost so much weight, that she was given parenteral nutrition as she just could not eat. Lucy then went on to have 27 proton beam treatments.

"Despite the aggressive and relentless treatment at the proton beam centre, there were days when Lucy, was still able to enjoy the shopping in Manchester."

Lucy completed her treatment 11 months after diagnosis. Her follow up appointments started every 3 months, then 4, then 6. Each time Lucy would have an MRI scan and a chest X-ray.

Sadly, in May 2022, Lucy's medical team spotted a recurrence of Ewing sarcoma in her lungs. She is currently on the rEECur trial and is receiving 6 cycles of carboplatin and etoposide with a round of treatment every 3 weeks. The aim is to shrink the tumour in her lung sufficiently so she can have surgery to remove it. She will then have radiotherapy.

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Aside from the side effects during treatment, Lucy now also suffers with pain in her back. Lucy has missed out on school, time with her friends, spent 5 months in England, and was only able to see her dad on visits. Lucy's treatment has affected all her family, especially her older brother.

Friends and family rallied and fundraised to help with family expenses. This allowed Lucy's family to focus on getting Lucy through her journey without the added stress of bills.

"I have always known Lucy is amazing, but I am just so proud of her and the way she has coped with her treatment and surgeries. She is such a smart, bright, funny little girl who keeps us all going with her personality. She's never too far away from a joke or a prank."

Research into new treatments is so important. We need more treatment options that will improve outcomes for patients like Lucy.

The Bone Cancer Research Trust is like a great big extended family with support for families in every aspect of their cancer journeys which makes even the most darkness days bearable."

- Lynne, Lucy's mum

Lucy's journey continues...



It is imperative that more healthcare professionals are trained on the signs and symptoms of primary bone cancer to ensure a timely diagnosis for all patients. Once diagnosed, it is also vitally important that more treatment options be developed and made available for patients just like Lucy.

Our new strategy will make this happen and will give patients the very best chance to survive primary bone cancer.



MORE PATIENTS THRIVING.

During and after treatment, patients like Pete deserve the very best quality of life. Treatment shouldn't be cruel or life-altering and all patients should be given the chance to not only survive, but to thrive. This is Pete's story...

In April 2011, Pete Lloyd was diagnosed with osteosarcoma of the left femur. Since treatment, Pete's focus has been very much on where he wants to be and not where he's been. His strength and determination have come from his family, Kate his wife and 3 children: Joshua, Lilli-Grace, and Annabelle.

In 2007, Pete fell over and shattered the inside of his bone, causing metabolic bone disease to occur (osseous fibrous dysplasia), which is benign but in rare circumstances can turn cancerous. Pete underwent treatment and all was improving, he even ran the Manchester 10K, but then his condition started to deteriorate and in 2011, he had his femur removed, which led to the diagnosis of osteosarcoma.

"I received a call from my surgeon, and he informed me I had osteosarcoma and that I would need to go to The Christie the following week. It completely floored me. It gutted us as a family, but I had to put my thinking head on and start processing. I was given a 20% chance of survival without chemotherapy, this increased to 60% with chemotherapy - it was a no brainer!"

Pete's treatment started quickly with PET and MRI scans and a Hickman line being inserted. Pete started the MAP regime of chemotherapy, consisting of cisplatin, doxorubicin and methotrexate. The treatment took a massive toll on Pete's family life, being in hospital from Tuesday through to Friday meant that weekends were the most precious of times.

"I had amazing nurses at The Christie, who talked me through chemo and sat with me whilst having chemo. They knew how important it was for me to be in and get home to my family."

The side effects of Pete's treatment were severe and included infections, sepsis, the need for platelet and blood transfusions, reflux and he developed oral thrush and mouth ulcers that were so bad, he could barely put a straw in his mouth.

