

BEATING CHILDHOOD CANCER: CURE MORE AND CURE BETTER, TOWARDS ZERO DEATHS AND ZERO LATE EFFECTS

European Elections 2019 Manifesto for the
paediatric oncology and haematology community





PAEDIATRIC CANCER IN THE EU POLICY AGENDA

During its 2014-2019 mandate, the European Parliament provided resolute support to the paediatric oncology and haematology community. Milestones include:

- Launch of the SIOP Europe Strategic Plan – A European Cancer Plan for Children and Adolescents in cooperation with the MEPs Against Cancer Group (MAC), November 2015
- European Parliament vote on the resolution regarding the Paediatric Regulation, December 2016
- Celebration of 20 years of action towards a brighter future for children and adolescents with cancer at a special event in cooperation with the MEPs Against Cancer Group (MAC), September 2018
- Expression of continuous commitment and support from our champion MEPs at the annual International Childhood Cancer Awareness Day event at the European Parliament



We would like to invite the next European Parliament to sustain and reinforce its support of the paediatric cancer cause.

STILL AN URGENT PROBLEM IN EUROPE

Paediatric cancer remains a major public health and societal issue in Europe:

- Each year more than **35,000¹** children and young people are diagnosed with cancer;
- **More than 6,000²** young patients die of cancer each year, and cancer remains the first cause of death by disease in Europe in children older than 1 year;
- There will be **nearly half a million childhood cancer survivors by 2020 – 2025³**
- **Over two-thirds of childhood cancer survivors experience long-term health and psychosocial problems due to their disease and treatment** which may be severe and affect their daily life and participation as EU citizens;
- While improvements have been achieved for some childhood cancers over the past years, there has been **little progress in patient survival for difficult-to-treat paediatric malignancies**, and too many young lives are still lost to the disease;
- **There are substantial inequalities in access to the best available care and expertise across Europe causing up to 20%⁴ differences in survival rates among European countries.**

YOUR COMMITMENT AND SUPPORT

The rarity of individual paediatric cancer types and their high collective health burden across Europe make coordinated EU level approaches crucial. By signing this manifesto, I declare my awareness and willingness to support the paediatric oncology and haematology community in Europe in fighting childhood cancer.

Together with the **European Society for Paediatric Oncology (SIOP Europe)**, the only pan-European organisation representing all professionals working in the field of childhood cancers and **Childhood Cancer International - Europe (CCI - Europe)** representing parents, patients and survivors, I will contribute towards ensuring that the paediatric oncology and haematology community is heard and will actively work for the achievement of more and better cures for childhood cancer in line with the following objectives.



BEATING CHILDHOOD CANCER: CURE MORE AND CURE BETTER, TOWARDS ZERO DEATHS AND ZERO LATE EFFECTS

OBJECTIVES FOR THE EUROPEAN PARLIAMENT TERM 2019 – 2024



1. Advance an enabling legislative environment for faster and more efficient development of affordable innovative medicines for children with cancer and other life-threatening diseases

Lack of therapeutic innovation is a principal reason behind the failure to improve the cure rates of difficult-to-treat childhood cancers and continues to result in adverse long-term side effects of treatment in survivors. The EU Paediatric⁵ and Orphan Regulations⁶ have not proven effective in boosting the development of novel anti-cancer drugs for children.

The evaluation of the few new anti-cancer medicines on the market still follows the same process for children as it does for adults. The European Parliament voted on a resolution on the EU Paediatric Regulation in December 2016⁷. As of 2019, the European Commission will consider a course of action based on the evaluation of

the Paediatric and Orphan Regulations as well as the incentive mechanisms currently in place.

ACTION

MEPs to call for the necessary regulatory changes in reference to the European Parliament Resolution of December 2016 and the latest evidence supplied by multi-stakeholder cooperative platforms on paediatric oncology drug development⁸.



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

The vast majority of innovative therapies in paediatric oncology have been developed in cross-border academic-driven research. In the face of rapid developments in immunotherapy and precision medicine, the focus is increasingly on big data. Improving researchers' access to and the sharing of biological, pathological and clinical data becomes urgent to foster further therapeutic innovation for childhood cancer.

Public funding is needed to generate, make available and enable the analysis of big data in paediatric oncology, such as by using artificial intelligence.

ACTION

MEPs to call for the EU Programme for research and innovation to enable stable and sustainable international research platforms, including for digital research, which can lead to a visionary change for children and adolescents with cancer and contribute to significant knowledge advancement in basic science.



3. Ensure sustainability of the European Reference Networks (ERNs), of which ERN PaedCan is dedicated to paediatric cancer, in particular to combat inequalities in access to the best available treatment and expertise for children across Europe

The quality and availability of paediatric cancer care varies across Europe: an estimated 10% to 20% of cancer-related deaths occur due to lack of access to the specialist care or expertise that children with cancer require. Stemming from the EU Cross-Border Healthcare Directive, the European Reference Network for Paediatric Oncology (ERN PaedCan) has been established to reduce inequalities in childhood cancer survival by providing high-quality, accessible and cost-effective cross-border healthcare.

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. Support collaborative efforts on the development and implementation of appropriate surveillance guidelines and long-term models of care for survivors of childhood cancer

There are currently approximately 300,000 - 500,000 long-term survivors of childhood cancer in Europe and this number increases over time. At least two-thirds of this population experience long-term physical and mental health problems as well as psychosocial difficulties that hinder their well-being and participation in society and the economy. The relative rarity of individual paediatric cancer types and their associated long-term side effects magnifies the critical importance of the European dimension to enable a smooth transition for childhood cancer survivors into a productive and healthier adulthood.

