

## Message from the President and the Office



Dear SIOPE members and friends,

In October 2012 in London, I took over the Presidency of our European society after three years of outstanding presidency by Ruth Ladenstein. In this first newsletter of 2013, I want to pay tribute to Ruth. Under her leadership, SIOPE became increasingly visible in Europe, and established itself as a major stakeholder within the oncology community through many actions in the European Parliament through engagement with those in the health and science policy field and participation in several EU-funded projects within the Seventh Framework Programme (FP7).

The largest and most exciting project for paediatric oncology in Europe is undoubtedly ENCCA, the European Network for Cancer Research in Children and Adolescents, which was conceived within SIOPE four years ago. Moreover, SIOPE has become an important partner in several other European initiatives, including Rare Cancers Europe and disseminating our European Standards of Care for Children with Cancer through the EU-

funded EPAAC project (European Partnership for Action Against Cancer).

Ruth has been instrumental in leading the advocacy work for SIOPE's concerns on the EU Clinical Trials Directive (now Regulation). Our voice must continue to be strong at a time when the proposed Regulation is being assessed by the European Parliament and the Member States (Council) and is expected to be voted upon this year.

We, as health professionals deeply involved in care and research for children, expect that the Regulation will simplify the implementation of our research agenda. SIOPE is in a strong position to make the voice of children and adolescents heard.

A sincere thank you should again go to Ruth for continuing to work on this issue along with Pam Kearns and for sustaining the pressure on policymakers to implement changes that can improve the lives of young people with cancer, and those who care for them.

SIOPE has also, and importantly, modified its Statutes allowing for a new and more dynamic membership, through the paediatric oncology national societies. This will strengthen our capacity to deliver our agenda.

The agenda for the next three years is extremely exciting. The major objective is to build the long-term sustainability of cancer research for children and adolescents with cancer in Europe. This is one of the main deliverables led by SIOPE within the ENCCA project, a project that will last until January 2015.

What are our scientific and medical goals for the next 15 years? How to best address the dual objective of increasing cure rate of children and adolescents with still incurable diseases and significantly improving quality of life of long-term survivors? How to accelerate translation of new knowledge into better diagnosis and better treatments? What platforms and tools should be developed to speed up and facilitate research, sharing



more than ever expertise, data and biological resources in order to address the formidable challenge of massive information generated by high-throughput technologies?

How to warrant equity of access to research and innovation for children and adolescents, as well as equity of access to high-quality standard care in specialised centres across Europe?

How to improve training of paediatric oncologists and all healthcare professionals for delivering high-quality care and research? How to work better with our colleagues from adult oncology, in particular (but not exclusively) in the area of teenagers and young adults?

How to reinforce our partnership with parents and parent advocacy groups, as well as patient and survivor groups? How to strengthen our collaborations worldwide in paediatric oncology to address the formidable challenges linked to the development of new therapies in rare and extremely rare biomarker-defined paediatric cancers? How to address the long-term effects of curing therapies and anticipate initiatives to reduce or avoid sequellae? How to work with the pharmaceutical and e-Health tech industry and the regulatory authorities? How to find the resources for funding such an ambitious research agenda in the context of the global economic crisis and competition for research funding?

Answering those questions, SIOPE and ENCCA will deliver within the next two years the long-term sustainability proposal that will structure European paediatric oncology research for the next 15 years. Contribution of European and national groups will be actively sought as well as advice from external experts and stakeholders. Proposals will be discussed within the community before approval and implementation.

This is a unique time for our community to have a vision and to build the foundation of the future.

Let's do it together.

*Gilles Vassal*



## SIOPE Board 2013



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Institut Gustave Roussy,  
Villejuif, France



Past President Professor Ruth Ladenstein  
(AT) St. Anna's Children's Hospital,  
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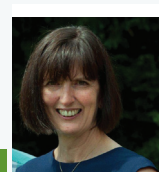
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University Hospital Skejby,  
Department of Paediatrics, Denmark



Professor Dragana Janic (RS)  
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Clinical Trials Unit, United Kingdom



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Professor Maria Grazia Valsecchi (IT)  
University of Milano, Department of Clinical  
Medicine and Biotechnology, Italy



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Children's Brain Tumour Research  
Centre, Nottingham, UK

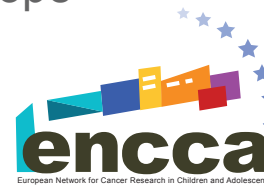
# SIOPE Europe's Community

## Outreach and awareness-building throughout Europe

### EU Projects Updates

#### Latest News from ENCCA

#### ENCCA Achievements: A look back at 2012



At the ENCCA General Assembly, partners, as well as some key stakeholders including the European Commission's Scientific Officer working on cancer-related projects, Dr. Jan van de Loo, came together in Brussels in January 2013 to discuss the progress made by project partners to date. Here is an overview of some key deliverables in 2012.

- ENCCA has created a 'Scientific Advisory Board': the objective is to acquire independent, scientific advice from external experts on the project's scientific output. Key opinion-leaders have accepted to be a member of this Board, namely Prof. Ulrik Ringborg (Karolinska Institute; Project Coordinator of the EU-funded EurocanPlatform project), Prof. Holger J. Schünemann (Buffalo University, Canada) and Prof. Peter Adamson (Chair, Children's Oncology Group; The Children's Hospital of Philadelphia).

