

SIOPE Press Release

Brussels, 19th November 2015



What can Europe and what can we all do to save more children's lives? The European Society for Paediatric Oncology ([SIOPE](#)) yesterday launched the [European Cancer Plan for Children and Adolescents](#) to answer this question. The event was kindly hosted by the President of the [Members of the European Parliament Against Cancer \(MAC\)](#) MEP Alojz Peterle (SL) and co-organised by SIOPE and the MAC Group. More than 6,000 European children die from cancer every year, and the majority of survivors experience adverse late-effects: *'this is unacceptable'* was the message expressed by more than 120 event participants, who said out loud that **childhood cancer should always be a priority for the European Union..**

In the framework of the EU FP7 project [ENCCA](#), paediatric oncology professionals committed to finding long-term sustainable solutions to increase the cure rate of childhood cancer and improve survivorship. This [Strategic Plan](#) was therefore defined by the paediatric cancer community through extensive consultation and the prominent role of parents, patients and survivors. SIOPE President-Elect Martin Schrappe (DE) and President Gilles Vassal (FR) introduced the document, which addresses each the following objectives by identifying **key areas where joint efforts are needed**: 1. Safe and effective *innovative treatments* in standard care; 2. *Precision cancer medicine* to guide therapeutic decisions; 3. Better knowledge of *tumour biology*; 4. *Equal access* to standard care and research; 5. Addressing specific needs of *teenagers and young adults (TYA)*; 6. Better *quality of long-term survivorship*; 7. Increased understanding of the *causes of paediatric cancers*. Prof Vassal highlighted the importance of collaboration in specific areas – such as clinical trials and drug development – via the dedicated platforms, programmes and partnerships detailed in the document.

The event at the European Parliament focused on 3 crucial areas:

1. **Inequalities: Eradicating inequalities in access to treatment, care, and expertise**

Access to quality healthcare is a citizen's basic right, but a child with cancer in Eastern Europe is 10-20% less likely to survive than one in richer Member States, as [standards of care](#) are not equally applied. Parent advocate Irina Ban (RS) explained that paediatric cancers are often ignored in national cancer plans and registries – if they exist – and patients' families often face serious economic problems when opting for better treatment abroad. She thanked SIOPE and the parent's network [CCI Europe](#) for their initiatives to provide access to better treatment options in Europe; one, [ExPO-r-Net](#), was illustrated by its coordinator Prof Ruth Ladenstein (AT). This DG SANTE project aims to make high-quality healthcare accessible to all European children and adolescents, no matter where they live. ExPO-r-Net will build a paediatric oncology European Reference Network (ERN) of healthcare centres with resources for specific malignancies, and will identify the best way for patients' families to access this expertise.

2. **Innovation: Boosting innovation in medicine development**

Targeted and innovative drugs are increasingly used in adult cancers, but such development for children is very slow. Significant changes are desperately needed: parent advocate Patricia Blanc (FR) and Prof Pamela Kearns (UK) observed that, although the EU Paediatric Regulation helped in speeding up paediatric drug development, it was still mainly driven by the adult cancer "market" and, if there's no adult indication, a drug will not be developed – as not profitable. In spite of recent EMA initiatives, meaningful incentives are still needed to drive paediatric oncology drug development, as it is already the case in the US. The SIOPE-CDDF-ITCC Paediatric Platform was created to address these bottlenecks by intensifying multi-stakeholder cooperation and making concrete proposals to change the current Regulation. Ms Blanc is co-founder of the parent-led network [Unite2Cure](#), currently calling for better access to treatment.

3. **Survivorship: securing optimal follow up for survivors**

In 2020 there will be 500,000 childhood cancer survivors in Europe. The majority will experience specific side-effects as adults – e.g. infertility and heart failure. Jaap den Hartogh (NL), a childhood cancer survivor, currently working in a Dutch parent organization, affirmed the need to increase research on late effects and improve survivors' long-term follow up and transition to adulthood. Childhood cancer survivors note that GPs are often unaware of the potential risk of late effects from childhood cancer treatment. Riccardo Haupt (IT) illustrated the 'Survivorship Passport', a tool developed via three EU projects ([ENCCA](#), [ExPO-r-Net](#) and [PanCareSurFup](#)) which provides instant access to the medical history of patients treated for cancer, and includes guidelines for survivors, a mobile application and a website.

The joint commitment of stakeholders to support the implementation of the SIOPE Strategic Plan was the main outcome

of this meeting. Participants and panellists re-affirmed the importance of considering the specificities of paediatric cancer in all European initiatives. Some underlined the risks of applying the “lowest common denominator” to expected changes, and the need for wider enabling of EU initiatives: although ‘Europe is moved by the force of ideas’, adequate funding and partnership with policymakers are key to producing the life-changing solutions proposed. Our children’s lives depend on how SIOPE’s demands will be met in the future.

More information:

- [The SIOPE European Cancer Plan for Children and Adolescents](#)
- [Event Webpage](#)
- [Event Video](#)
- [Event Pictures](#)

Did you miss this event? Don’t miss our [International Childhood Cancer Awareness Day](#) event next **27th January 2016 (16:00 – 18:00)**, kindly hosted by MEP Ms Glenis Willmott (UK) at the European Parliament in Brussels, Belgium. This next meeting will address the development of paediatric cancer medicines.

CONTACTS:

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EVENT INFORMATION:

[SIOPE – MAC Launch: European Cancer Plan for Children and Adolescents](#)

Hosted by MEP Mr Alojz Peterle, MAC President

Wednesday 18th November 2015 (12:30 – 14:30, starting with a networking lunch at 12:00)

European Parliament (Room JAN 6Q2), Brussels, Belgium

PROGRAMME:

Available [here](#) (presentations, video and pictures downloadable on the same page)

TWITTER:

#SIOPEstrategicPlan @SIOPEurope @MAC_MEPs

About SIOPE

The European Society for Paediatric Oncology represents more than 1,500 professional members across 31 European countries. SIOPE is the leading organisation in Europe fighting to ensure that children with cancer receive the best possible treatment and go on to live full and meaningful lives.

Learn more: www.siope.eu.



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