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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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ABSTRACT

Background: 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 in the Steering Committee of ERN PaedCan and strongly involved in all project activities. We act as a bridge between the ERN coordinator and patient and parent groups across Europe, providing guidance on ERN PaedCan, patient rights (e.g., second opinions), and access to expertise.

Methods: ERN PaedCan supports patients needing specialized expertise, particularly for rare cancers. Its key innovation is a roadmap outlining cancer backgrounds, standard treatments, and cases suited for expert referral and virtual tumor boards.

Results: The (1) European Standard of Clinical Practice (ESCP) Project within ERN developed approved clinical recommendations for common childhood cancers, ensuring best practices to enhance survival, outcomes, and quality of life. Until now, 26 ESCPs have been launched. The (2) Clinical Patient Management System (CPMS) offers access to a multidisciplinary international virtual tumor board of ERN experts, providing the best guidance on diagnosis and treatment.

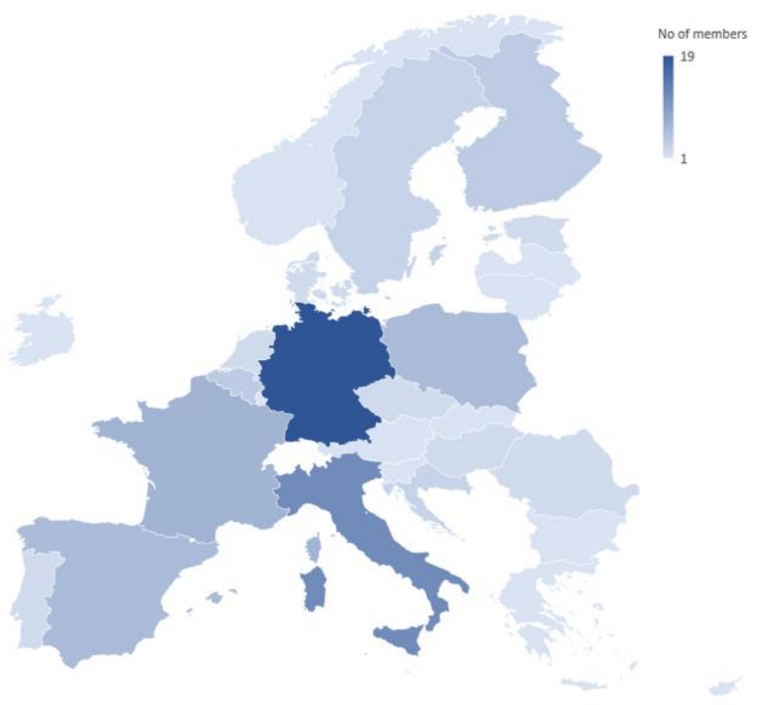
Conclusion: Via campaigns, training and other dissemination activities, CCI Europe plays a vital role in ensuring that ERN PaedCan's resources reach the patients who need them most. By working closely with the network coordinator, we facilitate access to ESCPs and establish clear patient pathways to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

Goals of ERN PaedCan

- Reduce inequalities across Member States
- Ensure that information travels rather than patients
- Unite the best specialists across Europe

ERN PaedCan members

- 90 Healthcare Providers in 28 countries
- Full EU coverage



For Patients & Families

CCI Europe Childhood Cancer International EUROPE
is the biggest pan-European childhood cancer parents´ and survivors´ organization in Europe and is strongly involved in all network activities.

- **CCI Europe** integrates 63 member organizations in 34 countries to the network´s activities. in the
- We act as a bridge between the ERN coordinator and patient and parent groups across Europe, providing guidance on ERN PaedCan, patient rights (e.g., second opinions), and access to expertise.

For Healthcare Professionals

Roadmap development

The European Standard Clinical Practice (ESCP) project

- Clinical recommendations reflecting current best practice for childhood cancers.
- For use when or where no frontline trials are open.

25+ ESCPs guideline documents developed

CPMS for Tumour Boards

Dedicated IT platform for virtual consultations.

- Access to leading experts in their field, anytime from anywhere
- Available for clinicians in whole EU + Norway

Registries

PARTNER study
Paediatric Very Rare Tumours

ESCP registry
Impact of the ESCP Guidance documents

Training and Education

- 42 webinars organised since 2021
- ERN PaedCan Training/Twinning Programme

Learn more about the network

European Reference Networks

This project has received funding from the European Union's EU4Health Programme under the grant agreement number 101085543.

Childhood Cancer International EUROPE

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the European Society for Paediatric Oncology

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