- A working group to address the long-term sustainability of ENCCA was created in July 2012. Sustainability is one of the key aims of ENCCA (composition of the working group here). After a discussion at the General Assembly and ECRC meeting, the two overall medical and scientific goals for the next 15 years have been defined (to increase cure rate of poor prognosis malignancies and to increase quality of cure in survivors) as well as 7 specific aims.

- The European Clinical Research Council for Paediatric Oncology (ECRC) has finalised its governing structure: ECRC members elected Prof. Ruth Ladenstein as Chair, Dr. Pam Kearns as Vice-Chair and Profs. Stefan Bielack, Gianni Bisogno, Martin Schrappe, Gilles Vassal and Michel Zwaan joined the Steering Committee.

- ENCCA IT partner AIT presented their initial plans for a new 'cloud-based platform' that will allow for increased functionality and is another step towards the creation of a 'virtual platform' for paediatric oncology in Europe, one of ENCCA's key deliverables. AIT presented more information on improving integration of different IT infrastructures, called ABCD-4-E: Advanced Biomedical Collaboration Domain for ENCCA. Fellow IT partner CINECA presented the latest developments for the creation of the 'Survivorship Passport'.

- ENCCA Coordinator Prof. Ruth Ladenstein and Dr. Pam Kearns provided an overview of the work that has been done to date on advocating for an improved [EU Clinical Trials Regulation](#). Amendments have been provided to the relevant policymakers: in particular it is clear clarification of the wording in the legislation, and how it will work in practice, is required.

- An overview on the Biology WP (5) presented by Prof. Angelika Eggert and R. Versteeg showed the achievements made so far. Great progress has been made in several areas, such as the functional tumour specific networks, common database and virtual biobank. Several meetings were held and have been planned in the coming months. Versteeg updated all partners on the progress made to date on the R2 clinical and molecular database and bioinformatics analysis programme for ENCCA user groups. There was consensus with the ITCC Biology on approaches for drug target validation and drug testing.

- WP6, which focuses on Innovative Methodology for Clinical Trial Design

and analysis in an effort to create a 'virtual biostatistician office' has been developing steadily, with several publications expected or already published. The next stage will be to enhance coordination with the other Work Packages. Work Package Leader Prof. Maria Grazia Valsecchi is working with her WP partners on possible involvement in another EU project focusing on rare cancers and related clinical trial design, sustaining the activities developed within ENCCA.

- On the area of early evaluation and prioritisation of new anticancer drugs (WP8 led by SIOPE President Prof. Gilles Vassal), plans are being made to integrate the biology-driven new drug development strategy into therapeutic strategies and ongoing or planned clinical trials. Trials presented include VIDAZA and NECTAR (the evaluation of new drugs in haematological diseases) and HERBY and BEACON (the evaluation of new drugs in solid tumours).

- Feedback was provided on the work being done to improve therapeutic strategies using predictive biomarkers in leukaemias (WP9). The German and Swiss AIEOP-BFM ALL study centres and the relapsed ALL trial in Berlin are in the initial stages of using the Scopeland software. A meta-database for interfacing Scopeland and other systems is expected to be functional very soon. The integration of existing biobank data systems of frontline (AIEOP-BFM ALL 2009) and second-line (INTREALL 2010) clinical trial groups is completed, and are Scopeland-based.

- Prof. François Doz presented his main achievements for assessing the molecular diagnostics as

*Continued on page 7*





## ■ ■ The ECRC is up-and-running

The European Clinical Research Council (ECRC) is composed of the chairs of each European tumour group and each national paediatric haemato-oncology groups. On 18 January 2013, the results of the election on the governance of this important body were announced. Ruth Ladenstein was elected Chair and Pam Kearns, Vice-Chair. Along with Stefan Bielack, Gianni Bisogno, Martin Schrappe, Gilles Vassal and Michel Zwaan, they will run the ECRC Steering Committee. Congratulations to all of them.

During the January session, the ECRC discussed, modified and approved the position on the draft Clinical Trials Regulation, proposed by the SIOPE Board, on behalf of the paediatric oncology community. In addition, the ECRC discussed the specific scientific and medical objectives for the next 15 years which were proposed by the [ENCCA Long-Term Sustainability Working Group](#).



## ■ ■ WP 12 ENCCA Rare Tumours Package



The main objective of the [ENCCA WP 12](#) (Clinical research in very rare tumours) is to improve the quality of care for children with rare tumours, namely hepatoblastoma (HB) as a template for international clinical research for rare childhood cancers which is called [CHIC](#) (Childhood Hepatic tumours International Collaboration) initiative. The organisation of the treatment of hepatoblastoma within Europe, as well as many other non-European countries is under the framework of [SIOPEL](#) (International Childhood Liver Tumours Strategy Group) and exemplify the pivotal role appropriate infrastructures can play in improving outcomes. The principal aim of the WP12 is the harmonisation of international research in hepatoblastoma through cooperation across Europe and with the American Children's Oncology Group (COG) and Japanese Paediatric Liver Tumour group (JPLT). Here WP12 leader, Prof. Piotr Czauderna discusses the advances that have been made.

The meeting was attended by participants from several countries. It constituted the largest inter-national meeting of paediatric liver tumours specialists which included oncologists, surgeons, transplant surgeons, pathologists and biologists. Also three dedicated international pathology workshops were organised which resulted in the development of a new pathology classification of paediatric liver tumours.

Over the years 2011 and 2012 the International Paediatric Liver Tumours Warehouse (IPLTW) was built with the support of [CINECA](#), the Italian interuniversity data management consortium.

