

## SIOPE News

### News from the office

After organising a successful Paediatric Track at the ECCO 15-ESMO 34 Multidisciplinary Congress in September, SIOPE has enjoyed reaping the benefits of this exposure. One of the highlights was the Symposium on 'European Standards of Care for Children with Cancer' that took place in Warsaw, Poland in October. Supported by EU Commissioner for Health, Androulla Vassiliou, the Symposium brought together medical professionals, patient and parent groups, as well as policymakers from across Europe to discuss the disparities in treatment and care standards that currently face our young cancer patients.

This 'first step' meeting was well-timed with the launch of the European Commission's milestone initiative, the European Partnership for Action against Cancer, taking place just a fortnight before.

Most significantly, the SIOPE-inspired 'ENCCA' proposal was submitted for the EU's FP7 Network of Excellence call on 'Structuring clinical research in paediatric and adolescent oncology in Europe' in November. ENCCA, the European Network of Cancer research in Children and Adolescents, will network and integrate the different tumour groups in order to define and run a global strategy in Europe for the development of new drugs and biology-driven therapeutic strategies. We have features on all these points in the newsletter, and much much more.

Finally, the SIOPE office would like to sincerely thank Prof. Kathy Pritchard-Jones for her dedication to SIOPE. As one of the foremost experts in childhood cancer, Kathy's passion and guidance was invaluable and we are hugely grateful for her leadership and drive as President. We also warmly welcome SIOPE's new President, Ass. Prof. Ruth Ladenstein and we look forward to further advancing SIOPE in its mission.

As usual, should you have any comments on the newsletter, please do let us know by contacting office<at>siope.eu (please replace <at> with @).

### Message from the President

I am delighted to be stepping into the role of President at this pivotal time for SIOPE Europe. Having just coordinated the European Network for Cancer research of Children and Adolescents (ENCCA) proposal as part of the EU's FP7 Network of Excellence call, it is inspiring to see the enthusiasm and joint efforts by so many to develop our current informal networks and support the construction of a durable, virtual network that will provide the framework for European clinical and translational research in paediatric and adolescent oncology for years to come.

As a Board member and now President, it is remarkable to see the progress SIOPE has made, even since the last edition of this newsletter. During the summer, SIOPE teamed up with ITCC once again to provide feedback on the revision of EMEA's off-patent medicines list, gathering the viewpoints of the chairs of the European clinical trials groups, and thus representing our collective needs and priorities and you can find our submission on the SIOPE website ([CLICK HERE](#) for more information). Since then, SIOPE has put its name in the hat to be a member of EMEA's Coordinating Group of the 'European paediatric network of networks'.

Related to this, it is quite obvious that the EU agenda is becoming more oncology-focused and we must not miss this opportunity. The issue of rare diseases continues to move up the EU political ladder and SIOPE will continue to play a role in increasing awareness that all paediatric cancers are rare, such as through its liaison with Eurordis, the European Organisation for Rare Diseases and RARECARE. SIOPE is also keen to be a stakeholder in the European Partnership for Action against Cancer and in particular to work closely with patient organisations like the European Cancer Patients Coalition (ECPC) and the European Institute of Women's Health, both of whom were represented at our Symposium on Standards of Care for Children with Cancer hosted by the former First Lady of Poland, Jolanta Kwasniewska. This event in particular was a high point for SIOPE in 2009 as it brought together professionals, former child cancer patients, parents, families and politicians to address the survival differences in Europe and ensure an empowered, coordinated response

We were also fortunate enough to have Professor Martin Schrappe join the Board. As Professor and Director of General Paediatrics in the University of Kiel and Chairman of the I-BFM International Study Group, we are delighted to have his expertise for the coming term.

I had the opportunity to come in as President at a unique time as mentioned above. This is the moment to express my sincere appreciation to Kathy Pritchard-Jones who has been central to SIOPE's success so far and I warmly thank her for her continuing support of SIOPE's aims and tasks. I look forward to working with the SIOPE Board members and our supporting team, Samira and Edel, at the SIOPE Brussel's office, the European tumour groups, researchers, patients and parents and supporting organisations on what appears to be a brighter future for SIOPE and childhood cancer in Europe. If you have any ideas on how best we can support you in the next year, please just let us know!

Ruth Ladenstein  
President, SIOPE Europe



Prof. Ruth Ladenstein  
SIOPE President

# SIOPE Europe's Community

## Outreach and awareness-building throughout Europe Symposium on Standards of Care in Paediatric Oncology

The provision of good-quality, multi-professional care for children and young people with cancer and comprehensive support mechanisms for their families is essential to ensure optimal outcomes. This was the 'take-home message' from the Symposium organised by the Jolanta Kwasniewska Foundation, 'Communication without Barriers' in association with SIOPE Europe (SIOPE), on 14th October in Warsaw, Poland.

Supported by EU Commissioner for Health, Androulla Vassiliou, the Symposium brought together medical professionals, patient and parent groups and policymakers from across Europe to discuss the disparities in treatment standards that currently exist in Europe. This consolidation of expertise from the key stakeholders in paediatric and adolescent cancer resulted in the agreement on the first draft of a document recommending standards of treatment and care for paediatric oncology units Europe-wide.

Commenting on the event, the ex-Polish First Lady and organiser, Jolanta Kwazniewska, stated, "Our aim is that the Symposium will contribute to the preparation and implementation of a system of care for children with cancer to ensure that all young patients in the EU have an equal chance to make a full recovery and return to normal life."

The Symposium was the outcome of a revealing SIOPE report coordinated by the Polish National Consultant for Paediatric Haematology and Oncology and SIOPE Board Member, Prof. Jerzy Kowalczyk in 2008 on the state regulations and standards of care in 25 European countries.

■ In total, 27 European countries out of a possible 49 responded to the survey disseminated by SIOPE, with 21 responses from the EU Member States.

■ 10 EU countries were found to have specific standards or regulations for a paediatric oncology-haematology ward, or at least were being planned by the relevant authorities.

■ According to Prof. Kowalczyk, "Only Austria, Belgium, France, Germany and Italy have officially recognised regulations in place; the most comprehensive document was created by the German authorities".

■ In 2005, the National Institute for Health and Clinical Excellence in the UK also created a 'Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer' document while the remaining European countries have no existing regulations but rather are managed according regular paediatric regulations.

■ Support for standardised guidelines for paediatric haematology and oncology care was expressed by all centres involved in the report.



Ex-Polish First Lady Jolanta Kwasniewska leads the discussions with the SIOPE Board Members Jerzy Kowalczyk, Ruth Ladenstein, Kathy Pritchard-Jones and Gilles Vassal.



