

European Elections 2024 Manifesto

for the paediatric
oncology & haematology
community



Beating childhood cancer

Cure more, cure better and tackle inequalities



Introduction

Every year in Europe, **35,000 children and young people are diagnosed with cancer**, a rare life-threatening disease. Paediatric cancer is the first cause of death by disease for children older than 1 year in Europe. All paediatric cancers are rare and require dedicated approaches across the patient journey to **increase cure rates, improve quality of care** and **eradicate inequalities** in access to high quality research and care. Over the past five years, the EU introduced crucial initiatives for childhood cancer, such as the [Europe's Beating Cancer Plan](#) and the [EU Cancer Mission](#), highlighting the political commitment to take action. Continued support and momentum are required, thus SIOPEurope (SIOPE) and CCI Europe (CCI-E) have been working closely together to achieve the following priorities:





SAVE MORE LIVES THANKS TO BETTER TREATMENTS

Childhood cancer constitutes the leading cause of children's death by disease over the age of one in Europe, with **6,000 lives lost annually**. Although 5-year survival rates are now up to 80%¹ with improvements in 10-year survival rates also reported², there are prevailing issues in the pace of development of treatments for paediatric cancers³.



SUPPORT THE RECOVERY OF CHILDREN AND ADOLESCENTS AFTER THEIR TREATMENT

While there are an estimated **500,000 childhood cancer survivors in Europe today**, with numbers growing substantially each year, **at least two-thirds of them experience long-term adverse side-effects into adulthood**⁴. These post treatment complications often necessitate life-long follow-up care and hinder equal participation in the economy and society. Adequate and continued psychosocial and medical support to improve the quality of survivorship are of paramount importance.



ERADICATE INEQUALITIES AMONG CHILDREN AND ADOLESCENTS WITH CANCER

Inequalities in access to treatment, care and research protocols across Europe contribute to an **estimated 20% gap in childhood cancer survival rates, with Eastern European countries facing challenges**¹. Action is needed to reduce inequalities in access to high quality care and research for all children and adolescents with cancer across Europe, incorporating a patient-centred approach throughout.



Become a champion for children with cancer:

How can you help us?

As incoming Members of the European Parliament, you can have a pivotal role in championing the needs of children and adolescents with cancer, through your impact on legislative and policy initiatives that make a difference for young patients, survivors and their families across Europe.



LEGISLATIVE ACTION

Children and adolescents with cancer in Europe require a medicine development strategy that will support and accelerate innovation, put their unmet medical needs at the centre, and eliminate inequalities in accessing the best available medicines. Also, a legislation that enables cross-border scientific collaboration using health data, both for research and care delivery purposes, is of vital importance.

Support a swift adoption of the EU Pharmaceutical legislation, which takes into account the needs of children with cancer

The previous legislation on paediatric and orphan medicines did not succeed to address the unmet needs of children and adolescents with cancer ³. As the development of high-quality, innovative products is vital for childhood cancer patients, we wish to ensure a swift adoption of the EU Pharmaceutical legislation. As the negotiations continue, your leading support is needed for these key topics:

- **Better medicines for children: Finding treatments that are less toxic.** Better medicines are medicines that are suitable for children, meaning not only treatments which improve cure rates but also that are designed specifically for the paediatric population to be less toxic, so that acute and/or long-term side effects are minimised, and children are restored to their full health after treatment.
- **Incentivising the development of specific paediatric cancer drugs ("first in child").** The complexities associated with paediatric

cancers, such as their rarity, challenges in designing clinical trials and the heterogeneity of the patient population, have resulted in limited market-driven development of medicines in this disease area. To increase commercial interest and contribute to cutting edge paediatric cancer medicine, incentives for “*first-in-child*” innovation should be supported.

- **Access to medicines: Reducing inequalities amongst Member States and preventing shortages.** Shortages and unequal access to essential anticancer medicines for children and adolescents unfortunately are a common reality for our Community⁵, and pose dangers in terms of treatment and survival for patients.

The proposals by the European Commission to improve equal access to medicines should be supported. Specifically, pharmaceutical companies should be incentivised to launch their new medicines in all Member States within comparable timeframes to ensure equality among European patients. Additionally, development and accessibility of Advanced Therapeutic Medical Products (ATMPs) in all paediatric malignancies, requires EU regulatory support.

Besides this, it is vital that each childhood cancer patient has a timely access to authorised medicinal products as postponement of treatment may have devastating effects. We believe a coordinated EU approach is needed to ensure safe and secure supply of medicines for children, including tackling medicine shortages across Europe.

As an MEP you can support us by:

- ✓ Including the reduction of acute or long-term toxicity in the definition of unmet and high unmet medical needs (high UMN).
- ✓ Advocating for incentives targeting the development of paediatric and orphan medicines, meaning that the first authorised indication should address a high UMN in a paediatric population.
- ✓ Supporting the proposal by the European Commission to improve equal access to medicines, incentivising pharmaceutical companies to launch new medicines in a timely manner across all Member States.
- ✓ Ensuring that the legislative initiatives and actions proposed by the European Commission to address medicine shortages are adopted without delay, namely a potential Critical Medicines Act.