This database merged retrospective data of all children treated on eight separate multicenter HB trials between 1989 and 2008 (all together 1602 patients). Each of the eight multicenter trials collected an average of about 200 patients, a number which lacked statistical power for detailed prognostic factor analysis. The combined dataset constitutes the largest single clinical database in history of pediatric rare tumour research. The CHIC database was made fully operational at the end of June 2012. The first prognostic factors analysis based on CHIC database took place in August 2012 and the first draft of the HB prognostic stratification and risk grouping at diagnosis (called 'CHICS', an acronym for the CHIC Stratification), which divided hepatoblastoma into 4 distinct risk groups, was formulated in January 2013.

After preliminary negotiations between SIOPEL, COG, GPOH (German Paediatric Oncology and Haematology Assoc.) and JPLT, the CHIC memorandum of understanding was prepared and signed in 2011. This provided the framework for the organisation of a CHIC Steering Committee which worked through a series of web-based conferences and face-to-face meetings. Additionally, the Gdansk International Paediatric Liver Tumours Consensus Meeting was organised in Poland in April 2012.

Since we needed an efficient working tool, a dedicated [SIOPEL website](#) with a Private Web Community Area was set up for the CHIC. It also contains patients on-line consultation module for physicians, as well as

a private area for information concerning SIOPEL Members only, a private area for remote data entry of SIOPEL protocols, private SIOPEL Web Community Area (WCA) for SIOPEL group documentation exchange and repository, internal communication tools (discussion forums, messaging) and meetings organisation. In order to disseminate the knowledge on hepatoblastoma diagnosis and treatment, several

web-based e-learning courses have been developed. Also the special Discussion Forum for patients and families has been developed in order to offer them required knowledge acquisition and necessary support.

Prof. Piotr Czauderna,  
WP 12 Leader  
The Medical University of Gdansk, Poland



## ENCCA Dissemination: A look back at 2012 achievements



As the Dissemination Manager of the European Network for Cancer Research in Children and Adolescents (ENCCA), SIOPE regularly and widely promotes the results and importance of this EU-funded FP7 project. In addition to dissemination at events and conferences, last year SIOPE further expanded and streamlined the ENCCA communication strategy, in order to facilitate the general understanding of the aims and impact of this very ambitious project.



With daily tweets and weekly LinkedIn updates, SIOPE social media tools have been developed and used to disseminate key ENCCA messages, aiming to enhance collaboration within the field of European paediatric oncology. The ENCCA website has been completely renewed, in order to make it more appealing and easy to use. In particular, a new window with Twitter updates and LinkedIn buttons (allowing visitors to join the community), a calendar with all upcoming events,

a better search engine and the "Latest News" section have been added to the Home page. Together with the possibility to translate the webpages in different languages (through Google Translator) and the new multimedia content available, we are aiming for the ENCCA website to be at the forefront of modern e-tools.

In addition, various educational activities have been promoted within the ENCCA community, like the SIOPE-ENCCA Case Studies (published every 2 months) in association with ECCO - the European CanCer Organisation, the 4th ESO-SIOPE-ENCCA Masterclass, the ITCC-ENCCA-SIOPE Training course and the Oncovideos project, as they provide useful E-learning tools and training for all paediatric oncologists.

A diverse range of communication collateral (e.g. ENCCA brochures, the ENCCA banner and science policy articles published by ENCCA partners) have also been developed including a new set

of colourful ENCCA brochures and postcards. While the general brochure, aiming to be more user-friendly and concise, includes general information on the project, 6 ENCCA postcards showing positive images of the many research and innovation activities have been created to address the different categories who benefit from the impact of ENCCA: paediatric oncologists, industry, teenagers and young adults with cancer (TYA), parents and patient groups, researchers and the academic community and the general public.

A new ENCCA newsletter is currently under construction, and ENCCA is featured in every issue of the SIOPE eNews with a section dedicated to the project.

Moreover, SIOPE secured ENCCA advertising in the European Journal of Cancer and in the magazine CancerWorld.

During the International Society for Paediatric Oncology (SIOP)



Congress 2012, a set of [video interviews](#) with ENCCA partners took place, in partnership with eCancer. Thanks to this initiative, leading personalities in the ENCCA network could illustrate the main project achievements, like the development of the Survivorship Passport and the efforts being made to sustain ENCCA in the future.

ENCCA has been showcased during several relevant meetings and workshops in 2012. During the [SIOP London congress](#) ENCCA was widely promoted to the international paediatric oncology community (over 2,200 delegates from 97 countries) from the visible SIOPE stand and, of course, at the annual SIOPE General Assembly.

Paediatric oncology representatives could therefore learn about the progress being made, in particular the work being carried out by Dr. Czuderna and his team on liver tumours. ENCCA Work Package 17 partnered with the UK's Teenage Cancer Trust to promote ENCCA activities and the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) – part of the newly-created [Parent Patient Advocacy Committee \(PPAC\)](#)

– gave an outstanding contribute to this congress. Images from ENCCA-related meetings at SIOP 2012 are can be viewed here.

The [event](#) marking Inter-national Childhood Cancer Day, in February 2012, at the European Parliament featured several ENCCA partners, who had the possibility to explain to key policymakers what the key issues in paediatric oncology in Europe are. Hosted by MEP Glenis Willmott, it focused on improving clinical research for young people with cancer, drug development and the need for earlier diagnosis, and it has been accompanied by two well-disseminated press releases (the [new edition of this event](#) is coming up on 20th February 2013.)

For the first time, ENCCA had well-positioned stands at the unique [7th International Teenage Cancer Trust conference](#), at the ECCO Oncopolicy Forum (on the future of personalised cancer medicine in Europe) and at the European Commission's Cancer Support Day.

