

- Message from the President and the Office
- EU policies for children with cancer
- EU Project Updates
- Our Community Profiled
- Special Features
- Parents & Patients news
- SIOPE Courses and Workshops
- About us
- Upcoming events

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**Creating a brighter future for young people with cancer**

**SIOPE creates a network of paediatric oncology reference expert centres**

**The Clinical Trials Regulation is ready for the vote in the Parliament**

**ENCCA successfully entered its 4<sup>th</sup> year!**

**Paediatric oncology in the Scandinavian countries**

**PanCareSurFup promoted everywhere, even on the seaside**

**Tackling European inequalities in childhood cancer care: hot topic in the European Parliament**

**A new multidisciplinary platform to speed up access to new drugs**

**Sam White and his fight for a better future for childhood cancer patients**

**Save the date for the ENCCA-SIOPE Conference 'Creating a Brighter Future for Children and Adolescents with Cancer: The European Roadmap to Horizon 2020'**

## Message from the President and the Office

The new year just began, but it is difficult to keep the pace of all the initiatives carried on by our Society, which are succeeding each other at a very fast speed. Being always at the forefront of paediatric oncology innovations, SIOPE will bring you a whole lot of not-to-be-missed events and initiatives in 2014, such as the SIOPE yearly event at the European Parliament as well as a very high-level congress on the future of paediatric oncology which will take place in Brussels next September. Stay with us!



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## EU policies for children with cancer

### Let's fight against health inequalities: don't miss SIOPE International Childhood Cancer awareness Day 2014

Every year SIOPE marks International Childhood Cancer Day (15 February) and, since 2011, we also organise a high-level event at the European Parliament to raise awareness on the challenges faced by children and adolescents with cancer in Europe, and those who care for them. This year the existing inequalities in paediatric cancer care and research across Europe, and the possible solutions to tackle them, will be the 'fil rouge' of the event.



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### Clinical Trials Regulation: at which stage are we?

The negotiations on the text of the revised Clinical Trials Regulation are finally coming to an end, and the final text will be voted in spring. The point of view of European paediatric oncologists has been successfully taken into account by the European Union and – although it is still not 'perfect' – our community can be overall satisfied of the current text.



[READ MORE](#)

### Increase access to innovative anticancer therapies: the BDA-SIOPE-ENCCA-ITCC Workshop

There is an urgent need to develop new drugs for childhood and adolescent cancers, which continue to be a major cause of morbidity and mortality in Europe. To identify solutions for this important problem SIOPE and ENCCA – together with BDA and ITCC – organised last November a paediatric workshop, which successfully gathered 16 speakers and 87 attendees from academia, industry, regulators and parent/patient representatives.



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# EU projects' updates



## ■ Latest News from EPAAC

### Standards of Care for Children with Cancer: survey report available soon

Developed by SIOPE in the context of the EPAAC project, the 'Standards of Care for Children with Cancer' sets the essential criteria to be met by paediatric haemato-oncology wards all over Europe. To evaluate the Standards' implementation after 5 years, Prof. Kowalczyk and SIOPE recently conducted a pan-European survey, whose results revealed the existence of broad national differences in the provision of childhood cancer treatment and care.



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## ■ Latest News from ExPO-r-NeT

### ExPO-r-Net: the new reference network in paediatric oncology will soon start its activities

As already announced in the previous newsletters, SIOPE and several partners from the European paediatric oncology community have given birth to a new innovative European project, which will address the current inequalities in childhood cancer survival and healthcare capabilities in the different European countries. The ExPO-r-NeT project will officially start with a kick-off meeting in Luxembourg on 21 March 2014.



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## ■ Latest News from ENCCA



### ITCC-ENCCA Workshop 'Imagine new drugs for the future in paediatric oncology'

In partnership with the ENCCA network, the Innovative Therapies for Children with Cancer (ITCC) Association organised last 15 November the first workshop 'Imagine New Drugs for Tomorrow in Paediatric Malignancies' in Paris.

