



For a Brighter Future for Children & Adolescents with Cancer



SIOP Europe
the European Society for Paediatric Oncology

Create a brighter future for children
and adolescents with cancer

International Childhood Cancer Awareness Day (ICCD 2019)

6 March 2019
15h00 – 17h00

European Parliament
Brussels, Belgium



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BEATING CHILDHOOD CANCER:

**CURE MORE AND CURE BETTER,
TOWARDS ZERO DEATHS & ZERO LATE EFFECTS**

**European Elections 2019 Manifesto
for the paediatric oncology and haematology
community**

PAEDIATRIC CANCER: STILL AN URGENT PROBLEM IN EUROPE

- **35,000 children and young people** diagnosed each year;
- **6,000 young patients die each year** : first cause of by disease
- **500,000 childhood cancer survivors** by 2020 – 2025: 2/3 with late effects
- **Little progress** in survival for difficult-to-treat paediatric malignancies but **major new avenues are opening**
- **Major inequalities** in access to the best available care, expertise and research : **20% differences in survival rate across Europe**

PAEDIATRIC CANCER ON THE EU PARLIAMENT AGENDA 2014 - 2019

- Host of annual **International Childhood Cancer Awareness Day event**
- Launch of the **SIOPE EU Strategic Cancer Plan**, Nov 2015
- European Parliament **Resolution on the Paediatric Regulation**, Dec 2016
- Support from the **MEPs Against Cancer (MAC) Group**
- Position paper calling for **the research budget for childhood cancer to be multiplied tenfold**

and many more actions of support

A BIG THANK YOU TO OUR CHAMPION MEPs!



LOOKING TOWARDS 2019 - 2024

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1. Accelerate therapeutic innovation for children with cancer and other life-threatening diseases



Action: MEPs to call for the necessary regulatory changes in reference to the European Parliament Resolution of Dec. 2016 and the latest evidence supplied by multi-stakeholder cooperative platforms on paediatric oncology drug development.

2. Foster allocation of resources to childhood cancer research with focus on big data and deep learning tools



Action: MEPs to call for the EU Programme for research and innovation to increase dedicated funding on childhood cancer research and enable stable and sustainable international research platforms, including for digital research

3. Sustainability of the European Reference Networks (ERNs), of which ERN PaedCan, to tackle inequalities



Action: MEPs to call for allocation of non-competitive funding to secure sustainability of the ERN model,

including **twinning**, EU Clinical Patient Management System (**CPMS**), cross-border **virtual advice**, **clinical guideline** development, and continued **parent/survivor involvement** in building/improving the ERN Network.

4. Appropriate surveillance guidelines and long-term models of care for survivors of childhood cancer



Action: MEPS to Call for EU support to collaborative approaches to further define, disseminate and enable:

- Standardised **surveillance guidelines**
- Organised **health care transition** (paediatric to adult)
- **Survivorship follow-up care plans** & inter-operable IT tools to apply them cross-border

5. interoperability, harmonisation and security of **eHealth** platforms to foster cross-border research and knowledge transfer



Action: MEPS to Support the vision on Digital Transformation of Health and Care in the Digital Single Market across its three priorities:

Citizens' **secure access to their health data**, including across borders, **precision medicine** through shared European data infrastructure and **citizen empowerment** with digital tools for user feedback and person-centred care.

6. Patient advocacy and empowerment in research, healthcare, and socio-economic areas.



Action: Support the vision of collaboration with all stakeholders on initiatives in research and healthcare by promoting patient, parent and survivor empowerment, with consideration for the socio-economic dimension.

THROUGHOUT:

**Proactively monitor EU legislative processes
to integrate
the health, research and socio-economic needs
of patients and the paediatric haematology
oncology community
into innovative new initiatives**



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WE COUNT ON YOUR SUPPORT

**Today 17:00 at European Parliament
(and later on: www.siope.eu/manifesto2019)**

WE INVITE YOU TO SIGN THE MANIFESTO!