At the last event, organised for the staff of the EU institutions, SIOPE's Giulia Petrarulo



ENCCA Activity Coordinator and SIOPE President Prof. G. Vassal interviewed at the SIOP congress

even had the opportunity to speak about ENCCA to the Vice-President of the European Commission Maroš Šefčovič!

SIOPE is also a key stakeholder in the policy arena and promotes the work of ENCCA through its initiatives. SIOPE and ENCCA will continue to raise awareness of the policy issues affecting European paediatric oncology research today, and those that will have an impact in the future.



ENCCA Parent-Patient Advocacy Committee member and ICCCP0 lead A. Kienesberger at the International Childhood Cancer Awareness Day 2012



Prof. I. Lewis from ENCCA WP 17 interviewed at the SIOP congress



G. Petrarulo (SIOPE) met the Vice President of the European Commission Maroš Šefčovič

## Last News from PanCareSurFup

### 11<sup>th</sup> PanCare Meeting - Genova, 17-19 April 2013

In close collaboration with Italy's Neuroblastoma Foundation, and organised by Dr. Riccardo Haupt, the 11th PanCare meeting is growing every year. Topics will include quality of life, the PanCare constitution and bylaws, the 'survivorship passport' being developed by ENCCA (the European Network for Cancer research in Children and Adolescents), models for transition, fertility issues and European or national projects/experiences.

#### Areas of focus include:

- The Nave Italia experience; using a tall ship for patient groups and the crews experience;
- A transition model from childhood/adolescence into adulthood; the Turin experience;
- Long term psychological follow-up of cancer survivors; the Catania experience;
- The Health Tracker, used to assess QoL in PNET patients.

Abstracts can be submitted! Please limit your abstract to 250 words using the sections: Objectives, Methods, Results and Conclusions. Please do so by March 1 at the latest. Presentations should take 20 minutes including 5 minutes for discussion.

SIOPE will be attending this important meeting, taking part in the [PanCareSurFup](#) General Assembly, an EU-funded FP7 project, of which SIOPE is a partner, involved in dissemination activities. The PanCare SurFup General Assembly takes place from 16-17 April in Genova, Italy.



#### *Continued from page 3*

prognostic biomarkers in low-risk eulloblastoma patients. The final version of the protocol was drafted in May 2012 providing SOPs for biological criteria identification, the SIOP-E PNET 5 study is planned to start soon and contracts have been sent to national sponsors.

- Work being done to evaluate the use of cancer registries for prospective collection of enhanced clinical data is moving, with the minimal standard set defined and an online questionnaire in the final stages being rolled out, on the collection practices of clinical data in population-based cancer registries and the conditions required for the collection of priority data items. In the same WP, Prof. Riccardo Haupt outlined that links to 19 population-based cancer registries are being

set up, in association with the EU-funded project [PanCareSurFup](#). A discussion is ongoing with data owners on how best to devise secure methods that maintain data anonymity. Prof. Kathy Pritchard-Jones also provided an update on her work, including the organisation of a biology-driven drug development workshop for renal tumours, She emphasized the need for the paediatric oncology community to become more involved in the [data protection legislative discussions](#) taking place at EU level as well as improving the efficiency of collaboration and data-pooling.

- In relation to ethical issues, a literature review on 451 journal articles was conducted, on ethical aspects of paediatric patients in clinical trials. Consultations and

interviews were set up with parent and patient representatives in ICCCP and the Birmingham Children's Hospital on topics such quality and safety issues and clinical trial design, and there will be a consultation on confidentiality issues with experts in biobanking.





■ ■ The Race of Brave Bikers in Marostica:  
Now an Annual Event !



G. Bode, L. Hjorth, J. Byrne and M. Jankovic from PanCareSurFup at the race



Many participants attending the 2012 edition of the race: many more this year!



Participants of the Race of Brave Bikers 2012

Prof. Momcilo Jankovic, Work Package Leader for dissemination (WP7) of the EU-funded FP7 project, PanCareSurFup discusses an awareness-raising event he will organise in Marostica, Italy. It will be the second event he has organised in this beautiful region of Italy close to Venice, but this year it will not only allow young cancer survivors from all over Europe to take part in a bike race but also in a fashion show!

This year the "Race of brave bikers" will be organised in Marostica, from 27 to 28 April. We deem this event to be very important as it allows international long-term survivors of childhood cancer to participate and show their skills, energy, vitality and positivity through sport, despite their former illness. 80% of young people with cancer survive nowadays and thus healthy living for the rest of their lives is essential. Aside from the bike race which is planned to take place on Sunday 28 April, a Round Table discussion

will be organised and open to both those from the public interested to hear about the project, as well as the media. In particular, there will be a discussion on the importance of sport and an active and healthy lifestyle for long-term survivors of childhood cancer. Several experts from the PanCareSurFup consortium will attend and participate in the discussions.

A fashion show in the main square of Marostica is expected to follow the Round Table discussions and several long-term survivors will model on the catwalk, confident and beautiful on the inside and outside, despite sometimes rather traumatic experiences during their illness.

We hope through this event, to disseminate the excellent work of the PanCare team at the EU level, informing the general public about the need to continue the work on this area as the numbers of long-term survivors increase and help patients integrate back into society and take control of their health.

The event is planned to continue for the next few years thanks to some

superb sponsors who will support us once again: NEAR (a company dealing with corporate social responsibility) and Fi'zi:k (a company specialised in suppliers for professional cyclists). Pictures from last year's successful event can be found [here](#).