Prof. Ruth Ladenstein, SIOPE President, Hildrun Sundseth, Board Member, European Institute for Women's Health and Prof. Jerzy Kowalczyk, SIOPE Board Member at the evening reception of the Symposium in the Hotel Polonia Palace, Warsaw, Poland.



E. Fitzgerald, SIOPE, R. Ladenstein, SIOPE President, L. Faulds-Wood, ECPC, E. A. Pomaska, Ahsoka Innowatorsky Dla Dobra Publicznego, H. Sundseth, European Institute of Women's Health, J. Kwasniewska, Communication without Barriers Foundation, S. Essiaf, SIOPE, J. Kowalczyk, SIOPE Board Member and M. Gwizdak, Communication without Barriers.

This first document, approved by all participants, provides best practice techniques and methods to shape a better care environment in an effort to ensure the best quality of life for the child patient. Numerous committed patients and parents groups have contributed, reinforcing the concept that partnership with all stakeholders is central to build political momentum and set basic standards for our national health systems.

Hildrun Sundseth, Board Member of the European Women's Institute for Health stated, "This consensus document for sharing best practice has the potential to save many children's lives across Europe and is just in time to be promoted under the Commission's 'European Partnership for Action against Cancer'.

## European Partnership for Action against Cancer

SIOPE represented childhood cancer at the first preparatory meeting of the European Partnership for Action against Cancer meeting on 07- 08 December in Brussels, attended by all key stakeholders, including health ministry representatives from twenty Member States. Current EU Commissioner for Health Androulla Vassiliou opened the meeting, which aimed to decide upon the structure and 'next steps' of the Partnership.

The European Partnership for Action against Cancer will provide 'added-value' to the work of EU Member States in prevention and cancer control. The Partnership will operate until the end of 2013 and is expected to provide a platform to identify and share information, capacity and expertise in order to help prevent and control the burden of cancer and to bring together stakeholders from across Europe to join forces in a collective effort to address the cancer epidemic. The European Commission has an ambitious goal for this project: to reduce the burden of cancer in the European Union by 15% by 2020 and represents approx. 510,000 cases.

The Partnership is focussed upon four areas:

- Health promotion and prevention;
- Identification and promotion of good practice in cancer-related healthcare;
- A coordinated and collaborative approach to cancer research;
- Health information, and the collection and analysis of comparable data.

Cancer is the leading cause of death from disease in young people across Europe. With inequality in survival rates in EU Member States and significant long-term effects in many survivors, it is essential that the quality of life and outcomes for children and adolescents are addressed and this working document provides the first steps to preventing young people from dying and suffering unnecessarily.

The SIOPE office would like to take this opportunity to sincerely thank the team at the Communication without Barriers Foundation for their superb efforts in organising this event and in particular to show our appreciation to Prof. Kowalczyk for his dedication to this vital initiative.

To view presentations from the Symposium, [CLICK HERE](#).



As the budget of the Partnership is very limited, SIOPE Europe is expected to concentrate its energies on the pillar, 'A coordinated and collaborative approach to cancer research', promoting the Standards of Care for Children with Cancer in cooperation with the 'Communication without Barriers' Foundation in Poland. Our main objective is to ensure greater public awareness of paediatric oncology in Europe and the many challenges the multi-professional community faces. We intend to work with numerous Member States, in particular in central and Eastern Europe to bring this initiative to the forefront of cancer policy and ensure Standards of Care for children with cancer are incorporated fully into national cancer plans.

This initiative is the result of the European Commission Communication, 'Action against Cancer: European Partnership' which was published earlier this year and was officially launched in September by Commissioner Vassiliou but also EU Commission President Manuel Barroso and HRH Princess Mathilde of Belgium. The Slovenian Ministry, who made the cancer burden a key priority during their EU Presidency in 2008, will be the leading Member State for this initiative. All identified actions will be need to be submitted in the form of a joint action as part of the 2010 Health Call coordinated by EU's Executive Agency for Health and Consumers. The deadline for this submission is expected to be at the end of March. For further information on the EAHC, please [CLICK HERE](#).

To find out more about the Partnership, [CLICK HERE](#).

# ECCO 15-ESMO 34

20 - 24 September, 2009

SIOPE Europe was heavily involved in the scientific programme design and coordination of the ECCO 15-ESMO 34 Multidisciplinary Congress in Berlin, Germany, specifically in this year's comprehensive Paediatric Oncology Track. The programme included an update from each of the major paediatric trial groups in Europe, teaching lectures including new approaches to clinical trial design for rare tumours and childhood cancer, a special session on advances in fertility preservation for children and adolescents, as well as scientific symposia on how to select a new drug in paediatric oncology, lessons from soft tissue sarcoma in young people, new imaging approaches and advances in leukaemia. Sharing knowledge, examining barriers and engaging with varied perspectives and expertise is central to SIOPE's work and ECCO 15-ESMO 34 represented the ideal forum to obtain a 'state of the art' update on novel anti-cancer therapies and all that is happening in paediatric oncology on your doorstep in Europe.

## SIOPE Europe Society Session

The SIOPE society session was one of the highlights of the paediatric track. Chaired by Prof. Kathy Pritchard-Jones and Dr. Ruth Ladenstein, this session featured the pick of the submitted abstracts with a paediatric oncology theme. SIOPE was also delighted to hand over its biennial award to Prof. Helmut Gadner, Head of the Children's Cancer Research Institute and St. Anna Children's Hospital, for his internationally recognised work on Histiocytosis.

Prof. Helmut Gadner has had a keen interest in the histiocytoses, a heterogeneous group of extremely rare and poorly understood diseases of the monocyte-macrophage system since the early 1980's. In 1983, together with colleagues from Austria, Germany, Switzerland and Holland, he initiated the first multicenter prospective standardised protocol for treatment of disseminated Langerhans Cell Histiocytosis (LCH) within the DAL (Deutsche Gemeinschaft für Leukämieforschung und Therapie) Cooperative Group. With the foundation of the International Histiocyte Society in 1985, Gadner became a driving force in increasing international cooperation in the field of LCH, and subsequently was appointed to chair the first randomized international clinical trial LCH-I, which was started in 1991 in cooperation with the former DAL-Study Group and clinics from Great Britain, Italy, Scandinavia and USA. Over time, many other countries joined the LCH study network and more than 3,000 LCH Patients have been enrolled onto one



of the LCH studies. The LCH-study Reference Center, based in Vienna, is acknowledged worldwide as leading the expertise in treating LCH and continually improving LCH therapy options. The work for the next study, LCH IV is in progress and Gadner will be a Senior Advisor. Gadner's scientific activities can be divided into the following topics:

