THE POWER OF PATIENT VOICE: COLLABORATIONS IN EWING SARCOMA

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INTRODUCTION

For 13 years, the Euro Ewing Consortium (EEC) has facilitated and supported collaboration among experts across Europe to improve outcomes for Ewing sarcoma patients. Through priorities such as uncovering better treatments, supporting global initiatives, optimising funding, and building consensus, the EEC represents an ambitious collaboration. To achieve this, patient advocacy is at the heart of the EEC. The current cohort of advocates is made up of adults, including those who are/were patients and others who are/were carers of a patient.

The EEC is led by the Executive Committee and supported by Bone Cancer Research Trust (BCRT) and The Ewing's Sarcoma Research Trust. The EEC network has over 200 active members from 30 countries, and a further 400 experts represented within the wider Ewing sarcoma community.

In 2013, the EEC received €5.7 million through the European Union's Seventh Framework Programme for research, technological development, and demonstration. It included two clinical trials, translational research, and strengthening both patient and public involvement and the ethical process. Since 2022, BCRT has been the main funder of the EEC, awarding a three-year consortium grant in 2023 followed by a one-year costed extension until 2027. Both organisations collaborate by facilitating network meetings and providing travel grants for early career researchers, for example.

OBJECTIVES

- Focusing on **new agents**
- **Facilitating collaboration between researchers** working in basic science, pre-clinical work, and both early-phase and late-phase trials
- Develop and validate biomarkers to allow better patient stratification
- Supporting open trials and future trials
- Identifying and supporting the needs of early career researchers
- **Continuing to develop and harness patient advocacy**
- Considering functional outcomes and quality of life

Mission

To improve all outcomes including duration and quality of survival for people diagnosed with Ewing sarcoma in Europe

Aim

The Consortium will be responsible for the development and maintenance of a strategy to strengthen, harmonise, and optimise collaborative efforts by a network of clinicians, scientists, and patient advocates working at a Pan-European level to achieve the mission of the Consortium

PATIENT ADVOCATES

Patient advocates play a vital role within the EEC. They actively participate in working groups, disseminate information, and collaborate across patient advocacy networks. Their expertise supports **meaningful** collaboration. Advocates bring the **patient voice** into scientific strategy by representing real patient priorities, ensuring research focuses on clinical problems, keeping attention where unmet need is greatest, and highlighting real-world patient experience.

Influence strategy and wider activities of the EEC

Provide advocate input into trial design and grant applications

Share lived experience including presenting posters and presentations at conferences and meetings

Involving and consulting with patient advocates is standard practice for researchers in the EEC community



Global EEC patient advocate representation with 40 members from 13 countries. They include patients, parents, caregivers, survivors, and advocates.

As both a Patient Advocate with the EEC 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. The EEC leverages international collaboration to unite top researchers, clinicians, and investigators across Europe. Together, these organisations create a powerful alliance that advances Ewing sarcoma research and improves patient outcomes through shared expertise and resources.

Andrew Westwood, EEC patient Advocate



To learn more about the EEC and how to become a patient advocate, please scan the QR code