



Sarcoma
Patients
EuroNet



Research Patient Involvement Programme

This project aimed to establish a framework to bring the perspectives of people with personal experience of sarcoma into our research programme, to influence the direction of our research funding. This involved creating a new team of volunteer Research Grant Lay Reviewers to assess the applications we receive, and bringing people affected by sarcoma onto our research panels to contribute to funding decisions.

Achievements

For the first time, we now have a formal framework for involving sarcoma patients and those close to them in our research programme, and are able to base our research funding decisions equally on the scientific merit of the applications and their relevance for people affected by sarcoma. Via our 20 selected Research Grant Lay Reviewers, we are able to draw on a diverse range of expertise upon which to shape our research programme, with 16 sarcoma subtypes represented. We've received feedback from several lay reviewers that our training sessions were useful and informative, and left them well-prepared to review the applications. By the time the project is complete, all research

funding applications submitted this year will have been assessed on the importance of the applications based on reviewers' personal experience of sarcoma, how well the researchers communicate their work to non-scientists, and the consideration to patient involvement in the project. With patients on our research panels, we are now able to direct our research investment more meaningfully, with a view to also launching our first targeted funding calls in areas which are most important to people affected by sarcoma.

Additional value for the sarcoma population

We've heard clearly from sarcoma patients that research is a high priority, and this first step towards a patient-led research programme will help ensure that we are supporting the most impactful research for people affected by sarcoma:

"Research is so important to improving our lives and I'm thrilled to be able to help shape the future funding allocated by the charity."

"I'm so keen to use my experience for something positive and help others diagnosed with sarcoma."



SarcomaUK
The bone & soft tissue
cancer charity

Sarcoma UK