Please do not hesitate to [contact us](#) for more information. If you would like to participate do let us know! Deadline is 15 March 2013!

Dr. Momcilo Jankovic  
Work Package leader  
Dissemination, PanCareSurFup





## Promoting better policies for children with cancer

- The EU Clinical Trials Regulation: improving clinical research for children and adolescents in Europe?



# International Childhood Cancer Awareness Day

Creating a brighter future for young people with cancer

Hosted by MEP Glenis Willmott, MEP  
Wednesday, 20 February 2013

Every year SIOPE organises a high-level meeting at the European Parliament in Brussels to mark International Childhood Cancer Day (15 February). This year the topic focuses on the proposal by the European Commission for a [Clinical Trials Regulation](#) following the huge regulatory burden of the [EU Clinical Trials Directive \(2001/20/EC\)](#).

There is real potential for this burden to be reversed by the legislative proposal, which is currently being assessed by Member States (Council) and the European Parliament.

The principle objective of trials for children and young people with cancer is treatment optimisation using well-established chemotherapy drugs, and the introduction of new, safe and effective innovative medicine in

standard care. These trials are non-commercial, sponsored and conducted by academic institutions and funded by public money and/ or charity support to cover the trials' organisational structures.

A pragmatic approach to trial governance for children and adolescents with cancer in Europe is needed. Therefore on this occasion, SIOPE and [ENCCA](#), the European Network for Cancer research in Children and Adolescents, on behalf of the European paediatric oncology community, call for:

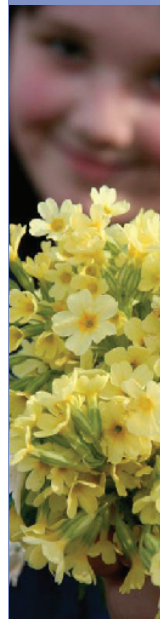
- **FAIR** and proportionate regulation of childhood cancer trials, where the aim is to improve survival using medicinal products that are already in common use
- **FAIR** and proportionate insurance for academic trials treating children with rare diseases, secured through the proposed 'national indemnity schemes'.

SIOPE and Member of the European Parliament (MEP) Glenis

Willmott, the Rapporteur of the EU Clinical Trials Regulation proposal, have invited experts and decision-makers to discuss key aspects of the Regulation. Exceptionally this year, experts from other paediatric diseases will join the meeting and provide their perspective on the new legislation. We are delighted that members of the [European Network of Paediatric Research at the European Medicines Agency](#) will join and anticipate a lively and forward-looking discussion on how to improve clinical research for children and adolescents in Europe.

### More information:

[Programme of the event](#)  
[View our position on the CTR](#)  
[View our proposed amendments on the CTR](#)



## ■ The EU Paediatric Medicines Regulation at 5 years: where are we?

In 2007, Europe launched its [Paediatric Medicines Regulation](#) to provide better and safer medicines for children in Europe. We, the paediatric oncology community, were desperately waiting for this Regulation to significantly increase the number of new anticancer drugs developed in Europe and thus to enhance access to innovative therapies for children and adolescents suffering from life-threatening disease. As per the Regulation, a survey on its implementation has been performed by the European Medicine Agency and the European Commission, including a public consultation to seek comments from all stakeholders. [SIOPE answered](#) to the public consultation as well as European groups such as the consortium, Innovative Therapies for Children with Cancer ([ITCC](#))



and several childhood cancer parent organisations and advocacy groups.

We hope that this gave a strong message to the European Commission and other relevant policymakers of the lack of progress to date and showed how this Regulation matters for young people with cancer. The positive aspects have been acknowledged but the major limitations have been highlighted and the groups strongly urged the European Commission to take more action. It is clear that

for the time being, the Regulation did not succeed so far in increasing the number of innovative oncology drugs for children and adolescents. The Commission will define and make public this year what changes they plan to make.

### More information:

- [View](#) the Public Consultation and responses
- [View](#) SIOPE's work on the Paediatric Regulation to date

## SIOPE Community Reports and Roundups

### ■ Report from the Annual General Assembly 2012 of SIOP Europe (SIOPE)

The Annual General Assembly of SIOP Europe (SIOPE) took place last 07 October, on the occasion of the 44th SIOP Congress in London. This occasion marked the 5th anniversary of our Society and the SIOPE Presidency hand-over after three very successful years, from Prof. Ruth Ladenstein (CCRI, Austria) to Prof. Gilles Vassal (IGR, France).

Today SIOPE is a widely recognised and well-established society for oncology professionals in Brussels. However, after five years of existence, the necessary step forward for the Association's growth and representativeness is to have direct access to the paediatric oncology community at the national

level. In the course of last year we have contacted the main National Paediatric Haemato-Oncology Societies/groups (NaPHOS), reaching out to the entire European paediatric oncology community in order to build together a more representative position for our Society.

This is why during the General Assembly 2012 an important amendment to the SIOPE Statutes on the new membership module has been approved. Since October 2012, there are three new categories of SIOPE membership: full, honorary and associate. SIOPE members enjoy several

advantages, and you can contact the office at [office<at>siope.eu](mailto:office@siope.eu) (please replace <at> with @) for more information.

SIOPE carried out several activities in 2012. Among those, the event organised on the occasion of the International Childhood Cancer Day at the European Parliament was an extraordinary success, which greatly contributed to improve SIOPE's position in the European health stakeholders' arena. Hosted again this year by Irish Member of the European Parliament Glennis Willmott, this event will be repeated on 20 February 2013, where several international paediatric experts will discuss the new EU Clinical Trials Regulation, which affects not only paediatric oncology research but also other paediatric disease areas. SIOPE is involved in many other EU projects like [ENCCA](#), [PanCareSurFup](#) and [EPAAC](#) (European Partnership for Action against Cancer Initiative).

