

European Reference Network on Paediatric Cancer (ERN PaedCan): Saving lives through access to quality care

Background

Paediatric Cancer is a major public health challenge. Each Year **6,000** children and young people die of cancer in Europe. However, the quality and availability of paediatric cancer treatment and care varies widely across Europe; 10%-20% of children die from curable forms of cancer where quality care is not accessible.



European Reference Network

for rare or low prevalence complex diseases



Network

Paediatric Cancer (ERN PaedCan)

Methods

By aiming to reduce inequalities of childhood cancer outcomes across Member States, **ERN PaedCan** enables access to up to date diagnostics and treatments by facilitating the exchange of expertise and knowledge by uniting the best specialists across Europe to tackle complex or rare paediatric cancer conditions that require highly specialized interventions and a concentration of knowledge and resources. ERN PaedCan interacts closely with SIOPE presenting one target of SIOPE's Strategic Plan. The coordination is run through Children's Cancer Research Institute in Vienna, Austria under the leadership of Prof. Ruth Ladenstein.

ERN PaedCan was inaugurated in Vilnius, March 9-10th, 2017 at the 3rd ERN Conference as one of 24 European Reference Networks

ERN PaedCan Kick-Off Meeting took place in Brussels, June 29th, 2017 in presence of five high level EU commissioners and an audience of about 100 engaged Paediatric Haemato-Oncologist

ERN PaedCan currently consists of 57 EU approved member hospitals with validated expertise in 18 countries, of whom 28% have a gross national income <90% of EU average

Results

Aiming at proportionate & appropriate Cross-Border Healthcare, the implementation of Virtual Tumour Boards using the Clinical Patient Management System (CPMS) as provided by the commission allows supporting patient care, diagnosis and treatment through virtual discussions including experts across Europe. Hence medical expertise and knowledge travels rather than patients. **ERN PaedCan** has started to create a European Childhood Cancer Roadmap planned as a guidance document for Health Care Providers to direct affected families to approved Hubs of Coordination with special Childhood Cancer expertise (reference diagnostics, highly specialized interventions) following CPMS advice. Already eight networks have been identified in a bottom up process. A special focus is on very rare tumours entities where case numbers are too low to consider a clinical trial setting and where combined registries are of vital importance to share knowledge and to create evidence. Through offering twinning structures (fellowships and educational programmes) to healthcare professionals in countries with lower resources, knowledge and capacity is being built.



Conclusions

The expected impact of **ERN PaedCan** is the increase of likelihood of early and accurate diagnosis and effective treatment supported by the development of guidelines. **ERN PaedCan** will help to increase childhood cancer survival and quality of life in the long term by fostering cooperation, research, training and knowledge sharing to end professional isolation, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities across Europe.

www.paedcan.ern-net.eu/



Co-funded by the Health Programme of the European Union



This poster was funded by the European Union's Health Programme (2014-2020)

Dissemination Management Team SIOPE Europe (SIOPE) www.siope.eu