Unleashing the potential of big data, guided by an efficient regulatory framework which enables the sharing of cross-border healthcare data

Our Community has previously outlined how health and/or research data sharing had become more difficult since the GDPR's entry into force⁶. A robust EU regulatory framework through the European Health Data Space (EHDS) is eagerly awaited to unlock greater opportunities for research and care delivery, to empower individual patients in the use of their data, and to enable trustworthy and seamless transfer of health research data.

Big data and Artificial Intelligence (AI) hold great potential to unlock new frontiers in paediatric cancer care and research. The UNICA4EU project, which has mapped the existing AI applications for childhood cancer, together with the UNCAN.eu project, which aims at improving our understanding of cancer including its causes, provide a strong foundation to firmly position the EU as a global leader in patient-centred data-driven interventions for childhood cancer. Coordinated EU data initiatives in paediatric oncology could bolster the potential of big data, particularly if partnered with the US National Childhood Cancer Data Initiative.

As an MEP you can support us by:

- ✓ Ensuring a swift adoption of EHDS and its implementation to ensure the safe collection of large amounts of data, and to enable seamless cross-border data sharing for research and care delivery in paediatric oncology.
- ✓ Calling on the European Commission to ensure continuity of childhood cancer AI and big data projects such as UNCAN.eu and UNICA4EU by consolidating their findings and orientations in a major new initiative on European Childhood Cancer Data.





HARNESSING THE EU BUDGET

There is a strong need to accelerate the childhood-cancer specific research and innovation capabilities across Europe with focus on areas of urgent unmet medical or insufficient research effort.

A prosperous budget that boosts research and development, and ensures continuity of EU health programmes

Dedicated EU public funding for research and innovation, based on a holistic mapping of unmet medical needs in childhood cancer, is needed to further complement the paediatric research landscape. Public investment into specific childhood cancer interventions, through EU4Health, Horizon Europe and the Digital Europe Programmes have been of an inestimable value for our community. Funding and tenders in the realm of research and innovation, mental health and challenges around survivorship are crucial for the childhood cancer community. Thanks to generous EU budget programmes targeting childhood cancer, we can foster innovation, share knowledge and connect among all the stakeholders in this field, having a direct positive impact on treatments and well-being of childhood cancer patients, survivors and their families.

In the period 2021-2027, the EU4Health budget increased considerably, and alongside Horizon Europe, is funding the EU's notable political commitments in tackling cancer: namely Europe's Beating Cancer Plan and the EU Cancer Mission. Thanks to this support, highly valuable initiatives and projects in the field of childhood cancer are underway to better to understand cancer, optimise diagnosis and treatment, and improve childhood cancer patients' quality of life. The momentum created by these programmes must be sustained to eradicate barriers and inequalities in access to research and care across Europe.

As an MEP you can support us by:

- ✓ Ensuring childhood cancer remains at the forefront of EU budgetary efforts, including in the upcoming Multiannual Financial Framework (2028-2034).
 - Build on existing investments to boost research and development of innovative therapies and diagnostics for children and adolescents with cancer, and support dedicated paediatric cancer care and treatment approaches.

Long-term support for Mental health, Psychosocial care, and Survivorship initiatives

Cancer diagnosis can have a psychosocial impact on the patient, both throughout treatment and beyond. Indeed, two-thirds of childhood and adolescent cancer survivors are confronted with adverse late effects of their cancer and its treatment, all of which affect their mental health.

The Europe Beating Cancer Plan placed a much-needed spotlight on these issues through the launch of various initiatives aimed at improving survivorship, which should be maintained in the long-term.

As an MEP you can support us by:

- ✓ Ensuring continued investment in psychosocial support and survivorship initiatives when negotiating the Multiannual Financial Framework (2028-2034).
 - Call on the European Commission to continue the Europe's Beating Cancer Plan and EU Cancer Mission funding commitments in mental health, psychosocial care and survivorship initiatives for young cancer patients, such as "[EU Network of Youth Cancer Survivors](#)" (EU-CAYAS-NET) and "[Cancer Survivor Smart Card](#)".





BECOMING A CHILDHOOD CANCER ADVOCATE

Spreading awareness of the Childhood Cancer Community's needs and priorities, and continuing the battle to tackle inequalities in research and care requires your ongoing support. You can become a champion for our cause through advocating for areas of interest for not of young patients.

Calling for dedicated paediatric cancer care and research approaches across the EU

There is a strong need to reduce inequalities in access to high quality care and standard treatment and to accelerate the childhood-cancer specific research and innovation capabilities across the EU. As the needs of children and adolescents with cancer cannot be addressed by adult comprehensive cancer centres, the creation of infrastructures specific to paediatric cancers requires urgent support. Also, the accreditation of centres treating childhood cancers and the sustainability of the European Reference Network on Paediatric Cancer (ERN PaedCan) necessitate coordinated approaches.

