

A cross-border healthcare network to cure childhood cancers

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Opinion Plus

Children with cancer deserve the best possible healthcare, wherever it may be found, writes Ruth Ladenstein.



EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

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European
Reference
Networks



European Reference Networks | *Photo credit: SIOPE*

Excellent European healthcare centres are renowned across the world for their expertise in treating paediatric malignancies.

However, at the same time some European countries lack the resources and highly-specialised know-how required to ensure the correct implementation of state-of-the art treatment protocols.

Children and adolescents with cancer deserve the best possible healthcare, no matter where they

live.

We at the [European Society for Paediatric Oncology \(SIOPE\)](#) [1] believe that it's not only access to standard care and cure rates for all paediatric cancer types that should improve, but that the best possible quality of life for long-term survivors should be ensured across the whole region.

We have been at the forefront of this fight against health inequalities in Europe for many years: first with our [electoral Manifesto in 2014](#) [2], then by pursuing the objective "Equal Access" in our central document '[Strategic Plan – A European Cancer Plan for Children and Adolescents](#) [3]', and finally by successfully structuring a European Reference Network for paediatric oncology (ERN PaedCan).

The European Commission established 24 "European Reference Networks" (ERNs) for rare diseases with the aim to establish disease specific reference centres serving as hubs of knowledge and research.

Through treating patients at expert centres and transferring knowledge, patients from all member states will have access to subsequent treatment facilities where necessary. Disease-specific ERNs will help them make informed choices by providing clear information regarding access, quality, safety and reimbursement for treatments received in another EU country.

The foundation of the ERN PaedCan network was laid by the [ExPO-r-Net](#) [4] project (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment), that brought together more than 60 centres specialised in paediatric oncology clinical research, treatment and care.

In December 2016, the board of EU member states formally approved the resulting ERN PaedCan, which will officially kick-off 29-30 June in Brussels, Belgium.

This incredible result has been achievable thanks to the great team effort and the strong commitment of all ExPO-r-Net partners, who managed to consolidate the preconditions for this large multinational network.

By improving interoperability and implementing eHealth technologies that will facilitate their lives, this ERN concretely means more treatment options and less red tape for young patients and their families.

Cancer is a life-threatening disease, and there's a long way to go to overcome inequalities and ensure safer and good quality treatment across EU borders.

We are confident however that this ERN will facilitate the existing structures in their provision of highly specialised, accessible and cost-effective cross-border healthcare to all childhood cancer patients.

SIOPE and the paediatric haemato-oncology community stress their willingness to make this important initiative work in the long term, for a future where all children and adolescents with cancer can be cured.

About the author

Prof. Dr. Ruth Ladenstein is:

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- Project Coordination: the European Reference Network in Paediatric Cancer (ERN PaedCan) since

2017, the European Expert Paediatric Oncology Research Network for Diagnostics and Treatment (ExPO-r-NeT) 2014 – 2017, the European Network for Cancer Research in Children and Adolescence (ENCCA) 2011 – 2015 and the Austrian Medicine for Children Research Network OKIDS GmbH since 2012

- Board member SIOP EUROPE & former president from September 2009 – October 2012
- Advisory board member of the SIOP Europe Neuroblastoma Group since May 2011; former SIOPEN president from 2007 – 2011; Principle Coordinating Investigator of SIOPEN High Risk Neuroblastoma Trials since 2002
- Chair of the Austrian Group for Paediatric Haematology-Oncology & Member of Oncology Advisory Board of the Ministry of Health Austria since 2013

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