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

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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

All European Clinical Trial Groups (ECTGs)

National Paediatric Haematology-Oncology Societies (NaPHOS) or paediatric oncology centres

35 countries incl. most EU Member States

SIOP Europe Clinical Research Council

www.siope.eu
PAEDIATRIC CANCERS IN EUROPE

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
SUCCESSFUL COLLABORATION WITH RARE CANCERS EUROPE ON THE EU POLICY AGENDA

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 SIOP 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...
Launched by European Commission in February 2021
Flagship initiative: Helping Children with Cancer

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 momentously 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

SIOP Europe looks forward to continued collaboration with the rare adult cancer community!
Thank you for your attention!