The establishment of the European Clinical Research Council for paediatric oncology (ECRC) had a substantial impact on the SIOPE's impressive performance in influencing the EU policy agenda and joining



forces with relevant advocacy organisations. SIOPE also established a strong partnership with [ICCCPO](#), incorporating thereby parent and patient groups as important stakeholders in paediatric oncology. Finally, during the past year SIOPE helped to organise and promote several education and training initiatives, such as the annual [Flims Workshop](#) (next edition taking place on 22-28 June 2013).

The new SIOPE President Prof. Vassal expressed his strong appreciation to Prof. Ladenstein for her strong commitment to the growth of SIOPE and for the many important results achieved during her presidency.

He also stressed out that, in spite of the global crisis, SIOPE's strategy for the future is still aims to improve the treatment and care of children and adolescents with cancer in Europe. Therefore, SIOPE will establish connections with the adult oncology field, as well as with advocates in the field

of rare cancers and teenagers and young adults (TYA), and reinforce the collaboration with parents and patients. Prof. Vassal concluded the General Assembly by stating his commitment to ensuring long-term sustainability of paediatric oncology and ENCCA in the long -term.

The next SIOPE General Assembly will take place during the [17th ECCO-38th ESMO-32nd ESTRO European Cancer Congress](#) in Amsterdam, from 27 September to 01 October 2013. The first day of the congress' Paediatric Track, led by SIOPE, will be the 28 September 2013.





# SIOPE Education and Training



## ■ ■ Upcoming courses and training

4th ESO-SIOPE masterclass in paediatric oncology  
24-29 November 2012, Castel Gandolfo (Rome), Italy

Prof. Riccardo Riccardi, SIOPE Board Member and lead partner for educational activities in the EU-funded FP7 project ENCCA (European Network for Cancer research in Children and Adolescents) project discusses here the highly successful ESO-SIOPE Masterclass which took place in Italy in November 2012.



Faculty and participants of the 4th ESO-SIOPE masterclass in paediatric oncology

The fourth edition of the [ESO-SIOPE Paediatric Oncology Masterclass](#) was held in Castel Gandolfo, Rome. "Translating knowledge into clinical practice" was the title chosen to better characterise this 5-day course, targeting young paediatric oncologists who wish to improve their skills in the clinical management of common childhood tumours.

A nice and quiet resort hosted 45 paediatric oncologists coming from different nations: most of them came from Europe but also from Singapore and from Egypt. Participants were selected on the basis of their personal CV and previous working experience.

The scientific programme featured:

- Sessions focusing on state-of-the-art treatment of the most common paediatric malignancy (CNS tumours, soft tissue and bone sarcoma, neuroblastoma and Wilms' tumor);
- Special lectures on more general topics such as radiotherapy, biomarkers and new drug development;
- Lectures focusing on new topics such as the specific treatment of teenagers and young adults with cancer and a discussion on ethical issues.

A unique aspect of this course was, for the first time, the preparation of case studies presented by the participants, discussed then in details by the faculty members.

The presence of the experts in the different specialities allowed for a formative discussion on diagnostic and therapeutic options and superb interaction and feedback for these paediatric oncology leaders of the future.

In relation to evaluating the course, students' feedback was very positive, rating particularly highly the structure of the course, the quality and the different lectures.

For example, to the specific question required by the ACOE accreditation questionnaire: "How would you rate the goals and learning outcomes of the meeting?", 80% of the attendees answered "excellent". In addition many professional relationships and plans for future collaborations were foreseen and established between the students and Faculty members.



# Special Features



## The European Cancer Congress 2013

The SIOPE Annual General Assembly, the latest data on paediatric oncology advances, the Paediatric Track, the SIOPE Lifetime Achievement Award, networking and information exchange with some of the biggest names in oncology and the centrality of multidisciplinary in cancer research, treatment and care: yes, it is once again the countdown to the 17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress, the biennial congress that is the largest of-its-kind in the world. This year it takes place in Amsterdam from 27 September to 01 October 2013, and is expected to be the biggest and most innovative cancer congress yet.

The 17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress will be the latest of a prestigious biennial series of meetings that have been growing in appeal and outreach across all disciplines and organisations since 1981. In partnership with ESSO 33, EACR, EONS and SIOPE - senior founding member organisations endorsing multidisciplinary as the way forward to best improve the prevention, diagnosis, treatment and care of cancer patients - the European Cancer Congress comprehensive programme of excellence consisting of 33 tracks spans the entire oncology spectrum from basic, applied and translational research to practice, treatment, care, prevention and advocacy for cancer patients.

### Regular abstract submission

Present your work at the largest platform for practice-changing data in Europe and take the opportunity to become part of the pioneering 2013 programme for this meeting by submitting an abstract. [Regular abstract submission](#) for the European Cancer Congress is open from until 17 April 2013 only.

By submitting an abstract, you underline the importance of paediatric oncology and you make a tangible contribution in establishing standards in Europe for our discipline, now and into the future. Presenting your data at this congress will also help you reach beyond the professional community, creating global outreach for your messages to lay audiences: in 2011, the largest

number of participants attended, the biggest number of abstracts ever was submitted, and the highest amount of new data was presented. Join our efforts to advance cancer treatment and care by ensuring paediatric oncology is well-represented and your messages delivered to the largest multidisciplinary audience in Europe!

