

Collaboration is key in tackling childhood cancer

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SIOPEAC continues to address the urgent needs of children and adolescents with cancer, explains Martin Schrappe.



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Paediatric cancer is a rare disease that comes in multiple subtypes and is both life threatening and a major public health issue.

Annually, across Europe, more than 35,000 children and adolescents are diagnosed with cancer and each year, 6000 children and young people die from Paediatric cancer.

Despite improvements in cure rates over the last two decades, childhood cancer remains the leading cause of death in children aged one or over in Europe. Additionally, childhood cancer survivors often face long-term side effects that negatively affect their quality of life and participation in society.

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Among the factors that define the policy and regulatory priorities for the paediatric cancer sector are the rarity of individual paediatric cancer types, their dissimilarity from adult cancers, and their high collective health burden across Europe.

Cross-border collaborative research is therefore vital in overcoming small sample sizes at national level and in fostering scientific advancement towards more and better cures.

The development of innovative therapies for children with cancer requires urgency since the medicines currently available are often decades old, leading to deteriorating cure rates and long-term complications.

Another important issue is cross-border access to the right expertise in ensuring optimal treatment and follow up and in addressing inequalities in survival rates.

Since 1998, the European Society for Paediatric Oncology (SIOP Europe or SIOPE) has been active across Europe, working closely with parents, patients and survivors on influencing legislation and taking part in European-funded projects.

In the process, we have formulated together with our community and are currently implementing the SIOPE Strategic Plan with the goal of increasing cure rates and quality of cure for children and adolescents by the year 2025.

"Annually, across Europe, more than 35,000 children and adolescents are diagnosed with cancer and each year, 6000 children and young people die from Paediatric cancer"

Coordinated funding for clinical trial activities across borders is a key challenge. A former EU-funded project – ENCCA (European Network for Cancer Research in Children and Adolescents) – resulted in the SIOPE Clinical Research Council bringing together all European clinical trial groups and national societies for paediatric haemato-oncology.

Continuity is instrumental in building on the results achieved and SIOPE has advocated that the next EU Research and Innovation Framework Programme further supports stable and sustainable clinical trial platforms and international collaborations for paediatric haematology and oncology.

In addition, SIOPE is closely monitoring the process leading up to the implementation of the EU Clinical Trials Regulation and has contributed to the legislative process.

Boosting access to innovative therapies for childhood cancer is vital. In 2007, the EU Paediatric Medicines Regulation was launched with the aim of meeting the specific therapeutic needs of children with better evaluated and authorised medicines.

However, whereas the adult cancer sector has seen a flurry of innovation over the past years, only very few new cancer medicines have been authorised for children since 2007.

SIOPEX Europe together with our partners from the parents and patients' community are working together with all stakeholders, including industry and regulatory agencies in the ACCELERATE platform.

"Poor diagnosis and treatment of childhood cancer is still a reality for certain cancer types and countries, with serious disparities in access to standards of care and specialised interventions across Europe"

ACCELERATE aims to improve implementation of the EU paediatric medicines regulation and continue to advocate a series of targeted changes to accelerate the development of medicines for paediatric cancers.

Specific proposals include running the paediatric strategy forums - jointly coordinated by the ACCELERATE platform and the European Medicines Agency (EMA) - in order to share information and advance learning in a pre-competitive setting, breaking the 18-years age restriction for participation in clinical trials, FDA and EMA alignment, earlier submission of paediatric investigation plans, and implementing development plans based on paediatric tumour biology and drugs' mechanism of action.

Poor diagnosis and treatment of childhood cancer is still a reality for certain cancer types and countries, with serious disparities in access to standards of care and specialised interventions across Europe.

The EU Directive on Cross-Border Healthcare prompted the development of the European Reference Networks (ERNs), one of which is fully dedicated to childhood cancers (ERN PaedCan).

This network has been instrumental in furthering the paediatric cancer agenda, making it possible to share expertise across Europe, thereby facilitating the lives of both healthcare providers and patients whose conditions require specialist expertise and tools not widely available due to low case volumes or lack of resources.

As the EU Commissioner for Health and Food Safety, Vytenis Andriukaitis has said, "no country alone has the knowledge and capacity to treat all rare and complex conditions".

"It is increasingly important that we put in place mutually agreed guidelines on the surveillance of childhood cancer survivors and their appropriate models of care"

ERN PaedCan aims to increase childhood cancer survival and quality of life in the long term by fostering cooperation and training, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities across EU Member States.

Sustainability of this new mechanism is vital in ensuring equal access to the best knowledge for all

children and young people with cancer, no matter where they live in Europe.

Another area that calls for policy makers' attention is childhood cancer survivorship. The population of childhood cancer survivors in Europe is growing and they are often faced with distinct and severe chronic health challenges throughout their lives.

It is increasingly important that we put in place mutually agreed guidelines on the surveillance of childhood cancer survivors and their appropriate models of care.

It is also clear that multidisciplinary collaboration in therapeutic research makes improvements in outcomes possible and SIOPE will continue to further dialogue and cooperation with EU stakeholders to address the urgent needs of children and adolescents with cancer.

Progress is only possible through joint efforts and an enabling legislative and regulatory environment that facilitates cross-border approaches and targets the priority areas identified jointly by professionals, parents, patients, and survivors.

The importance of collaboration between all relevant stakeholders in developing paediatric cancer therapies cannot be stated enough.

About the author

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