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abstract

Towards Better Treatment Through Collaboration: The role of patient advocates in the European Reference Network on Pediatric Cancer (ERN PaedCan)

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St. Jude Global

St. Jude Global Alliance, Euro
Regional Meeting2025, Poland

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Towards Better Treatment Through Collaboration: The role of patient advocates in the European Reference Network on Pediatric Cancer (ERN PaedCan)

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Introduction: ERN PaedCan is a European Reference Network dedicated to improving care for children and adolescents with cancer by connecting experts, facilitating cross-border collaboration, and ensuring access to the best available diagnosis and treatment. CCI Europe is part of the Steering Committee of ERN PaedCan and is actively involved in all project activities. Serving as a bridge between the ERN coordinator and patient and parent groups across Europe, CCI Europe provides guidance on ERN PaedCan, patient rights (e.g., second opinions), and access to expertise.

Methodology: ERN PaedCan supports patients requiring specialized expertise, particularly those with rare cancers. Its key innovation is a roadmap that outlines cancer backgrounds, standard treatments, and cases suitable for expert referral through virtual tumor boards.

Results: The European Standard of Clinical Practice (ESCP) Project within ERN PaedCan has developed and approved clinical recommendations for common childhood cancers, ensuring best practices to enhance survival, outcomes, and quality of life. To date, 26 ESCPs have been launched. Additionally, the Clinical Patient Management System (CPMS) provides access to a multidisciplinary international virtual tumor board, allowing ERN experts to offer the best guidance on diagnosis and treatment.

Conclusion: Through campaigns, training, and other dissemination activities, CCI Europe plays a vital role in ensuring that ERN PaedCan's resources reach the patients who need them most. By working closely with the network coordinator, CCI Europe facilitates access to ESCPs and establishes clear patient pathways to the CPMS, enabling patients across Europe to benefit from expert guidance and virtual tumor board consultations.