As an MEP you can support us by:

- ✓ **Calling for recognition of dedicated initiatives to strengthen integrated childhood cancer care and research, namely:**
 - The creation of Comprehensive Paediatric Cancer Infrastructures*, and the amplification of a paediatric cancer twinning programme**.
 - Enhancing the sustainability of existing cross-border collaborations in paediatric cancer, in particular the ERN PaedCan, and greater clarity on access to cross-border clinical trials.
 - Supporting the concept of accreditation of centres delivering childhood cancer care, building on existing EU instruments such as the ERN PaedCan accreditation, to be co-developed by policy makers in consultation/collaboration with health professionals and patient groups.
 - Supporting the European childhood cancer networks that run the clinical trials necessary to improve survival and reduce long-term toxicity. These networks are also necessary to overcome inequities by making standard of care treatments available in all member states. These networks are investigator/professional-driven and involve participation of patient/parent/survivors.

* **Comprehensive Paediatric Cancer Infrastructures** – Currently, the [Europe's Beating Cancer Plan](#) aims to establish an EU Network of Comprehensive Cancer Centres. However, this initiative **cannot address the paediatric cancer care and research needs** as the EU organisation of care and research in paediatric cancers is different from that in adult cancers. **Therefore, specific Comprehensive Paediatric Cancer Infrastructures should be established, adequately resourced and integrated in the overarching European paediatric cancer network – the ERN PaedCan.**

These infrastructures would recognise the crucial differences in the organisation of care and research of paediatric and adult cancer patients and accelerate the EU cancer research and innovation agenda for children and adolescents. They would collaborate with all centres of the ERN PaedCan and with the EU Network of Comprehensive Cancer Centres for adult cancer patients.

** **Twinning programmes** – The pilot twinning projects in paediatric oncology between centres from widening countries and high reference centres have demonstrated the value of twinning for reducing inequalities. These projects include education activities, sharing practices and improving access to expertise including online platforms to transfer expertise and exchange of professionals on site for training. The goal is to amplify the paediatric cancer twinning programme as a major EU initiative to reduce inequalities in access to high quality care and innovation.



Promote the need for European wide Standards of Care

Accelerating guidelines on standards of care for children and adolescents with cancer across Europe is an ongoing aim of our Community. To support this, we recommend the implementation of the European Standards of Care for Children with Cancer, recently updated through the ESCALIER project.

As an MEP you can support us by:

- ✓ Promoting the endorsement and implementation by Member States of the European Standards of Care for Children with Cancer; already developed by CCI-E and SIOPE, for instance, through policy events at the European Parliament or other advocacy tools.

Shedding light on the cause and risk factors for childhood cancer

There are no known modifiable risk factors for most childhood cancers to date but genetic prescription is known to have a role ⁷. Understanding the causes of childhood cancer, including research on the genetic causes of paediatric cancers is a priority. In addition, addressing environmental risk factors through innovative research methods could shed light on effective prevention and/or early detection strategies.

As an MEP you can support us by:

- ✓ Building on the European Commission initiatives on environmental determinants of childhood cancer in the framework of Europe's Beating Cancer Plan and the EU Cancer Mission, maintain visibility of this topic and stimulate further debate with the European institutions, patients and academia to inform meaningful EU research investment into the causes of childhood cancer.
- ✓ Support access to genetic testing and implementation of genetic counselling for all children and adolescents in Europe. DNA sequencing for all newly diagnosed children and molecular profiling of tumours across Europe would provide opportunities for enhanced understanding of childhood cancers.



Your Endorsement is Key

The period 2024-2029 is **THE** chance to make ongoing European Union initiatives come together and progress in an integrated childhood cancer-specific programme that will **save lives, improve the quality of survival, and eradicate inequalities**. As incoming Members of the European Parliament, you will have a pivotal role in furthering life-changing progress in childhood cancer.

We kindly ask that you endorse this manifesto and support us in our ongoing mission to ensure the best possible care and outcome for all children and adolescents with cancer in Europe.

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About SIOPE and CCI-E



The **European Society for Paediatric Oncology (SIOPE, or SIOPE Europe)** is the single united European organisation representing all professionals working in the field of childhood cancers. With more than 2,500 members across 35 countries, SIOPE Europe is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe.

www.siope.eu



Childhood Cancer International - Europe (CCI-E, or CCI Europe) represents childhood cancer parent and survivor groups as well as other childhood cancer organisations in Europe: more than 65 organisations in 34 European countries are members of CCI-E. CCI Europe works together with all relevant stakeholders for the same goal: help children and adolescents with cancer to be cured, with no - or as few as possible - long-term health problems/late effects.

www.ccieurope.eu

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