- Collaborative Austrian trials on childhood acute lymphoblastic leukemia (A-BFM ALL), acute myeloid leukemia (A-BFM AML), non-Hodgkin lymphoma (A-BFM NHL), rhabdomyosarcoma (A-RMS), neuroblastoma (A-NB).
- Core center for the international trial of disseminated LCH (Histiocyte Society); cooperation with GPOH, SIOPE in prospective therapy trials for Hodgkin disease, bone tumours, germ cell tumours, Wilms tumours, CML, SAA etc.
- Allogeneic BMT in children and adolescents including unrelated donors and haploidentical donors, autologous BMT and PSCT in solid tumours w/o immunomodulating therapy.
- Molecular genetic characterization of leukemic cells and detection of minimal residual disease in childhood ALL, genetic and immunological characterization of Ewing tumours, biological properties of subtypes in neuroblastoma, cultivation and characterization of hematopoietic stem cells, transplantation immunology gene therapy and tumor vaccination.
- Assessment of quality of life in cancer patients, study and prophylaxis of psychologic and somatic side effects of chemotherapy.

Professor Helmut Gadner has won many prestigious titles during his lifetime dedication to improving the lives of our young patients struck with cancer. In 2007 for example he was awarded the Ordinul "Ofiter Meritul Sanitar" by the President of Romania and in 2008 ÖFFG awarded him the prestigious title, 'Austrian Champion in European Research'; that same year he also won the Grand Decoration of Honour for services to the Republic of Austria. Gadner has also received numerous honorary memberships in recognition of his achievements, including the Dotorem Honoris Cuasa, Medical University Victor Babes, Temeswar, Romania in 2006, The City of Vienna Scientific Award in 2004, the Hansjörg Riehm Award for Excellence in Pediatric Oncology in 2000 and the First Class Cross of honour for Science and Culture of the Republic of Austria, as well as many other honorary titles.

SIOPE Europe was delighted to offer the Lifetime Achievement award to this eminent scientist.

## Report from SIOPE Fellow, Prof. Jelena Roganovic

As a SIOPE fellowship recipient, I had a unique opportunity to join the ECCO 15 and 34th ESMO Multidisciplinary Congress held in Berlin, 20-24 September 2009. This first joint ECCO (the European CanCer Organisation) and ESMO (the European Society for Medical Oncology) congress confirmed the success of a great collaboration between these two organisations. The congress was a very good opportunity for the entire cancer community to inform us about the latest news and exciting developments of European basic, translational and clinical studies, and confirmed the position of the premier European cancer meeting.

The opening ceremony was spectacular, with Richard Bottram, marathon-runner, as the keynote speaker, followed by internationally-acclaimed Max Raabe and Palast Orchestra. During the following days around 15,000 people participated in an outstanding range of plenary sessions, teaching lectures, educational symposia, scientific symposia, workshops, debates and proffered paper sessions. Some new tracks were integrated in the congress programme, such as Oncopolicy, Patient Advocacy/Ethics, Oncology Nursing, and The Young Oncologists Track.

### Oncopolicy Track

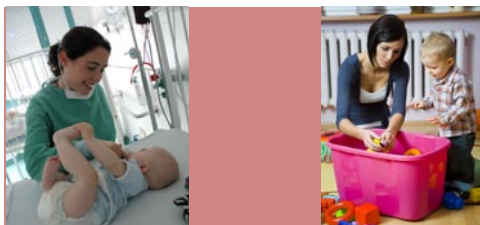
For the first time, political issues came into the spotlight at a multidisciplinary scientific congress in Europe. With the aim of ensuring cancer is prioritised on the EU health and research agenda, EU Commissioner for Health Androulla Vassiliou and Commissioner for Research Janez Potocnik joined other high-profile stakeholders at ECCO 15-ESMO 34 to debate the hot topics that are currently being addressed by the cancer community at the political level, including the European Partnership for Action against Cancer, a European Platform for Translational Research, the High-level Pharmaceutical Forum, national cancer plans, drug and lifestyle-mediated prevention initiatives, optimising drug development and the establishment of a European Academy of Cancer Sciences. To view many of the presentations from these sessions, [CLICK HERE](#).



Paediatric sessions covered very interesting topics including new approaches to clinical trial designs for rare paediatric tumours, advances in fertility preservation for children and adolescents with cancer, new imaging approaches to response assessment in childhood cancer, and advances in childhood leukaemia.

For me the most impressive part of the meeting was the SIOPE Award lecture by Prof. Helmut Gadner, and his brilliant overview of Langerhans cell histiocytosis. Altogether, I benefitted from and enjoyed the multidisciplinary of the congress. Thank you to all for allowing me to attend this great meeting.

Jelena Roganovic, MD, Prof.  
Department of Hematology and Oncology  
University Children's Hospital Rijeka, Croatia





Participants from the ITCC Training Days in Rome this October.

## COMMITTEE Reports and Roundups

### ■ SIOPE Education and Training

#### Training Days in Rome, Italy in October, 2009

Report from Prof. Riccardi, SIOPE Education and Training Committee Chair on the ITCC

Despite high cure rates, cancer is still a life-threatening disease in children, and remains the major cause of death from disease beyond the age of 1 year.

ITCC Consortium (Innovative Therapies for Children with Cancer) was created in 2003 as a network of paediatric oncology centres with expertise in early drug clinical trials, aiming at developing novel therapies for paediatric malignancies through the translation of tumour biology into clinical evaluation of compounds developed in adults.

Providing an updated training course for young researchers and clinicians acting in paediatric oncology all over Europe is an essential step to improve knowledge and skills in the conduct of phase I/II trials.

With this in mind, the main goal for the ITCC Education Task Force in 2008 was to organise postgraduate courses addressed to young European paediatric oncologists interested in the different aspects related to the development of new agents.

The second training course, "ITCC Training Days" was held at the Catholic University of Rome, Italy, from 22-24th October, 2009.

While the previous event incorporated the 44 ITCC-accredited centres, this year's event targeted motivated doctors and research nurses working in other European centres of paediatric oncology as well as interested pharmaceutical companies, the objective being to engage with a small number of enthusiastic individuals.

36 participants from centres across Europe, namely Austria, France, Germany, Italy, the Netherlands, UK, Czech Republic, Switzerland and Turkey were registered along with two representatives from pharmaceutical companies totalling 38 attendees. The average age of attendees was 38 years, ranging from 22 to 56 years.

