



Rare Cancers in All Policies: A Rare Cancers Europe Call to Action

Prof. Carmelo Rizzari (SIOPE Europe President-Elect)

28.09.2021

For a Brighter Future for
Children & Adolescents with
Cancer

SIOP EUROPE – THE EUROPEAN SOCIETY FOR PAEDIATRIC ONCOLOGY

- Representing all professionals working in the field of childhood cancers in Europe
- More than 2,000 members across 35 countries
- Memorandum-based core partnerships with patients', parents', survivors' community in Europe (Childhood Cancer International – Europe & PanCare)
- Interlinked with the European Reference Network for Paediatric Oncology (ERN PaedCan)
- Long-term member of Rare Cancers Europe collaborating on areas of mutual interest



PAEDIATRIC CANCERS IN EUROPE: THE COMMUNITY



European Reference Network
for rare or low prevalence complex diseases

Network
Paediatric Cancer
(ERN PaedCan)

SIOPE Brain Tumour group	Brain Tumour	EpSSG (European Paediatric Soft Tissue Sarcoma Study Group)	Soft Tissue Sarcomas	Soft Tissue Sarcomas	CWS (Cooperative Soft Tissue Sarcoma Study Group)
Germ Cell Tumours	Germ Cell Tumours	Ewing's Tumour	EURO-E.W.I.N.G.	Very Rare Paediatric Tumours	EXPeRT (European Paediatric Cooperative Study Group on Paediatric Rare Tumours)
Histiocyte Society	Langerhans Cell Histiocytosis	Hodgkin's Lymphoma	EHL (European Hodgkin Consortium, EuroNet-PHL)	EURBG (European Retinoblastoma Group)	Retinoblastoma
SIOPEL (paediatric Liver Tumour Study Group)	Liver Tumours	Leukemias and Lymphomas	I-BFM (The International BFM Study Group)	Stem Cell Transplantation	EBMT (European Group for Bone Marrow and Stem Cell Transplantation Paediatric Working Party)
SIOPEL (paediatric Neuroblastoma Study Group)	Neuroblastoma	Myelodysplasia	EWOG-MDS	New Anticancer Agents	ITCC (Innovative Therapies for Children with Cancer)
EICNHL (European Inter-Group Cooperative in Childhood and Adolescent NHL)	Non-Hodgkin Lymphoma	Osteosarcoma	EURAMOS	PanCare	Survivorship and Late Effects
SIOPE-R (paediatric Renal Tumour Study Group)	Renal Tumours				

35 countries incl. most EU Member States



SIOPE Europe Clinical Research Council

Major Health and Socio-economic Burden

- First cause of death by disease in children older than 1 year
- 35,000 cases diagnosed annually
- More than 6,000 young patients die each year
- At least 60% of survivors experience adverse late-effects in adulthood
- Specific needs across the research and care continuum

PAEDIATRIC CANCERS IN EUROPE: THE UNMET NEEDS

Inequalities

- Unequal access to the best available multi-disciplinary care
- Up to 20% difference in children's survival rates across Europe



Lack of therapeutic innovation

- Most systemic treatment agents are old & originally developed for adults
- Only 9 new medicines in the last decade in contrast to over 150 for adult cancers
- Access to early phase clinical trials – a second chance at life – very limited



Under-served survivors

- 500,000 paediatric cancer survivors in Europe and growing
- Lack of organised surveillance of long-term side effects & follow-up care delivery



Vulnerable families

- Importance of parental involvement throughout the course of disease



Rare Cancer Agenda 2030 – Ten Recommendations from the EU Joint Action on Rare Cancers

“Paediatric cancers are rare cancers that often require specific approaches, in line with their distinct age-related biological, clinical and organisational characteristics.”

- “The multistakeholder-endorsed SIOPE Europe Strategic Plan – A European Cancer Plan for Children and Adolescents can serve as guidance for childhood cancer strategies at the national and European levels.”
- Need for “sustained public investments to address the unmet needs in the paediatric cancer sector, with reference to the objectives and implementation models defined by the scientific, clinical and patient community”
- “The regulatory environment for therapeutic innovation in childhood cancer, also in relation to the EU Paediatric Regulation and its implementation, should be significantly improved, even in the light of the global regulatory developments in this area.”

and more...

OPPORTUNITIES FOR PAEDIATRIC CANCERS ON THE EU AGENDA



Launched by European Commission
in February 2021

**Flagship initiative:
Helping Children with Cancer**



#EUPharmaStrategy



Launched by European
Commission in November 2020

**Revision of Paediatric &
Orphan Regulations**



Launched by Expert Advisory Board to
the Commission in September 2020
**Rec. 11 Cancers in children, adolescents,
young adults: cure more and cure better**

**Childhood cancer momentarily recognised in Europe's Beating Cancer Plan, the
Pharmaceutical Strategy for Europe and the Expert Advisory Board's Cancer Mission Report!**

SPECIFICITIES OF CHILDHOOD CANCERS AND COMMON AREAS SHARED WITH ADULT RARE CANCERS

Specificities of childhood cancers:

- Development early in life over a much shorter time period
- Biological specificities and distinct classification (ICCC 3)
- Heterogeneous patient populations with different needs (including children, adolescents and their families)
- To minimise the burden on families, the ERN PaedCan prioritises virtual tumour board consultations as opposed to travel, whenever possible
- Long-term organised sector at the European level

Common areas of interest with adult rare cancers:

- Advocating for the sustainability of the European Reference Networks
- Transitioning from paediatric to adult care
- Cancers in adolescents and young adults (AYA)
- Very rare tumours in children typical for adult tumour types

SIOPE Europe looks forward to continued collaboration with the rare adult cancer community!

Thank you for your attention!