### SIOPE Paediatric Oncology Track

SIOPE has worked hard to create a comprehensive and high-quality [Paediatric Oncology Track](#). This year the Track will include:

- Unique teaching lectures on several topics, including bypassing the blood brain barrier in paediatric oncology and tailored therapy of childhood leukaemia;
- Excellent scientific symposia on subjects ranging from the future of paediatric oncology in Europe to personalised medicine, and the peculiarities of cancer in teenage and young adults;
- and a promising and scientifically challenging debate on the screening of children with sarcoma and their families for family cancer syndrome mutations.

This Paediatric Track is the ideal forum to obtain state-of-the-art updates on novel anti-cancer therapies, new advances in cancer biology and all that is happening in paediatric oncology. See you in Amsterdam!

### Take advantage of your SIOPE membership !

SIOPE members can attend the **European Cancer Congress** at a reduced rate

#### More information:

17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress, 27 September - 1st October 2013, Amsterdam, The Netherlands

The European Cancer Congress [Advance Programme](#)

The European Cancer Congress [Registration Programme](#)

## Save the Dates

European Cancer Congress 27 September - 1 October, 2013

### Registration Deadlines

Early rate registration opens	1 October 2012
Early rate registration closes ( <i>receipt of payment by</i> )	9 April 2013
Regular rate registration opens	10 April 2013
Regular rate registration closes ( <i>receipt of payment by</i> )	6 August 2013
Late rate registration opens	7 August 2013
Late rate registration closes	20 September 2013
Onsite registration as of	21 September 2013

### Submission Deadlines

Regular abstract submission opens	25 January 2013
Regular abstract submission closes	17 April 2013
Fellowship grant application opens	25 January 2013
Fellowship grant application closes	17 April 2013
Late-breaking abstract submission opens	24 July 2013
Late-breaking abstract submission closes	7 August 2013

### Housing

Housing reservation closes	15 August 2013
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## Fun run/walk in Paris raises over € 200,000 for childhood cancer research



The French charity, *Imagine for Margo*, organised in September 2012 its first 'Children without Cancer run/walk', fundraising a phenomenal € 203,000, the first time the charity ever organised an event like this. 3500 donors, 600 participants and 104 teams made the Children without Cancer run/walk a great success and will support ITCC-Innovative Therapies for Children with Cancer to increase brain tumour research.

ITCC gathers 42 European Paediatric Oncology Departments with expertise in conducting early phase trials in children and adolescents, and 9 European research laboratories.

The aim of this organisation is to develop novel therapies for the treatment of paediatric and adolescent cancers in cooperation with regulatory bodies, pharmaceutical enterprises, parents and patients.

The ITCC-022 Vinilo study, which *Imagine for Margo* fundraised for, aims to explore a new treatment strategy for children affected with relapsed low grade gliomas. 150 children will participate in the study in 40 investigating centres in Europe.

Vinilo will be opened soon ... In the meantime you can download videos and view photos from the event [here](#).



## ■ ■ ECPC and ENCCA partner for teenagers and young adults with cancer

Nickie Colson from the European Cancer Patient Coalition (ECPC) discusses a meeting recently organised with ECPC members working on teenage and young adult issues (TYA) and ENCCA on sharing experiences and how best to collaborate.

In October 2012, European organisations working with teenagers and young people with cancer came together to share experiences. With several young cancer survivors in the room alongside carers – from Norway to Turkey and from Ireland to Poland – there was an energy and enthusiasm rarely seen in international gatherings.

Teenagers and young adults are an age group that often falls into the gap between service provision for adults and for children. The specific medical and psychosocial needs of these patients and their families has been known for some time, but interest in this area among patient groups is now growing and a number of organisations have been set up in recent years, who are keen to engage with international partners and projects.

Prompted by a request from a number of ECPC members to create a space for this often overlooked age group and their specific needs, this meeting was a small step in an increasingly vibrant field. SIOPE was identified as a crucial partner in this area, and a major focus of the meeting was to present the work of ENCCA and highlight the opportunities to get involved.

ECPC Board member and teenage cancer survivor Šarūnas Narbutas briefly presented his own story. After being diagnosed with chronic myeloid leukaemia at the age of 18, he started a national campaign to obtain access to imatinib for all CML patients, which was standard treatment in other parts of Europe. After collecting signatures from 6% of the Lithuanian population – the largest petition in national history – he secured access to treatment for all CML patients in Lithuania. He spoke about the passion and enthusiasm he experienced at the first World Congress for Young Cancer Patients and Survivors in Ecuador earlier this year, and was particularly struck by the open and uninhibited support for young people and cancer demonstrated by politicians.



During discussions, it immediately became apparent that there were wide differences between the countries represented, both in terms of the cultural attitudes towards cancer in young people and in terms of access to treatment, but in spite of this we quickly identified a range of common issues to address. The organisations themselves also had very different focus areas, from building and funding specialised treatment centres to raising awareness, from summer camps to sports activities. The variety of the initiatives and activities demonstrated just how much can be learned from these organisations.

Moving forwards, the group will share details of their events and activities and will arrange to meet in the first half of 2013. ECPC hopes to work closely with SIOPE and with ICCCO, who regrettably were not able to participate, to support these organisations in taking their activities further.