The programme consisted of full lectures presented by the various ITCC coordinator members but also by experts in the field of new models in statistics and of the conduct of early clinical trials. The presence of speakers representing pharmaceutical companies allowed for an interesting and open debate on the integration of clinical research and drug development with particular attention given to academia – pharma regulation in paediatric oncology.

In addition, the course contained workshop sessions led by an interactive methodology, as participants faced particular situations connected with the conduct of phase I/II trials with all actions and decisions in relation to these trials discussed in detail.

The primary goal of these 'Training Days' was to create a course that focused upon the central role of participants who were able to experience and evaluate examples of trial designs by discussing case studies and creating role plays in order to simulate the interaction between clinical staff and parents when planning a new trial.

Interesting aspects related to biomarkers in anticancer drug development presented by Herbie Newell and classical and new designs of phase I trials by Marie Cecile le Deley. A significant part of the course was devoted to ethical aspects with a presentation on “How to propose an early clinical trial to patients and parents” by Francois Doz and Riccardo Riccardi.

The course was very positively evaluated by participants who praised the course’s general organisation and scientific structure through an evaluation sheet administered at the end of the course. In particular participants found the

workshop system very useful and a productive means for greater debate and interaction.

Many thanks to SIOPE for the excellent dissemination work of the general information about the event, especially through the SIOPE website.

Given these positive results, we are planning to have the third edition of the ITCC Training Days at the end of 2010.



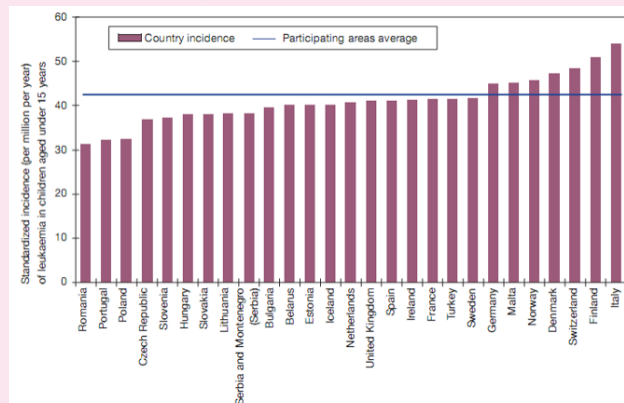
## Training in Paediatric Haematology and Oncology in Eastern Europe

A European Training Programme in Paediatric Haematology and Oncology (PHO) has been accepted by a number of European countries. Although the programme sets out the minimum requirements for PHO training, the SIOP Europe Education and Training Committee was aware of the difficulties less-developed European countries faced in running such a programme.

With the intention to consider the educational needs and problems in all European countries and how they may best be addressed, an analysis of the status of PHO education and training in Eastern Europe was performed. The choice of countries to include was not straightforward, as there are numerous contrasting definitions of the boundaries of the region. For the purpose of this report, the following countries were analysed: new EU member states (according to the last EU accession) – Bulgaria and Romania, three EU candidate states – Turkey, Croatia and the Former Yugoslav Republic of Macedonia, as well as a number of other countries in the region, namely Albania, Azerbaijan, Armenia, Belarus, Bosnia and Herzegovina, Croatia, Moldova, Montenegro, Serbia and Ukraine.

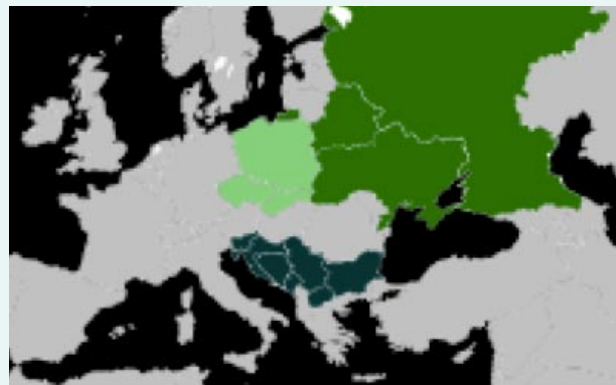
Based on the official World Bank assessment, most of the countries fall into the category of middle-income countries (Azerbaijan, Albania, Armenia, Belarus, Bosnia and Herzegovina, Former Yugoslav Republic of Macedonia, Georgia, Moldova and Ukraine are in the subgroup of lower-middle income, while Montenegro, Serbia, Romania, Bulgaria, Turkey are in the subgroup of upper-middle income). Croatia is the only high-income country in the region.

STANDARDISED ESTIMATES OF LEUKAEMIA IN CHILDREN AGED UNDER 15 YEARS, SELECTED COUNTRIES, 1970 - 1999



Source: Incidence of Childhood Leukemia, European Environment and Health Information System Factsheet N° 4, 1, May 2007

SLAVIC LANGUAGES SPEAKING COUNTRIES OF EASTERN EUROPE



Source : Wikipedia  
en.wikipedia.org/wiki/Eastern\_Europe, 21 October 2009

Extracting information regarding childhood malignancies in these European countries proved to be highly problematic, as for the most part no childhood malignancy registry is available. Of the 15 countries considered, only Belarus appeared to have an official registry. The expected number of paediatric patients suffering from cancer was estimated based on the overall annual incidence of malignant disease and demographic data of the proportion of children. The projected incidence of malignancies is about 7700 in the total paediatric population of the region, amounting to about 56.6 million.

Examining the infrastructure presumed to be necessary for PHO training, we looked into the number of centres and universities in each country. The conclusion is that the above infrastructure in fact does exist in most of the countries, since there are between one and five medical schools per country, apart from Ukraine and Turkey, where the number is even greater. Likewise, in most of the countries, there is one or more paediatric haematology and oncology treatment centres. Nine of the fifteen countries analysed did not have a paediatric oncology society established and it was unclear if such a society existed in two of the states examined. Eight of the states had paediatric oncology parental organisations set up according to the ICCPO data.

Currently, in all countries assessed, there seems to be very little regulation on ensuring that training in PHO is conducted for doctors working in PHO tertiary care units as well as lack of systemic auditing and/or assessment. While a site inspection of the training centres by SIOPE would be an ideal way to handle this problem, this is very difficult both to organise and, in particular, to fund.

Many western European institutions have links with their eastern European counterparts, in the form of twinning programmes, which seems to be an efficient model of providing help in PHO training. Therefore we assessed the contacts within the international medical community who held SIOPE membership. The number of SIOPE members per country varied widely: Albania, Armenia, Azerbaijan, Georgia, Moldova and Montenegro have none, Bosnia and Herzegovina 1, Ukraine and the Former Yugoslav Republic of Macedonia 2, Belarus 3, Bulgaria 5, Serbia 10, Croatia 11, Romania 12, while in Turkey there appears to be more than 50 registered members.

