

SIOPE-ENCCA
Conference 2014

Brussels 18-19 September
Belgium 2014

Joining Efforts for a Brighter Future for
Children and Adolescents with Cancer

The European Roadmap
to Horizon 2020



Press Release

Brussels, 23rd September 2014

Towards a European Paediatric Cancer Plan

Last Friday, some **160 paediatric oncology stakeholders from 31 countries** left Brussels committed to a strategic undertaking with life-enhancing potential: a long-term **European Paediatric Cancer Plan** for better care and research for children and adolescents with cancer. This impressive multi-stakeholder group attending the **SIOPE-ENCCA Conference 2014** 'Joining Efforts for a Brighter Future for Children and Adolescents with Cancer – The European Roadmap to Horizon 2020' (18-19 September 2014, Brussels, Belgium) shared and discussed expert opinions, experiences and best practices in every area of paediatric oncology research, treatment, care and follow up.

Childhood cancer remains a serious public health issue: 6,000 children still die of cancer every year, access to paediatric oncology standard care and research varies enormously across Europe and there has been little progress in difficult-to-treat diseases over the last 5 years. At the same time, there are strategic/quality of life issues facing childhood cancer survivors, who are now 1 of every 1,000 European citizens.

The SIOPE-ENCCA Conference – co-organised with the parents' representatives from **ICCCPO Europe** – therefore aimed to ensure the widest possible consensus on a **comprehensive Roadmap** designed to increase the cure rate in poor prognosis malignancies, to eradicate inequalities in childhood cancer care in Europe and to increase the quality of life of childhood cancer survivors. This Roadmap is the outcome of the coordinating efforts of **SIOPE** (the European Society for Paediatric Oncology) and **ENCCA** (the FP7 project 'European Network for Cancer research in Children and Adolescents') at the European level. The full strategy will take into account the discussions held during the event and will be published extensively in the next months, further defining how to run and implement the future 'European Paediatric Cancer Plan'.

'Europe remains strongly committed to making progress for children with cancer and childhood cancer survivors', said President of the European Council **H. Van Rompuy** in his video address at the event, where he also acknowledged the impact of paediatric oncology clinical research in enabling life-saving achievements over the past decades. Ms **G. Willmott**, Member of the European Parliament, reiterated her long-standing support to EU regulatory initiatives in line with the newly adopted Roadmap, highlighting the recent endorsement by 16 MEPs of the **Manifesto for Paediatric Oncology**.

At the same time, challenges remain. Participants agreed with Prof **R. Sullivan** that the needs of children with cancer are '*not high (enough) on the political radar*'. Thus, Prof **N. Forgo** focused on the EU Data Protection Regulation, which could threaten clinical research and therefore requires the urgent involvement of the European haemato-oncology community, while Prof **G. Vassal**, SIOPE President, drew attention to the need to develop paediatric medicines against specific targets to increase the cure rate. Furthermore, survivors need access to adequate follow-up and relevant high-quality care, but currently face an extreme variability of services in Europe – a problem that the 'Survivorship Passport' initiative, developed via ENCCA and other EU projects and also presented at the event, tries to address.

Other insights on key areas linked to the Roadmap came from Prof **K. Pritchard-Jones**, who stressed the need to invest in outcomes research. Prof **J. Kowalczyk** presented the results of a SIOPE-led **survey** which showed that only 50% of the paediatric haemato-oncology centres in Europe fulfil the criteria set in the '**Standards of care**'. To address this situation, Prof **R. Ladenstein**, ENCCA Coordinator, described ExPO-r-Net, the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment, which will bring available treatments to a better level of quality and accessibility. SIOPE President-Elect Prof **M. Schrappe** underlined the need to speed up innovative paediatric drug development in Europe'.

Participants strongly agreed on the need for concerted efforts of health professionals, researchers, parents, industry, policy makers, regulators and charities in order to speed up developments with regards to the newly agreed roadmap.

SIOPE and the European paediatric haemato-oncology community joined forces to create a brighter future for all children and adolescents with cancer: this ground-breaking event successfully ended with the commitment of all participants to jointly work on a 'European Paediatric Cancer Plan' addressing both care and research. This Conference – taking place in September, the international '**Childhood Cancer Awareness Month**' – has been a crucial step towards making this future a reality.



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EVENT INFORMATION:

SIOPE-ENCCA Conference 2014
'Joining Efforts for a Brighter Future for Children and Adolescents with Cancer –The European Roadmap to Horizon 2020'
18-19 September 2014, Brussels, Belgium (Renaissance Brussels Hotel)

STRATEGY:

[Paediatric Haematology Oncology: the European Roadmap to Horizon 2020](#)
The full strategy will take into account the discussions during the event, and it will be **published in the next months**.

PROGRAMME:

Available [here](#) (presentation soon downloadable on the same page)

PICTURES:

Available [here](#)

VIDEOS:

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