

## ***SIOPE Spring Meeting***

### **SIOPE EUROPE Report October 2014 - May 2015**

#### **1. Further developing the Strategic Plan for paediatric haematology oncology**

After the success of the [SIOPE-ENCCA conference](#) (18-19 September 2014, Brussels, Belgium), SIOPE is continuing to further develop its [long-term Roadmap](#) to increase the cure rate in poor prognosis malignancies and eradicate inequalities in childhood cancer care in Europe. Our Society is widely sharing this Roadmap with all kind of stakeholders from the European paediatric oncology community, in order to actively engage all those who could make the difference by concretely implementing some aspects of this strategy.

The Roadmap has been officially presented at the global level during the SIOPE Congress 2014 in Toronto, Canada (SIOPE General Assembly, 23<sup>rd</sup> October 2014), at the ENCCA General Assembly (15-16 January 2015, Brussels, Belgium), at the CDDF-SIOPE-ENCCA-ITCC Paediatric Workshop (5-6 February 2015, Vienna, Austria, see [below](#)), during the International Childhood Cancer Day celebrations around 15<sup>th</sup> February 2015 (see [below](#)), and at the CCI Meeting on 8-10 May 2015 in Malmö, Sweden.

Taking into account all the discussions held on these occasions, the fully finalised strategy will further define how to run and implement the future 'European Paediatric Cancer Plan'. Following the previously published article '[Challenges for Children and Adolescents With Cancer in Europe: The SIOPE-Europe Agenda](#)', a new version of the strategy – integrating all comments received during the long process of document sharing with all stakeholders – will be extensively published and disseminated in the upcoming months.

#### **2. Advocacy at the European Parliament - International Childhood Cancer Day**

European Union policies and legislation on health and research considerably influence how childhood cancer research and care are performed in Europe. Thanks to its consolidated reputation with the European institutions, SIOPE is currently considered as a key stakeholder in the field of EU advocacy and works to ensure that the needs of the paediatric haemato-oncology community are always taken into account by EU policy-makers.

Every year SIOPE organises an influential event to mark the date of **International Childhood Cancer Day - ICCD** (15<sup>th</sup> February) and raise awareness on the needs of children with cancer and all those who care for them among EU policy-makers and other important stakeholders. [This year's event](#) took place at the European Parliament on 3<sup>rd</sup> February 2015 and addressed the projected consequences of the new **EU Data Protection Regulation** on childhood cancer research. More than 80 participants (childhood cancer survivors and parents, healthcare professionals and representatives from the European institutions) attended this high level event and expressed their shared concern that the proposed Regulation may hamper biomedical cancer research for children (see [SIOPE Press Release](#)).

Around the date of 15<sup>th</sup> February SIOPE President Prof Gilles Vassal also released several awareness raising interviews via the French, Swiss and Luxembourg media, while SIOPE engaged in the [Global ICCD Campaign](#) launched by Childhood Cancer International – close partner of SIOPE (see [below](#)) – to promote a deeper understanding of childhood cancer.

SIOPE is also involved in the current implementation at the national level of the recently revised **EU Clinical Trials Directive**, making sure that the priorities of paediatric oncology professionals continue to be correctly taken into consideration.

SIOPE is also currently advocating an appropriate inclusion of paediatric haematology oncology in the **EU Joint Action on Rare Cancers**, part of the EU Health Programme - Action Plan 2015.

Finally, SIOPE closely monitors EU legislation of high relevance for paediatric oncology drug development, including the revision of the **EU Paediatric Regulation**, foreseen in early 2017.

### **3. Improving cooperation for new drug development - The Paediatric Platform**

Since 2013, SIOPE contributed to the creation of a joint **CDDF-SIOPE-ENCCA-ITCC Paediatric Platform** to intensify cooperation between four different types of stakeholders: academia, industry, parents and patients, regulators and policymakers. Currently well-structured, this platform regularly meets to propose solutions to improve the implementation of the current [EU Paediatric Regulation](#) and suggest improvements in view of its revision (see [article on the European Journal of Cancer](#)).

On 5-6 February 2015 SIOPE co-organised the [3<sup>rd</sup> Paediatric Oncology Conference 'Prioritisation in Paediatric Oncology Drug Development'](#) in Vienna, Austria, the 3<sup>rd</sup> meeting of an ongoing series of biennial conferences jointly organised by [SIOPE](#), [ENCCA](#), [CDDF](#) and [ITCC](#). This multi-stakeholder event aimed to increase and speed up access to innovative therapies for all patients, and it has also been the occasion for the Paediatric Platform working groups to report on their advances and proposals. The next Paediatric Oncology Conference will take place in January 2016.

### **4. Improving access to care and research - ExPO-r-Net**

Based on the [European Standards of Care for Children with Cancer](#), as well as the EU Cross-border Healthcare Directive and European Reference Networks' initiative, the project [ExPO-r-Net](#) (the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment) aims to improve the quality of paediatric oncology treatment and care across Europe and to increase access of children and adolescents to high-level care.

Project partners are currently liaising with the existing collaborative structures among the European Clinical Trial Groups in a common effort to create a Paediatric Oncology European Reference Network, and the project's scope of activity spans over several aspects, from technical solutions for cross-border paediatric oncology tumour boards, to the translation and dissemination of the European Standards of Care for Children with Cancer and the development of the Survivorship Passport initiative (see [dole](#)).