Pete suffered from chronic fatigue, exhaustion and a constant pressure to close his eyes and sleep. Despite this, Pete kept going and would not be beaten. Pete's chemotherapy lasted for 8 months and finished on the 12th January 2012. Two months later he had his acetabulum (socket of the hip bone) replaced.

For the next few years, Pete carried on as best as possible with a stick and crutches. But in 2017, whilst playing with his son in the garden, his leg went from under him, and he made the decision to have a hip disarticulation (full leg amputation).

"I just couldn't do it. I wanted to play with my kids in the back garden without fear of falling or hurting myself."

Chemotherapy was very harsh and in total, Pete had 10 operations, but his determination remained steadfast. Since his amputation, Pete feels he got his life back.

"I still don't think I am fully over it, but I can play with my 3 wonderful children on the floor or in the back garden now. If new treatment developments could be made by the Bone Cancer Research Trust and it alleviates just one symptom it will mean the world to patients. The treatment needs to affect just the tumour and not every cell in the body. The work they do, funding research to treat, reduce side effects and increase longevity of life is incredible." - Pete



It was the most gruelling, debilitating, sickness inducing, awful regime you could possibly imagine. It is horrid.



Despite the challenges of his treatment, Pete found new interests and focus. From learning to ride a motorbike to taking part in record-breaking physical challenges. He even turned his head to professional sport, becoming a wheelchair racer. His advocacy for other patients is exemplary, Pete regularly supports the development of new research projects by putting the patient voice up front and centre in the minds of researchers.

Pete is now a Patient Ambassador for the Bone Cancer Research Trust, and his story is the perfect example of how work still needs to be done to improve the quality of life for patients during treatment. His story also demonstrates how, by getting the support he needed, Pete's life did not stop at primary bone cancer and that every patient has the potential to reach their fullest potential when they get the correct support.



With the development of new treatments, it is essential that these be kinder for patients with less side effects during and after treatment. All patients also deserve the correct support to live full and happy lives after a journey with primary bone cancer.

Our new strategy will drive the development of those kinder treatments and we will reach all patients, providing them with the help and support they need to thrive beyond primary bone cancer.

OUR 2022-2032 AIMS & OBJECTIVES.

The aims and objectives that follow will be our key focus. We will report on progress made against them continually through our public communications and annually in our Annual Report & Accounts.



RESEARCH.

OUR AIM. There will be new, kinder, and more effective treatments available for primary bone cancer patients by 2033. As a result, more patients will be surviving.

OUR OBJECTIVES.

- 1** We will deliver a new and flexible Grant Programme that will support research focused on every form of primary bone cancer and tumour and facilitate the development of new clinical trials, committing £10 million to life-saving research over the next 10 years.
- 2** We will put patients at the heart of our research through our Patient & Public Involvement Panel. Their voice will inform all our decision making.
- 3** We will ensure all patients can contribute to research through sample donation and participation in clinical trials and biological studies.
- 4** We will bring all aspects of current primary bone cancer research together, harnessing data, technology, and skills to combine efforts and understanding to accelerate progress.
- 5** We will facilitate and promote collaborative working, enabling consortia, stimulating partnerships, and bridging skills gaps.
- 6** We will continue to support the development of the next generation of world class, primary bone cancer researchers.
- 7** We will ensure all forms of primary bone cancer and tumour are represented in research, regardless of rarity.



**£10
MILLION
TO LIFE-
SAVING
RESEARCH
OVER THE
NEXT 10
YEARS.**

OUR 2022-2032 GRANT PROGRAMME.

Our Grant Programme is our public commitment to our supporters and the research community. It is both ambitious and flexible, allowing us to respond to emerging needs over the next 10 years whilst also giving clear transparency to researchers when planning future research.