The data analysis provided is preliminary and the SIOPE Europe Education and Training Committee envisages the promotion of a rational and achievable strategy to address the major discrepancies in the standards of education and training between European countries to enable all European countries to implement the same strategy of PHO training outlined in the SIOPE document.



## Joint SIOPE Europe/ EONS/ ECCO Special Project Collaboration Between Nurses and Doctors in Paediatric Oncology

Report from Alison Arnfield,  
Project Co-ordinator

A SIOPE Europe - EONS project funded by the European CanCer Organisation (ECCO) to develop collaborative working between nurses and doctors in children's cancer units across Europe is about to conclude. In this fourth and final year, six pairs of nurses and doctors from Serbia, Belgium, Poland, Greece, Germany and the UK have continued their local work under the auspices of the collaborative project. Appreciative Inquiry continues to

underpin the work and its use has been a challenge and inspiration to all concerned. The local projects, each led by a senior nurse and doctor from the units involved have included: the introduction of a telephone support line for families, a staff education programme, development and implementation of a pain protocol, launching a staff support network and introducing collaborative clinical decision making.





The six doctor-nurse teams from across Europe and their mentors gathered for the final Special Projects seminar on 19th September, 2009 in Berlin, Germany

The teams and project coordinators, led by Professor Faith Gibson, met for the last and final time at a two day seminar in Berlin in September where they shared their experiences over the life of the project and offered support and ideas to a new team from Portugal who are just starting to develop their own project. Plans to publish the overall work are in progress and several of the local

teams are also planning to publish their own work in the near future.

To conclude the project, work is in development to make materials and information available to a wider audience on line. Once it is completed it will be advertised widely across the European cancer professional's community.

## SIOPE Clinical Trial Groups

### SIOPEL featured in NEJM

SIOPE Europe was delighted to hear the good news that the SIOPEL group has been featured in the New England Journal of Medicine. Their report on the prospective randomised trial in standard risk hepatoblastoma (SIOPEL 3) was featured in the October issue. This reflects the clear advances that are being made in clinical research in paediatric oncology in Europe! The New England Journal of Medicine (N Engl J Med or NEJM) is an English-language peer-reviewed medical journal published by the Massachusetts Medical Society. It is the oldest continuously published medical journal in the world, and is the most widely read, cited, and influential general medical periodical in the world.

Ref: Cisplatin versus Cisplatin plus Doxorubicin for Standard-Risk Hepatoblastoma  
NEJM, October 22, 2009, No. 17, Vol. 361, pp. 1662-1670.

Contributors: Giorgio Perilongo, M.D., Rudolf Maibach, Ph.D., Elisabeth Shafford, M.D., Laurence Brugieres, M.D., Penelope Brock, M.D., Bruce Morland, M.D., Beatriz de Camargo, M.D., Jozsef Zsiros, M.D., Derek Roebuck, M.D., Arthur Zimmermann, M.D., Daniel Aronson, M.D., Margaret Childs, Eva Widing, M.D., Veronique Laithier, M.D., Jack Plaschkes, M.D., Jon Pritchard, M.D., Marcello Scopinaro, M.D., Gordon MacKinlay, M.D., and Piotr Czauderna, M.D.

### MEP Alojz Peterle visits SIOPE Clinical Trials Groups

During our last Clinical Trials meeting in ECCO 15-ESMO 34, SIOPE welcomed a member of the European Parliament, Alojz Peterle, for a short briefing on what the Parliament is currently working on in cancer policy. Mr. Peterle has been a member of the European Parliament since 2004. Previously Slovenia's Prime Minister, the first since the country's independence, he also held the position of Minister for Foreign Affairs twice.

Peterle has been an active promoter of cancer care, in particular as co-chair of the informal all-party forum, 'MEPs against Cancer'. Peterle himself has promoted a healthy lifestyle for a number of years and, after his own experience of cancer, has invested great effort in raising awareness of cancer issues.



# ENCCA, European Network for Cancer research in Children and Adolescents (EU FP7 Project)

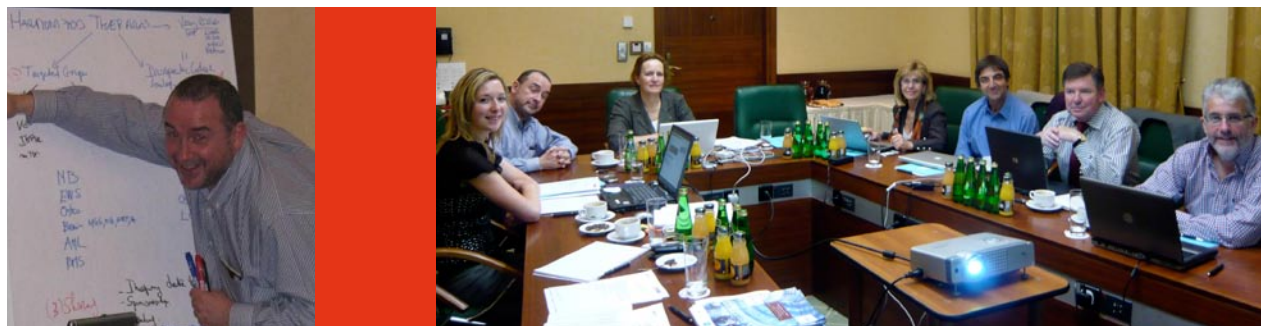
After major joint efforts of all the European multinational clinical trial and research groups, we are very pleased to announce that we have achieved a major step by submitting a joint application for a Virtual Institute of Clinical Research in Paediatric and Adolescent Oncology and its acronym is ENCCA (European Network for Cancer research in Children and Adolescents).

The ENCCA Network of Excellence aims to bring together the existing informal Clinical Trials Groups in Paediatric and Adolescent Oncology towards a European Virtual Institute to reduce knowledge fragmentation and enhance their communication, collaboration and management of effective clinical research in Europe. The objective is to restructure knowledge-sharing through the integration of the whole chain of stakeholders (epidemiologists, biologists, clinicians, drug developers, statisticians, industrials, imaging developers and IT partners in electronic health records, parents and ethical and regular authorities) and to support the acceleration of the development of innovative therapeutic strategies for children and adolescents with cancer. This will in turn facilitate access to efficient cure services for children and adolescents across Europe and support enhanced interest in scientific and clinical careers for young European students. It will in addition contribute to better care and quality of life for children, adolescents and parents. Within this project, we are also planning to create a European Clinical Research Council for Paediatric and Adolescent Oncology which will be composed of the chairmen of the different European disease groups and will contribute significantly to the political vision of creating a European Research Area (ERA). This Council will help to address common issues in paediatric oncology, facilitate access of the various groups to the ENCCA network and

thus encourage the creation of the links between ENCCA and the paediatric and adolescent oncology community through the established disease-groups. It will steer ENCCA in an effort to achieve its goals.

