

PLACING THE PRIMARY BONE CANCER COMMUNITY AT THE HEART OF THE BONE CANCER RESEARCH TRUST



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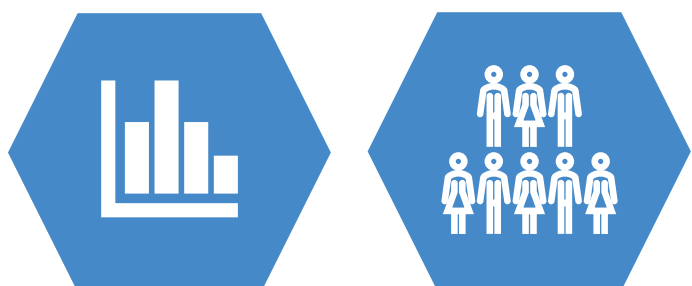
INFORMATION

We are committed to providing our community with **high-quality, evidence-based** and **up to date information**, across all sub-types of primary bone cancer and tumour, to ensure that patients, their families & loved ones feel informed and supported as they navigate the journey through diagnosis and treatment.

In January 2023, the quality of our information was recognised by the **Patient Information Forum**, who awarded us the 'PIF tick', the UK's only assessed quality mark for health information.

Patients & members of the primary bone cancer community are actively involved in **the development and review** of our resources, ensuring that their voices & lived experiences guide the information we share.

We also pride ourselves on gathering, collating and reporting the **latest available statistics** across all primary bone cancer types.



Without this vital information, our ability to identify sub-type specific clinical and research priorities and to advocate for patients' individual needs remains limited.



Here at the **Bone Cancer Research Trust**, we advocate for the primary bone cancer community in everything we do, through the **research** we fund, the wide-ranging **support & information** we provide, and the **awareness** we raise.

These four key pillars are the foundation upon which the Bone Cancer Research Trust is built, with **patients, families & their support networks placed at the very heart**, guiding our core values and activities.

We not only **advocate for our community**, but also **empower them to self-advocate**, to feel heard and represented, and, together, to drive forwards change which will lead to improved outcomes for patients.

TAKING STEPS TOWARDS CHANGE, TOGETHER.

SUPPORT

In 2019, we launched our dedicated Support & Information Service, providing a diverse range of support to the primary bone cancer community, regardless of their age, background or geographical location.

Whether through our **support line, virtual & digital support groups, 'get-togethers'** or opportunities to **share stories** and experiences of primary bone cancer, we aim to advocate for and address the needs of patients & families at all stages of their journey.

The **Bone Cancer Conference** is our award-winning, flagship support event, bringing together the primary bone cancer community and providing a supportive space to connect with others, share experiences and hear the latest research updates.



We also recognise the significant financial challenges which patients & families can face throughout diagnosis, treatment and beyond. We therefore offer several non-means tested **financial assistance grants** to help with the expenses associated with hospital visits & treatment, and with travel costs for UK patients undergoing Proton Beam Therapy or enrolled in a clinical trial.

RESEARCH

Since 2006, the Bone Cancer Research Trust has committed over **£8.4 million** to primary bone cancer research, with the aim of improving our understanding of this disease, developing kinder and more effective treatments for patients and, ultimately, achieving a cure.



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

Thanks to our **Patient & Public Involvement Panel (PPIP)**, the primary bone cancer community are not only the motivation driving this research, but they are also actively involved **in identifying key research priorities, shaping projects** and **guiding funding decisions**.



Patient & Public Involvement (PPI) aims to ensure that research is carried out collaboratively **'with' patients and members of the public**, rather than 'to', 'about' or 'for' them.

Through PPIP, **lived experiences** are brought to the forefront of the research we fund.



"I feel it is important that all those touched by primary bone cancer have a representative that will give them a voice, especially as outcomes have improved so little for so many years."

Through PPIP, I can make a contribution that might improve the outcome for others."

PPIP member & parent

AWARENESS

We know that, for far too many members of the primary bone cancer community, diagnosis is delayed due to a lack of understanding and awareness.

We strive to raise awareness amongst the healthcare professionals of today and of the future, whether through sharing our **dedicated information & resources** with nurses, clinicians, GPs, radiologists & allied healthcare professionals, or through our partnership with the University of Sheffield, which has raised vital awareness amongst **medical students** committed to learning from and supporting the primary bone cancer community.

OUR FUTURE

Our latest 10-year strategy, **'More patients surviving. More patients thriving'**, was **shaped in response to the needs & priorities voiced by our community**, placing renewed focus on ensuring that patients are not only able to survive their diagnosis, but also live well beyond it.



HELP SHAPE OUR FUTURE

FIND OUT MORE

Please contact us for more information:
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