GRANT TYPE / YEAR	2022	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032
Idea	✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Project	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
PhD Studentship		✓		✓		✓		✓		✓	
Infrastructure	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓	✓✓✓ ✓✓
Clinical Trial Support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Skills Development	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Research Meeting	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Consortia	✓✓				✓✓						
Early Career Fellowship	✓					✓					
Translational			✓							✓	

Should a new treatment or surgical study be ready for early-stage trials within the set timeline, we will fund a Clinical Trial Grant in 2028. However, should a treatment or surgical study not be at the required stage of development by this time, or if a more urgent priority is identified, this funding will be re-allocated to other grant types within the Grant Programme.

GRANT TYPE / YEAR	2022	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032
Clinical Trial							✓				

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GRANT DESCRIPTIONS.

IDEA.

Can be used to collect preliminary data for a larger application, or to demonstrate the validity of a hypothesis / study.

PROJECT.

Supports researchers to undertake a more substantial, multi-year project or theme of research.

PHD STUDENTSHIP.

For committed primary bone cancer researchers that wish to acquire a PhD / MD qualification.

INFRASTRUCTURE.

Available for surgical centres to support the collection of patient samples for use in research, underpinning primary bone cancer research across the UK. These grants also enable centres to deliver whole genome sequencing for primary bone cancer patients.

CLINICAL TRIAL SUPPORT.

Provide additional support for ongoing clinical trials. The trial may be observational or interventional and can be oncological or surgical.

SKILLS DEVELOPMENT.

To enable researchers to learn new skills through short-term laboratory visits.

RESEARCH MEETING.

Provides funding to support primary bone cancer research meetings, ensuring progress is shared across the UK and driving forward collaborative research.

CONSORTIA.

To support the establishment or continuation of primary bone cancer consortia that will facilitate both biological and clinical research, with the ultimate aim of improving outcomes for patients.

EARLY CAREER FELLOWSHIP.

To develop a researcher into a principal investigator to run their own group and develop their own research interests. Can be used to provide data for larger / programme funding applications or to further substantiate studies for which some preliminary work / consolidated hypothesis / demonstrated interest already exists.

TRANSLATIONAL.

Support research that has reached a point of development to be progressed from the laboratory to patients.

CLINICAL TRIAL.

To support the delivery of a clinical trial for primary bone cancer patients.





AWARENESS.

OUR AIM. By 2033 all patients will have an accurate and timely diagnosis, being referred within 1 month of first seeking healthcare professional advice following onset of symptoms, ensuring more patients survive and thrive after treatment.

OUR OBJECTIVES.

- 1** We will take an evidence-based approach to develop guidelines and change standards of care in the UK.
- 2** We will align our efforts to the National Health Service (NHS) Long Term Plan, reinforcing their ambition to have more patients diagnosed at stages I and II. Our campaign messaging will educate the public and healthcare professionals specifically on the signs and symptoms of primary bone cancer.
- 3** We will adopt a multi-stakeholder approach to educating healthcare professionals.
- 4** We will embed a GP-led programme of education and continual training across the UK.
- 5** We will harness the power of our community and the media to share lived experiences of primary bone cancer, increasing public understanding and knowledge.

SUPPORT & INFORMATION.

OUR AIM. We will reach all newly diagnosed patients in the UK, providing the support and information they need through and beyond treatment, equipping them with the tools and knowledge to thrive after primary bone cancer.

OUR OBJECTIVES.

- 1** We will complete a national audit to understand current care and support provisions available for patients through the NHS and other patient organisations to promote equity of care and reduce gaps and differences in services.
- 2** We will develop and maintain a comprehensive support and information directory for all those affected by primary bone cancer.
- 3** We will become the authoritative voice for primary bone cancer statistics and information.
- 4** We will ensure our Support & Information Service meets the needs and is accessible to all those affected by primary bone cancer regardless of community, background, spoken language or age.
- 5** We will foster collaborative relationships with healthcare professionals to ensure all patients and their families know how to access our Support & Information Service.
- 6** We will provide greater financial support for patients as they face the increased costs associated with a primary bone cancer diagnosis.
- 7** We will deliver a programme of dedicated events to provide face-to-face and virtual-based support to our community.

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