### Participating organisations:

Belgium >> Jongeren Tegen Kanker  
Denmark >> DrivKraeften, Proof of Life  
Ireland >> CanTeen Ireland (ECPC member)  
Netherlands >> Stichting Jongeren en Kanker (ECPC member)  
Norway >> Ungdomsgruppen  
Poland >> Alivia (ECPC member)  
Romania >> Temerarii (ECPC member)  
Turkey >> Genç Birikim Dernegi (ECPC member)  
UK >> Teenage Cancer Trust (ECPC member)  
Europe >> SIOPE

# Treasurer's Corner

Dear colleagues,

At the moment SIOPE is not discussing major financial issues (yes, this can even happen in the EU!).

The research of many of us and (partly) also of SIOPE is being financed by EU initiatives and I am happy that the funding relates to the highly important initiatives to harmonise and structure paediatric oncology research. To consolidate and develop this pan-European research, within the FP7 project ENCCA, in which SIOPE is heavily involved, there is a [working group](#) exploring possibilities to create an environment for sustainable development of paediatric oncology research in Europe. This includes integration of basic and clinical research, access to new drugs, approaches to eliminate disparity of treatment standards across Europe and related topics, but also an exploration of ways of continued funding which will enable us to build on the achievements so far.

In 2014, the new research framework of the [EU, Horizon 2020](#), will start and the first calls will be launched. At the moment, not only the budgetary structure, but also the prioritisation of research topics is being debated and we are all called upon to get involved in the discussion by contacting our national contact points, ministries or Members of the European Parliament.

The most influential development right now is the changing European legal perspective on clinical trials, including its financial consequences.



A revision of the EU Directive (now "[Regulation](#)") on clinical trials in Europe is currently hotly debated. This Regulation will have a crucial impact on clinical trials in Europe, their conduct and their financing, as it covers for example the interconnected topics of risk categorisation of trials, off-label use of drugs and insurance obligations.

SIOPE is currently the only pan-European paediatric stakeholder in the debate. Its main objective is the classification of paediatric oncology trials as "low-risk interventional clinical trials". This categorisation is new and may prove very helpful, however, currently paediatric oncology trials risk to fall under the "high-risk" category as the majority of drugs are used off-label, which involves highly work-intensive reporting procedures. Also, SIOPE is arguing that all medicinal products being used as part of a backbone standard therapy will be considered auxiliary medical products. This is also when treatments are being used off-label as the general safety information is long in existence. The proposal introduced national indemnity schemes which will considerably facilitate academia-driven clinical trials with the goal to improve standard practice.

I hope for your continuous support, please remember to become member!

Martin Schrappe



## Upcoming Event

BDA IMMUNOTHERAPY WORKSHOP  
28-29 January 2013, Frankfurt, Germany  
[MORE DETAILS](#)

INTERNATIONAL CHILDHOOD CANCER DAY 2013  
20 February 2013, Brussels, Belgium  
[MORE DETAILS](#)

EFGCP ANNUAL CONFERENCE 2013: VIRTUAL FUTURE: WHAT ARE THE ETHICAL DIMENSIONS OF USING EMERGING TECHNOLOGIES IN CLINICAL TRIALS AND RESEARCH?  
29-30 January 2013, Brussels, Belgium  
[MORE DETAILS](#)

RARE DISEASE DAY, "FASTER ACCESS TO MEDICINES FOR RD PATIENTS"  
26 February 2013, Brussels, Belgium  
[MORE DETAILS](#)

8th INTERNATIONAL CONFERENCE ON PEDIATRIC RENAL TUMOR BIOLOGY  
8-10 May 2013, Washington DC  
[MORE DETAILS](#)

EUROPEAN-ARAB SCHOOL OF ONCOLOGY  
17-18 May 2013, Cairo, Egypt  
[MORE DETAILS](#)

**ENTYAC EUROPEAN COURSE**

17-19 April 2013, Paris, France

[MORE DETAILS](#)

**PANCARESURFUP GENERAL ASSEMBLY**

17-19 April 2013, Genoa, Italy

[MORE DETAILS](#)

**RACE OF BRAVE BIKERS (AWARENESS RAISING BIKE RACE)**

28 April 2013, Marostica Italy

[MORE DETAILS](#)

**8TH INTERNATIONAL CONFERENCE ON PEDIATRIC RENAL TUMOR BIOLOGY**

8-10 May 2013, Washington DC

[MORE DETAILS](#)

**EUROPEAN-ARAB SCHOOL OF ONCOLOGY**

17-18 May 2013, Cairo, Egypt

[MORE DETAILS](#)

**ICCCPO EUROPE MEETING**

24-26 May 2013, Basel, Switzerland

[MORE DETAILS](#)

**PAEDIATRIC CANCER RESEARCH AT THE INTERFACE**

06-09 June 2013, Vienna, Austria

[MORE DETAILS](#)

**FLIMS 15: ECCO-AACR-EORTC-ESMO WORKSHOP ON METHODS IN CLINICAL CANCER RESEARCH**

22-28 June 2013, Waldhaus Flims, Switzerland

[MORE DETAILS](#)

**17TH ECCO - 38TH ESMO - 32ND ESTRO EUROPEAN CANCER CONGRESS**

27 September-1 October 2013, Amsterdam, The Netherlands

[MORE DETAILS](#)

**IARC PAEDIATRIC ONCOLOGY CANCER REGISTRIES COURSE**

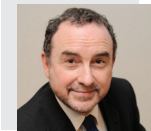
November/December 2013 (date tbc), Lyon, France

[MORE DETAILS](#)



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

To find out how you can help, please contact us at [office\[at\]siope.eu](mailto:office[at]siope.eu) (please replace [at] with @)



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