### ENCCA Goals:

- Structure and integrate on a sustainable basis, and European scale, the way that clinical and translational research in children and young people with cancer operate by proposing a European Strategy for Clinical and Translational Research in paediatric and adolescent Oncology
- Use the existing European research tools and equipment efficiently in paediatric oncology.
- Promote innovative methodology and designs for clinical trials, as well as their implementation and integration to address the specific needs in rare diseases
- Initiate harmonised therapeutic strategies by increasing significantly access to knowledge on paediatric tumour biology and interactions between tumour and host.
- Facilitate strategic discussions and joint research between scientists and clinical investigators for prioritisation of drugs to be studied in the paediatric age range and the translation of this knowledge into biology-driven and risk-adapted treatments
- Facilitate the sharing of knowledge and technologies across disciplines and the chain of all stakeholders in Europe (academia, parent and patient organisations, pharmaceutical companies and regulatory bodies) and improve the career structure in paediatric and adolescent oncology clinical and translational medicine.



■ Improve substantially the quality of life of children and adolescents with cancer, in particular the long-term side-effects of current and future treatments

■ Propose common ethical definitions of issues and solutions adapted to national and cultural requirements, while monitoring ethical issues in the implementation of the European agenda in clinical research.

■ Streamline and facilitate funding of clinical research from European and national public fundings as well as from charity and other private funds.

We look forward to a positive response from the European Commission

On behalf of the ENCCA Writing Committee:

Ruth Ladenstein, St. Anna's Institute, Vienna

Kathy Pritchard-Jones, Royal Marsden Hospital, London

Gilles Vassal, Institut Gustave Rouissy, Paris

Martin Schrappe, University Medical Center

Schleswig-Holstein, Kiel

ALMA Consulting Group, Paris

SIOPE, Brussels

## SPECIAL Features

### Profile of **incoming** President

Incoming President Ass. Prof. Ruth Ladenstein from the Children's Cancer Research Institute in Vienna, Austria became a SIOPE Board Member in 2006 and since then has been committed to developing the organisation. With her depth of experience in clinical trials activities and as the SIOPE Europe Neuroblastoma President, she has led the SIOPE Clinical Trials Committee. She will now hold the position of President for two years..



Ruth and Kathy attending the ECCO 15-ESMO 34 Presidential Dinner in Berlin, Germany. Courtesy of <http://www.franknuemberger.de>, ECCO 15 – ESMO 34

### Profile of **outgoing** President

The SIOPE office would like to take this opportunity to sincerely thank Prof. Kathy Pritchard-Jones for her outstanding work both as President and Board Member of SIOPE. A paediatric oncologist and translational researcher based at The Institute of Cancer Research/Royal Marsden Hospital (UK) since 1992, she was appointed Professor of Childhood Cancer Biology in 2003 and is the chief investigator for UK participation in the current multinational phase III clinical trial, SIOPE WT 2001, and is active in new drug trials of biologically targeted therapies in childhood solid tumours, amongst many other activities. She will continue to contribute to SIOPE as Past President

### NEW SIOPE Board Member : Martin Schrappe



There was unanimous agreement by the SIOPE Board to invite Professor Martin Schrappe to join the Board of Directors.

As Professor and Director of General Paediatrics in the University of Kiel and chair of the I-BFM group, Martin will be an important asset to the SIOPE time at this critical time for haemato-oncology in Europe.

## Report from **Flims fellows**

11th joint ECCO - AACR - ASCO Workshop on "Methods in Clinical Cancer Research"

Waldhaus, Flims, Switzerland, 20 – 26 June 2009

Conducting clinical trials is essential to the development of new cancer treatments but researchers face many challenges and the right combination of knowledge and expertise is needed. The FLIMS workshop offers young oncologists the opportunity to learn the fundamentals required for clinical trial design. This annual joint workshop, held deep in the Swiss mountains in early summer, facilitates oncology researchers to improve the design and conduct of clinical trials. Starting from 2008, SIOPE sponsors outstanding candidates to help the next generation of young paediatric oncologists.



Dr. Daniel Morgenstein, based in the Institute of Child Health in Great Ormond Street Hospital in London, writes an interesting piece on his experience as a SIOPE fellow at the Flims Workshop in June 2009, organised by ECCO, AACR and ASCO

The joint ECCO-AACR-ASCO Workshop on Methods in Clinical Cancer Research – more usually known simply as 'the Flims Workshop', after the small Swiss town in which it is held – has built an unmatched reputation for developing the clinical trial skills of trainee oncologists. It was therefore with no small measure of trepidation that I learnt that my application for the June 2009 meeting had been accepted. The prospect of writing an entire clinical protocol within the week-long duration of the course seemed something of a daunting, if not impossible, task; a feeling that I was later reassured to discover was held by many, perhaps most, of the other delegates.

The Flims Workshop itself includes a series of lectures throughout the week covering the key topics of trial design; ethical, statistical, practical and legal considerations; patient perspectives and so on. Whilst these provide a foundation of knowledge, probably the most important elements of the course are the small protocol development groups (PDGs), workshops and opportunities for one-to-one interaction with members of the faculty – a hugely impressive group of individuals drawn from around the world and including many leading experts in a wide variety of fields. The PDGs provided opportunity for discussion of the protocol concepts proposed by each delegate and for subsequent detailed consideration of some of the intricacies of further protocol development and trial implementation. From a personal perspective as a paediatric oncologist in training, it was hugely valuable to have the opportunity to interact with those from a range of adult disciplines including surgeons, clinical and medical oncologists. The range of trial protocols under discussion was really something of a revelation and, for me at least, reinforced the need to

try to expand the scope and range of clinical trial work in the paediatric field, albeit with the additional difficulties that that entails. The workshop also provided something of a rare opportunity for interaction with medical statisticians, to hear from them about the importance of considering statistics early on in trial design and crucially to discuss the details of individuals protocols on a one-to-one basis. It was, I think, hugely beneficial that these discussions could be both theoretical and practical, i.e. discussing specific issues relating to the protocols under development. It is rare that a course provides both the opportunity to acquire knowledge and then, immediately, to practice implementing it; this is, perhaps, one of the key successes of the Flims Workshop.