### **5. Partnership with parents, patients and survivors**

SIOPE is further deepening its close partnership with engaged parent/patient and survivors advocates and has established over the years a strong collaboration with the representatives of European parents, patients and survivors through the **Childhood Cancer International (CCI) Europe Regional Committee** and the **Parent and Patient Advisory Committee** (PPAC, established within the ENCCA Project).

Parent/patient advocates have been actively **involved in SIOPE's most important initiatives** like the SIOPE-ENCCA Manifesto, the BDA-ITCC-ENCCA-SIOPE Paediatric Platform. Most importantly, SIOPE and the Childhood Cancer International (CCI) Europe Regional Committee have jointly organised the SIOPE-ENCCA Conference last September 2014 (see [above](#)), and adhered to the very successful [Global Campaign](#) to mark International Childhood Cancer Day in February 2015.

Representatives from CCI already regularly attend the yearly SIOPE General Assembly, and representatives from SIOPE attend the yearly CCI Europe Regional Committee Regional Annual Meeting. This was the case at the recent CCI Europe Meeting in Malmö, Sweden (8-10 May 2015), where SIOPE President Gilles Vassal presented the efforts of SIOPE and CCI Europe to implement and raise awareness about the joint European long-term strategic plan.

## 6. Education and training

SIOPE regularly provides financial support to cover the attendance of young oncologists to the joint ECCO-AACR-EORTC-ESMO **Flims workshop** on '[Methods in Clinical Cancer Research](#)'. This initiative aims to support and prepare the next generation of paediatric oncologists, as the selected fellows will improve their research skills by developing a clinical trial protocol on childhood cancer. This year - of the 80 participants who will take part in Flims in June 2015 - 5 paediatric oncologist have been selected, and 2 of them financially supported by SIOPE via a scholarship.

## 7. SIOPE as a partner in European projects

SIOPE is currently part of and constantly driving the dissemination of the following **EU projects**:

- [ENCCA](#), the European Network for Cancer Research in Children and Adolescents;
- [PanCareSurFup](#), PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies;
- [EXPO-r-Net](#), the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment (see above)

Our Society is currently preparing the **closing event of ENCCA** (December 2015, Brussels, Belgium) **and of PanCareSurFup** (23-24 May 2016, Brussels, Belgium), and joined other stakeholders in several research project applications under the [Horizon 2020](#) EU calls. Moreover, SIOPE is also contributing to the finalisation of the design and branding of the '[Survivorship Passport](#)', an innovative initiative which is supported across different EU projects ([ENCCA](#), [PanCareSurFup](#) and [ExPO-r-Net](#)).

SIOPE also took part in the following **past EU projects**:

- [EPAAC](#), the European Partnership for Action Against Cancer
- [EuroCancerComs](#), to establish an efficient network for cancer communication in Europe
- [RareCareNet](#), Surveillance of Rare Cancers in Europe
- [Oncovideos](#), Developing vocational skills in oncology through e-learning

## 8. SIOPE at the next SIOPE Congress in Cape Town

SIOPE will be present on the occasion of the 47<sup>th</sup> Congress of the International Society of Paediatric Oncology (8-11 October 2015, Cape Town, South Africa), to show its constant contribution to the global agenda of SIOPE to improve and optimise treatments throughout the world. In particular, a SIOPE booth will be made available in the exhibition area, and there will be an ExPO-r-Net small meeting on 10<sup>th</sup> October 2015.

## 9. About the organisation and management of SIOPE

### 9.1 SIOPE Board

Current members of the SIOPE Board:

- President: Gilles Vassal (FR), Institut Gustave Roussy, Villejuif, France
- President-Elect: Martin Schrappe (DE), University Hospital Kiel, Germany
- Treasurer: Henrik Hasle (DK), Aarhus University Hospital Skejby, Department of Paediatrics, Denmark

- ECRC Chair: Ruth Ladenstein (AT), Stt. Anna's Children's Hospital, Vienna, Austria
- ECRC Vice-Chair: Pam Kearns (UK), University of Birmingham, Cancer Research Clinical Trials Unit, United Kingdom
- Stefan Bielack (DE), Paediatric Hospital Olgahospital Klinikum, Stuttgart, Germany
- Tom Boterberg (BE), University of Ghent, Belgium
- Kathy Pritchard-Jones (UK), University College London, United Kingdom
- Riccardo Riccardi (IT), Università Cattolica, Roma, Italy
- Jan Starý (CZ), University Hospital Motol, Prague, Czech Republic
- Maria Grazia Valsecchi (IT), University of Milano, Department of Clinical Medicine and Biotechnology, Italy

Two new members joined the SIOPE Board in 2015 because of their considerable expertise in the field of outcome research and quality assurance in radiotherapy: Prof Kathy Pritchard-Jones (former President of SIOPE, partner in ENCCA and ExPO-r-Net and initiator of the Horizon 2020 PICORET project proposal) and Dr Tom Boterberg (head of the radiotherapy committee of the SIOPEN study and of the SIOPE radiotherapy quality assurance working group).

### 9.2 SIOPE General Assembly

The next **SIOPE General Assembly** will take place on Monday 28<sup>th</sup> September 2015 on the occasion of the European Cancer Congress in Vienna, Austria.

### 9.3 SIOPE Office

Current SIOPE Office [staff members](#):

- Secretary General: Samira Essiaf (BE)
- Public Affairs and Communication Coordinator: Olga Kozhaeva (BE)
- Communication Administrator: Giulia Petrarulo (IT)