



## SIOPE Press Release

Brussels, 28<sup>th</sup> January 2016

A **call for concrete action** to improve the availability of effective innovative cancer medicines for children and adolescents with cancer was launched at the event '[Development of Paediatric Cancer Medicines - Speeding up Innovation, Saving Lives](#)'. Although cancer remains the first cause of death by disease beyond one year of age, very few new medicines reach children and adolescents with cancer in Europe, even after the implementation of the 2007 [EU Paediatric Medicine Regulation](#).

Participants at this yearly SIOPE event to mark International Childhood Cancer Day (15<sup>th</sup> February) at the European Parliament proposed solutions to the current lack of therapeutic innovations in childhood cancer treatments. Member of the European Parliament *Glenis Willmott (S&D, UK)*, a strenuous supporter of the causes of childhood cancer community over the past years, hosted and introduced the event. *Martin Schrappe (DE)*, President of SIOPE, presented the 'SIOPE-ITCC-CDDF Multistakeholder Platform', created in 2013 by representatives of parent/patient advocates, academia, industry and regulators. The Platform works on proposals to increase innovative drug development that are regularly presented to decision-makers during a series of Paediatric Oncology Conferences, the [last of which](#) led to three [stakeholders' joint proposals](#) to improve the effectiveness of the Regulation's implementation:

1. **Mandatory** paediatric investigation of medicines based on '**mechanism of action**' rather than adult disease;
2. **Prioritisation of drugs** in order to preserve and match rare and frail children with cancer to the best available therapies;
3. **More effective and flexible rewards** to drive early clinical development of drugs for childhood cancers and specifically for those cancers which only occur in children.

Today, less than 1 in 10 children with a relapsed terminal cancer have access to innovative treatments. The urgency to accelerate paediatric drug development was stressed by *Christopher Copland (UK)*, a Platform parent advocate and founding member of [Unite2Cure](#). Mr Copland observed the need for more attractive rewards for the pharmaceutical industry developing innovative drugs for paediatric malignancies, following the example of the "Creating Hope Act" system in the USA. From the academic perspective, SIOPE Past President *Gilles Vassal (FR)* encouraged all stakeholders to increase their cooperation in research and development (R&D). After acknowledging a change of paradigm thanks to the EU Regulation, he nevertheless explained that: i) there are unjustified waivers to paediatric investigation plans (PIPs) – mostly because the adult condition does not exist in children; ii) there are major delays in starting paediatric oncology clinical trials; iii) economic incentives to develop treatments for childhood cancer come too late in the drug development process. Representing the industry standpoint, *Raphaël Rousseau (USA)* agreed on this last point and noticed that the current incentives discourage smaller companies to consider investing in this field. He also explained the challenges linked to the rarity and specificities of paediatric cancers.

Statements from different categories of stakeholders and an open discussion characterised the second part of the event. Representing the European Medicines Agency (EMA), *Jordi Llinares (UK)* explained that the EMA Paediatric Committee – although actively cooperating to improve the situation – only has a limited role as regards the initiative to start a PIP, which belongs to industry. SIOPE Board Member *Pamela Kearns (UK)* underlined the major role played so far by academia in developing effective paediatric cancer treatments, and suggested an increase in public-private partnerships with industry. *Magda Chlebus (BE)* declared the full support of the European Federation of Pharmaceutical Industries and Associations (EFPIA) to engage cooperatively, also by exploring existing instruments for action (such as the Innovative Medicines Initiative). *Anne Goeres (LU)*, Unite2Cure partner from the Foundation Kriibskrank Kanner, stressed the need to join forces with the rare diseases' community in advocating better treatments.

In conclusion, the event emphasized the need to accelerate drug development for paediatric cancers and to amend the Paediatric Medicines Regulation, when it might come up for revision in 2017. All stakeholders – including policy-makers – will prepare and suggest suitable solutions in view of this revision, while keeping this issue high on the political agenda. Participants acknowledged that the situation is slowly progressing in the right direction, and relevant stakeholders from the childhood cancer community – including parents, patients and survivors – recently committed to jointly implement the [SIOPE European Cancer Plan for Children and Adolescents](#), a common vision to address key issues for children and adolescents with cancer – including the need for safer and more effective innovative treatments.

**More information:**

- [Event Webpage: Programme, Video and Pictures](#)
- [Proposal by Stakeholders - International Childhood Cancer Awareness Day 2016](#)
- [The SIOPE European Cancer Plan for Children and Adolescents](#)

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<b>EVENT INFORMATION:</b>	SIOPE International Childhood Cancer Awareness Day (ICCD 2016) Development of Paediatric Cancer Medicines - 'Speeding up Innovation, Saving Lives' Hosted by MEP Ms Glenis Willmott (S&D, UK) Wednesday 27 <sup>th</sup> January 2016 European Parliament (Room PHS 1A002), Brussels, Belgium
<b>PROGRAMME:</b>	Available <a href="#">here</a> (presentations, video and pictures downloadable on the same page)
<b>TWITTER:</b>	#ICCD2016 @SIOPEurope

### **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](http://www.siope.eu).



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