The busy programme of organised sessions was supplemented with undirected time in which delegates were free to work on their protocols, such that by the end of the week everyone was able to hand in a complete (or, at least, almost complete) protocol. Excellent IT facilities were provided for the duration of the workshop and it was an impressive sight to see rows of delegates tapping away at computer keyboards well into the night – whether a result of individual enthusiasm or the tightly defined deadlines is perhaps less easy to know. Overall logistical organisation was truly excellent and this was surely a crucial component to the success of the meeting.

For me, whilst the Workshop has brought home how incredibly complex and potentially difficult the process of clinical research can be – having to tackle scientific, ethical, practical and regulatory issues – it has, importantly, also provided a structure by which to consider and address these complexities.

The workshop process of going from a clinical trial concept to completed protocol within the week showed what is possible and was, for many of us, something of an eye-opener. Finding trial funding and securing ethics and regulatory approval remain challenges for another day – although, if the data are to be believed, challenges

that Flims Workshop alumni have an impressive record of over-coming.

Dr. Daniel Morgenstern  
UCL Institute of Child Health, London, UK



I was one of the selected participants in Flims last June and I would like to describe in a few words the extraordinary experience that I lived. In terms of Oncology is easy to be involved in clinical trials, especially when you are close to the end of your fellowship training, but it's a complicated issue to find the right place and the right people to learn the design of these clinical trials from every point of view.

I had the possibility during this intensive Workshop of learning, investigating, literature reviewing, discussing about the different aspects of my trial with renowned oncology experts and statisticians from the whole world. I enjoyed during that week a great exchange of information thanks to lectures, small discussion sessions and roundtable sessions with the faculty members. In addition I had the opportunity to receive particular advice and counseling from the expert in face-to-face sessions and I obtained specific answers about my project.

Flims was personally very enriching and in spite of the exhausting days, great moments with the fellow students and the faculty members were possible.

Definitively I had a very fruitful experience and I encourage every young physician involved in oncology to participate in such a memorable workshop.

Dr. Maria del Mar Andres  
Children's Hospital "La Fe" Valencia, Spain

The work in my protocol group let me discuss in greater depth the issues raised during talks and establish nice contacts that will also be of importance in my future career and day-to-day work.

## NEWS Bites

### Flims 2010

The 12th intensive workshop for European junior clinical oncologists in any clinical research specialty area, ECCO- AACR-EORTC- ESMO 'Methods in Clinical Cancer Research' takes place once again in Waldhaus Flims, Switzerland from 19-25 June, 2010. SIOPE Board Member, Prof. Riccardo Riccardi is once again a Faculty Member of this innovative initiative. The deadline for receipt of applications is **12th February 2010!** To find out more, just [CLICK HERE](#).

### ESO-SIOP Europe Masterclass

The 3rd ESO-SIOP Europe Masterclass in Paediatric Oncology Castel Gandolfo takes place in Rome, Italy on 12-18 June, 2010. This clinically-oriented educational programme has been designed for young paediatric oncologists who wish to improve their skills in clinical management of common childhood tumours. The application deadline is **19th February, 2010**.

### Childhood Cancer in ECCO PAC

We were delighted that ECCO, the European Cancer Organisation, has just announced its acceptance of our nomination for Anita Kienesberger of the Austrian parent organisation, ÖKKH and head of ICCPO Europe, to be a member of their Patients Advisory Committee (PAC) which will ensure the voice of childhood and rare cancers will be represented.

### Guido Paolucci International Award 2010

The Società Italiana di Ricerca Pediatrica (SIRP) Accademia delle Scienze Istituto di Bologna is offering an award of EUR10, 000 for papers on clinical research in paediatric oncology and haematology. The submission deadline is **12th February, 2010**. For further information e-mail at [premiopaolucci@unibo.it](mailto:premiopaolucci@unibo.it) (please replace @ with @) mentioning "Guido Paolucci International Award 2010" in the subject line.

## Survivors of childhood cancer have lifelong higher risk for new cancer

Four out of five children who get cancer survive today. Unfortunately the treatment also means a higher risk of a new cancer later in life. A new, large-scale Scandinavian study shows that this is a lifelong higher risk. The study also shows that it includes other cancer types than known so far.

People who have survived cancer as a child, have three and a half times higher risk of developing a second cancer later in life. That is the result from the new study published in the Journal of the National Cancer Institute, JNCI.

Using data from cancer registries in Denmark, Norway, Sweden, Finland and Iceland, 47.697 people have been identified who survived childhood cancer between 1943 and 2005. That is the largest group of childhood cancer survivors ever studied in the world. The oldest have been followed up to the age of 79. All in all there were 1088 extra cases of cancer than what you would have expected in a group of the same size and age.

Many studies have previously shown a significant higher risk of new cancer a few years after the treatment. But with a group we can lay down a map of the risk over a longer period of time, and that has been unknown so far because it takes a large group of patients to get an overview of this fairly rare consequence of the cancer treatment. Unfortunately we find that the higher risk is lifelong, and that it doesn't decline but increases with age, says head of research department Jørgen H. Olsen of the Danish Cancer Society who is the lead scientist behind the study.

### Not only leukaemia and lymphoma

It has long been known that the treatment against childhood cancer increases the risk of getting lymphoma, leukemia, sarcoma and thyroid cancer in a number of years after the treatment. But the new study shows that as the childhood cancer survivors get older extra cases of other forms of cancer appear, compared to what you might expect in a group of people that age. This is mainly cancer in the brain, breast and gastro intestinal cancer.

Of course this evidence is vital for doctors and childhood cancer survivors. They need to be aware of symptoms of these forms of cancer and respond to them and go to their doctor.

Consideration also needs to be made on whether it is possible to modify the treatment of children with cancer while still keeping the successful result of the treatment with the same survival rate, says Professor Olsen.

### Effect of treatment more important than side effects

The history of treating children with cancer is a history of success. In 1950 about one child out of four survived a cancer disease. Today the number is four out of five. The development is primarily due to the discovery in the 1970s of treating a number of cancers with several forms of chemotherapy in combination with radiation. The new study also demonstrates that the more effective the treatment, the higher risk of getting a second cancer.

The downside of the huge treatment success is this cancer risk further down the line in the life of a survivor. But the success story remains the treatment the child receives to live his life. There is absolutely no reason whatsoever to consider whether it is worth giving the treatment because of the higher risk of new cancer or because of other side effects. That is how effective today's childhood cancer treatment is. It means, that the majority of these children survives cancer and lives a long and good life, says Jørgen H. Olsen.

Source: Helle Falborg, Danish Cancer Society.