ACTION

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

- Standardised surveillance guidelines for late-occurring side effects of childhood cancers
- Organised health care transition (paediatric to adult) as a standard of care across Europe
- Survivorship follow-up care plans & interoperable IT tools to apply them cross-border



5. Support initiatives on interoperability, harmonisation and security of eHealth platforms to foster cross-border research and knowledge transfer for the benefit of childhood cancer patients and survivors

Fostering interconnection in Europe is the only way to arrive at a sustainable base for future joint data analysis and research in childhood cancers as well as to enable the travel of expertise to all parts of Europe. Many areas of health ICT innovation require greater capacity – both trained workforce and analytical platforms. Successful approaches are about taking into account all perspectives via a reinforced collaboration among stakeholders in order to successfully balance individual data privacy and the need for progress in research and care.

ACTION

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. Support initiatives that foster and promote patient advocacy and empowerment in research, healthcare, and socio-economic areas

Patient, parent and survivor empowerment should go hand in hand with actions to improve cooperation on research and healthcare across Europe. For this, patient advocates should be encouraged to participate in these initiatives and helped to acquire the tools and skills to become educated and informed. Patient empowerment also calls for socio-economic provisions such as extended paid leave for parents when taking care of a sick child and equal rights in access to financial services for survivors of childhood cancer.

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.



There are currently 300,000 - 500,000 long-term survivors of childhood cancer in Europe and this number increases over time.

THROUGHOUT

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

Individual types of cancer in children and adolescents are rare, but taken together they represent a leading public health and socio-economic issue in Europe. Patients and affected families stand to gain considerably from pan-European cooperation on research and healthcare as a result of the disease's rarity at the national level combined with its important shared burden across Europe. Ensuring equal rights and adequate social protection for parents, patients and survivors is an important underlying priority.

THE EUROPEAN PAEDIATRIC ONCOLOGY COMMUNITY COUNTS ON YOU TO BEAT CHILDHOOD CANCER AND ACHIEVE MORE AND BETTER CURES, TOWARDS ZERO DEATHS & ZERO LATE EFFECTS



1 Globocan 2018 (<http://gco.iarc.fr>)

2 idem source i

3 Hjorth, L, Haupt L, Skinner R, et al. Survivorship after childhood cancer: PanCare: A European Network to promote optimal long-term care. *European Journal of Cancer* 2015, Volume 51, Issue 10, 1203 – 1211 <https://www.sciencedirect.com/science/article/pii/S0959804915003068>

4 Gatta G, Botta L, Rossi S, et al. EURO CARE Working Group. Childhood cancer survival in Europe 1999-2007: results of EURO CARE-5--a population-based study. *Lancet Oncol.* 2014 Jan;15(1):35-47. Erratum in: *Lancet Oncol.* 2014 Feb;15(2): e52 [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70548-5/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70548-5/fulltext)

5 Position statement: Paediatric Cancer Medicines - Urgent need to speed up life-saving innovation: https://www.siope.eu/wp-content/uploads/2013/06/1.-Paediatric_Reg_Position_paper.pdf

6 Vassal, Gilles et al. Orphan Drug Regulation: A missed opportunity for children and adolescents with cancer, *European Journal of Cancer* , Volume 84 , 149 – 158

7 European Parliament resolution of 15 December 2016 on the regulation on paediatric medicines (2016/2902(RSP))

8 ACCELERATE Platform: <https://www.accelerate-platform.eu>. Vassal Gilles et al. Creating a unique, multi-stakeholder Paediatric Oncology Platform to improve drug development for children and adolescents with cancer. *Eur J Cancer.* 2015 Jan; 51: 218-224. <https://www.ejccancer.com/article/S0959-8049%2814%2901065-X/fulltext?code=ejc-site>

ABOUT SIOP EUROPE



The European Society for Paediatric Oncology (SIOP Europe or SIOPE) is the only pan-European organisation representing all professionals working in the field of childhood cancers. With more than 1,850 members across 35 countries, SIOP Europe is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe. The SIOPE Strategic Plan 'A European Cancer Plan for Children and Adolescents' includes specific objectives and implementation platforms to achieve this mission.

ABOUT CHILDHOOD CANCER INTERNATIONAL – EUROPE



Childhood Cancer International - Europe (CCI-E) represents childhood cancer parents' and survivors' groups as well as other childhood cancer organisations in Europe. More precisely, 67 organisations in 33 European countries are members of CCI. CCI Europe works together with all relevant stakeholders for the same aim, namely to help children and adolescents with cancer to be cured, with no - or as few as possible - long term health problems/late effects.

CONTACT DETAILS

SIOP Europe

c/o BLSI
Clos Chapelle-aux-Champs 30, Bte 1.30.30
1200 Brussels, Belgium
www.siope.eu
office@siope.eu
Tel: +32 2 880 62 82
Twitter: @SIOPEurope

CCI Europe

c/o Österreichische Kinder-Krebs-Hilfe
(ÖKKH)
Borschkegasse 1/7
1090 Vienna, Austria
www.childhoodcancerinternational.org/cci-global-network/europe
europe@cci.care
Tel: +43 1 402 88 99 – 15
Twitter: @CCI_Europe