Sara Calmanti, ITCC, France



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### ENCCA's work on very rare tumours awarded as best clinical trials work at SIOP 2013

A state-of-the-art management of cancers requires a comprehensive database, from which specific variables may be interrogated in order to effectively identify treatment approaches. To this aim, CHIC established within ENCCA the largest database reported to date for a paediatric rare tumour, and this new stratification system (CHICS) has been awarded as best clinical trials work during the last SIOP Congress 2013 in Hong Kong.



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## ■ Latest News from PanCareSurFup

### PanCareSurFup successes promoted in incredible ways

PanCareSurFup partners constantly identify new ways to inform the lay public about the importance of the cooperative work of European research groups and projects, the progress made in treating European children and adolescents affected by cancer as well as the importance of caring about the health status of long-term survivors.



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## Our Community Profiled



### Paediatric Oncology in Europe, from national activities to pan-European research approaches: The case of NOPHO

The Nordic countries (Norway, Sweden, Denmark, Finland and Iceland) have a long tradition of research collaboration, which dates back to the early 20th century. To be even more integrated at the European level, NOPHO joined SIOPE in 2013 and all NOPHO's members have become individual members of SIOPE, with 126 full members and other affiliated members. Today NOPHO and SIOPE are close partners and, together, they aim to increase both the cure rate and the quality-of-life of childhood cancer patients in Europe.



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## Special Features

### SIOPE and ENCCA at the European Cancer Congress 2013

Thank you for making ECC 2013 a big success for multidisciplinary and paediatric oncology! Approximately 20.000 participants attended the 17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress, which took place in Amsterdam, The Netherlands from 27 September to 1 October 2013. This has been the most important cancer congress in Europe, and both SIOPE and ENCCA were widely represented and showcased.



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### More should be done to enhance childhood cancer survival in Europe, study shows

Last December, an outstanding article on childhood cancer 5-year survival in Europe showed that unacceptable disparities in survival still exist across Europe, and that survival of children with tumours that have the worst prognosis registered no improvement. These data were presented during the high-level round table on the 'Key Determinants of Inequalities in Cancer Survival across Europe', hosted by MEP Alojz Peterle and organised by MEPs Against Cancer.



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# Parents & Patients' news

## 'Enfants sans cancer' raised €400,000 to foster childhood cancer research

This 2nd edition of the run "Enfants sans cancer - Children without cancer" took place near Paris (Saint-Cloud) on 29 September 2013. Aiming to raise awareness on the need to improve research in childhood cancers, the event has been a huge success, full of emotions and shared solidarity. More than 1,000 runners with a big heart were present, together with 7,300 donors, 100 volunteers and a wonderful check of 400,000 euros were donated to researchers in ITCC to make progress in childhood cancer research.



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## How a local boy with cancer helped to change European law

When Pam and Mike White's son Sam was diagnosed with a brain tumour at the age of 12, it was the start of a remarkable journey. Determined to improve the available treatment for other children and teenagers suffering from rare cancers, Sam began his advocacy work. Sadly Sam passed away last September 2013, but his parents and Ms Glenis Willmott, Member of the European Parliament, are determined to continue his work and change the EU legislation to improve treatments for young people with cancer.



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## Mentoring projects of survivors attract increasing attention in Europe

When Pam and Mike White's son Sam was diagnosed with a brain tumour at the age of 12, it was the start of a remarkable journey. Determined to improve the available treatment for other children and teenagers suffering from rare cancers, Sam began his advocacy work. Sadly Sam passed away last September 2013, but his parents and Ms Glenis Willmott, Member of the European Parliament, are determined to continue his work and change the EU legislation to improve treatments for young people with cancer.



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## 5th ICCCPO meeting of European member groups

2014 is a special year for ICCCPO. It will celebrate its 20th anniversary in Valencia (Spain). The International Confederation of Childhood Cancer Parent Organisations will hold its 5th ICCCPO meeting of European member groups at the same time in Valencia: from 16th to 18th May 2014.

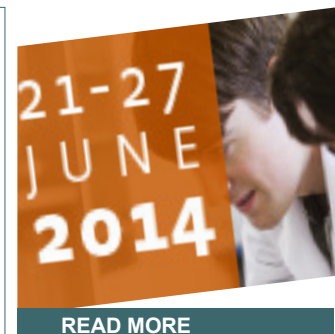


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# SIOPE Courses and Workshops

## A lifetime opportunity: the Flims 16 Workshop

Flims is the way thousands of young professionals and medical students call the most exclusive opportunity to learn the essentials of an oncological clinical trial design in Europe. The presence of a strong research base is essential to the future of good quality paediatric cancer care, as clinical scientists who are able to set up and run high-quality clinical trials are vital to the advancement of new therapies.