# Dates to Bookmark

## **The ECRIN Multidisciplinary Workshop on Risk-Based Approach in Clinical Trials**

takes place on 18 January, 2010, in Barcelona, Spain. More information is available [HERE](#).

The EFGCP Annual Conference 2010 on **Aspects of Personalised Medicine for Society – a Challenge Yet to be Met** takes place on 26 and 27 January, 2010, in Brussels, Belgium. For more details, [CLICK HERE](#).

February is Childhood Cancer Awareness Month! **World Cancer Day** (04th), **International Childhood Cancer Day** (15th) and **Rare Disease Day** (28th) all take place in February!

The ECRIN Multidisciplinary Workshop, **Towards a Better Future for Pharmacovigilance in Clinical Trials** takes place on 08th February 2010 at the EORTC Headquarters in Brussels, Belgium. To find out more [CLICK HERE](#).

The **7th EONS Spring Convention** takes place on 15-16 April, 2010 in the Hague, the Netherlands. To find out more, [CLICK HERE](#).

The **International Paediatric Oncology and Haematology Update Meeting (IPHOUM)** will take place in April 29-30, 2010 in Edinburgh, Scotland.

For further information, please contact the IPHOUM office (iphoum<at>indexcommunications.com (please replace <at> with @)).

The **5th European Conference on Rare Diseases** meets on 13- 15 May, 2010 in Krakow, Poland. To view the programme and to register, check out the website, [www.rare-diseases.eu](http://www.rare-diseases.eu)

The **Joint ECCO - AACR - ASCO Workshop on Methods in Clinical Cancer Research** ('Flims' takes place from 19-25 June, 2010 in Flims, Switzerland. For workshop updates, please [CLICK HERE](#).

The **6th International Conference on Teenage and Young Adult Cancer Medicine** takes place from 07-09 June, 2010 in London, UK. To find out more, contact Sam Greshoff (sam@greshoff.free-online.co.uk).

The **Advances in Neuroblastoma Research (ANR 2010)** meeting will take place from 21-24 June, 2010 in Stockholm, Sweden. For further information, just [CLICK HERE](#).

The **3rd ESO-SIOP Europe Masterclass in Paediatric Oncology** takes place from 12-18 June, 2010 in Castel Gandolfo (Rome), Italy. To find out more, check out the European School of Oncology website, [www.eso.net](http://www.eso.net).

The **Innovative Therapies for Children with Cancer (ITCC) Annual Meeting** is scheduled to take place from 30 September – 01 October, 2010 in Paris, France. For more information, check out the ITCC website, [www.itcc-consortium.org](http://www.itcc-consortium.org)

The **13th European Health Forum Gastein** takes place from 06-09 October 2010 in Bad Hofgastein, Austria. To find out more on this event, please [CLICK HERE](#).

The **33rd World Congress of the International Society of Hematology (ISH 2010)** will take place from 10-14 October, 2010 in Jerusalem, Israel and more information is available by [CLICK HERE](#).

## **SIOP 2010- the 42nd Congress of the International Society for Paediatric Oncology**

takes place from 21-24 October, 2010 in Boston, USA. Further information is available here, <http://www.siopboston2010.com/>.

# About SIOPE

**Support** and facilitate professional, medical, scientific and educational co-operation and training across Europe

**Integrate** patients and parents and bridge the gap between family groups, professionals and policymakers in Europe

**Optimise** access to information and promote multi-centre and multinational clinical trials, forming a common platform for best practice guidelines in clinical research

**Promote** better policies for children with cancer and raise awareness of the numerous challenges faced by paediatric oncology professionals to EU policymakers

**Elevate** standards for training and care in paediatric oncology and develop European guidelines

## Why become a Subscriber of SIOPE?

SIOPE, the European Society of Paediatric Oncology, is the only pan-European organisation actively engaged in promoting awareness of childhood cancers. Join an active network of oncologists, radiotherapists, surgeons, nurses and scientists dedicated to optimising the care of children and adolescents with cancer.

Benefits of subscribership include:

### ■ Use our connections

You will have exclusive access to our database including the European Clinical Trials Groups and National Childhood Cancer Organisations.

### ■ Be represented

You will be represented at EU conferences and seminars. SIOPE canvasses its subscribers to ensure a coordinated response in order to voice your opinion to key policymakers.

### ■ Access the European Journal of Cancer

With 18 issues annually, you can benefit from online access to the international oncology journal that publishes original research, editorial comments and review articles on experimental oncology, clinical oncology (medical, paediatric, radiation, surgical), and on cancer epidemiology and prevention.

### ■ Influence

As a subscriber, you can influence the EU decision-making process. SIOPE is part of a powerful network, including being a member of the European CanCer Organisation.

### ■ Be regularly informed by email

You will receive regularly updates by email on SIOPE activities, EU decision-making, job opportunities, training seminars and relevant conferences and events.



Working to ensure the best possible care and outcomes for all children and young people

### ■ Receive our e- newsletter

You will receive three newsletters per year which gives a wealth of information on upcoming meetings, educational courses, proceedings at EU level, SIOPE activities and information on how to get involved.

### ■ Gain training

SIOPE is dedicated to promoting information-sharing and training. Educational projects include the organisation of workshops and seminars related specifically to paediatric oncology. SIOPE works on training projects with the European School of Oncology (ESO), Innovative Therapies for Children with Cancer Consortium (ITCC) and the European Oncology Nursing Society (EONS), for example.

### ■ Share best practice and experience

As a subscriber, you are part of a large, interdisciplinary network that allows you to share best practices and network across Europe.

### ■ Be actively involved

Contribute to SIOPE by pinpointing the issues and helping us achieve results at EU level.

### ■ Save money

You can receive reductions to conferences and seminars such as the ECCO-ESMO biennial conference as well as the opportunity to apply for travel grants.

### ■ Be part of a global network

SIOPE is part of the worldwide organisation, SIOP, the International Society of Paediatric Oncology, with over 800 members situated in Europe.

To join an active network dedicated to improving the care of children with cancer, please email [office@siope.eu](mailto:office@siope.eu) or visit our website, [www.siope.eu](http://www.siope.eu)





*Seasons Greetings to you and your  
family and a very Happy New Year  
from the SIOPE office!*

*Samira and Edel*

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

SIOP EUROPE (the European Society for Paediatric Oncology)  
Avenue E. Mounier 83  
B-1200 Brussels  
Belgium

Tel: +32 2 775 02 01  
Fax: +32 2 775 02 00  
Direct: +32 2 775 29 34  
[www.siope.eu](http://www.siope.eu)