[READ MORE](#)

## 5th ESO-SIOPE Masterclass in Paediatric Oncology

We are pleased to announce that the 5th ESO-SIOPE Masterclass in Paediatric Oncology will be held in Ljubljana, Slovenia, on 17-22 May 2014 thanks to the long-lasting collaboration between the European School of Oncology (ESO) and SIOP Europe.



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## Training course 'Paediatric Oncology for Cancer Registries'

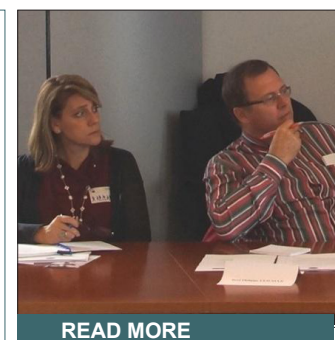
The acquisition and use of clinically relevant information in population based research is essential in paediatric oncology. In order to improve the knowledge of clinical practice as well as the understanding of the linkage between clinical data and population-based cancer registries, a very interesting course co-sponsored by ENCCA took place last November at the International Agency for Research on Cancer.



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## Can the new Advanced Therapy Medicinal Products innovate treatments for children with cancer?

New technologies, therapies and medicines (e.g. regenerative medicine, nanomedicines and immunotherapies) are emerging. The European Commission is monitoring scientific progress and reviewing EU legislation in the light of new developments so as to make safe, novel treatments available to patients as early as possible. In this framework, last October a meeting on the challenges of working on immunotherapy treatments under the Advanced Therapy for Medicinal Products Legislation took place at the European Parliament.



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# Upcoming events

## RARE DISEASE DAY EVENT, EURORDIS

28 February 2014, Brussels, Belgium

[MORE DETAILS](#)

## SECOND INTERNATIONAL COURSE ON ADOLESCENTS AND YOUNG ADULTS WITH CANCER

27-28 March, 2014, Madrid, Spain. Application deadline: 1 March 2014

[MORE DETAILS](#)

## 25TH ANNUAL MEETING OF THE I-BFM SG

26-27 April 2014, Prague, Czech Republic

[MORE DETAILS](#)

## 9TH BIENNIAL CHILDHOOD LEUKEMIA SYMPOSIUM

28-29 April 2014, Prague, Czech Republic

[MORE DETAILS](#)

## JOINT EONS - TEENAGE CANCER TRUST TYA NURSE LEADERSHIP SUMMIT

1 May 2014, Dublin, Ireland

[MORE DETAILS](#)

## 14TH INTERNATIONAL PAEDIATRIC HAEMATOLOGY AND ONCOLOGY UPDATE MEETING

1-2 May 2014, Edinburgh, UK

[MORE DETAILS](#)

## 2ND INTERNATIONAL SYMPOSIUM 'CHILDHOOD, ADOLESCENT AND YOUNG ADULT HODGKIN LYMPHOMA'

7-10 May, 2014 Berlin, Germany

[MORE DETAILS](#)

## INTENSIVE EUROPEAN BIOETHICS COURSE "ETHICS OF PAEDIATRIC RESEARCH"

12-14 May 2014, Padova, Italy

[MORE DETAILS](#)

## PANCARESURFUP GENERAL ASSEMBLY

14-15 May 2014, Wroclaw, Poland

[MORE DETAILS](#)

## 5TH ICCCPO MEETING OF EUROPEAN MEMBER GROUPS

16-18 May 2014, Valencia, Spain

[MORE DETAILS](#)

## 5TH ESO-SIOPE MASTERCLASS IN PAEDIATRIC ONCOLOGY

17-22 May 2014, Ljubljana, Slovenia.

[MORE DETAILS](#)

## About Us



Working to ensure the best possible care and outcomes for all children and young people with cancer in Europe



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