

SIOPE News from the Office

Dear Readers,

We hope you all had an excellent winter vacation. The team was really glad to meet some of you in Berlin at the SIOPE 40th Congress. Hereby we would like to thank you for your support and those warm regards which we received in Berlin.

The fourth edition of SIOPE news announces the launch of the SIOPE subscriber category, the latest activities of the SIOPE Clinical Trials Support Desk, reports from the ESO-SIOPE Masterclass in Paediatric Oncology in November 2008, our survey of national recommendations for standards for Paediatric Cancer Units, as well as news surrounding SIOPE advocacy and networking activities and changes at the office.

We hope that this issue of SIOPE news fully informs our supporters, readers and community about our activities and achievements since October 2008. Should you have any comments and suggestions please contact the SIOPE office via Email at: office@siope.eu



Message from the President



Prof. Kathy Pritchard-Jones
SIOPE President

Dear colleagues,

Welcome to 2009, the first year of SIOPE's new initiatives that aim to reach out to all those practising in childhood cancer in Europe. With the enthusiastic support of our office staff (Samira Essiaf and Jocelyne Wang), we launched our new website and subscriber category in January. I urge you all to visit our new platform for connecting and informing health professionals working in the field of childhood cancer in Europe. This important initiative will only succeed with your support. Therefore please do take a moment to sign up as a personal SIOPE subscriber – you will not only be contributing to the success of our initiative, but also ensuring that you remain at the cutting edge for easy access to communications of high relevance to your research and practice. The benefits of being a SIOPE subscriber are laid out in the following pages.

During 2009, the SIOPE Board will be focussing on the clinical trials agenda, continuing to increase education and training opportunities of the highest calibre for young oncologists and defining the basic standards that should be provided in specialist treatment centres. These areas are being ably led by Professors Ruth Ladenstein (Austria), Riccardo Riccardi (Italy) and Jerzy Kowalczyk (Poland) who have provided details inside.

On the political front, SIOPE has been active in ensuring the voice of children with cancer has been at the forefront of European-wide initiatives to highlight the challenges imposed on multinational clinical trials by the current implementation of the EU Clinical Trials Directive. Despite the EU itself investing funds from the seventh Framework Programme into a project to look at the impact of European legislation on clinical trials (the ICREL project), we learnt at a meeting in the autumn 2008 that any major changes would have to await the change of the European Parliament! So, we have to work with the current legislation for some time to come, hence the importance of learning from each other's experiences in trial design and implementation, to minimise bureaucracy. Please do all contribute to the important work being taken forward by Professor Ruth Ladenstein. We expect that there will be opportunities for support announced in the next FP7 call due in March 2009 – we need to be ready to work together to make the most effective use of European funding. It is therefore excellent to have Professor Gilles Vassal on the Board, who has enormous experience of working with Pharma to develop European projects for early phase clinical trials.

The paediatric track of the next ECCO-ESMO congress (20-24 September 2009, Berlin) will provide an excellent opportunity to hear updates on the current and future planned activities of the major clinical trial groups in

Europe (Click here to see the programme as well as specific symposia on leukaemia, soft tissue sarcomas, fertility preservation and an educational session on how to develop a new drug for paediatric cancer. SIOPE is providing generous scholarship support to fund 5-6 young doctors in training to attend ECCO 2009. Please encourage your staff to apply for these and don't forget that you need to submit an abstract before the deadline of 29 April 2009. For those of you who are beyond the scholarship stage, please don't forget that you must subscribe to SIOPE in order to benefit from the considerably reduced fees for the ECCO congress. But remember to get the most affordable registration fee of only (385 Euro), you must register by 31 March 2009 – only a few weeks away!

We've been working with parents' groups in Europe to update the 1991 SIOPE Recommendations for the Organisation of a Paediatric Cancer Unit' and make them relevant to Europe. Professor Jerzy Kowalczyk has coordinated a survey of current national standards, where they exist. He is bringing together a multi-disciplinary forum at a specially convened conference to be held on 13 May in Warsaw, to discuss how to develop these into a Europe-wide recognised basic standard that health care providers should be expected to adhere to. Please see his article for more details and contact him if you wish to attend or contribute to this important work.

Finally, although 2009 is already well underway, I would like to take this opportunity to wish you all a successful and enjoyable year ahead. The SIOPE team of office and Board look forward to working with you all towards our common ambition, to see every child with cancer in Europe having the best possible chance of cure with the minimum risk of late sequelae and a healthy active life to look forward to.

SIOPE Europe's Community

SIOPE stand at the SIOPE 40th congress, 3-6 October 2008 in Berlin, Germany



Thank you to all of you who visited our stand during the 40th SIOPE congress in Berlin in October 2008. The congress was an excellent opportunity for the SIOPE office staff to interact with SIOPE members and experience at first hand, the diversity and camaraderie of the SIOPE community around the world. We very much appreciated the many warm regards received from members during the SIOPE congress.

SIOPE launches its Subscriber Category: Join the Community!

After months of preparation, we are pleased to inform you that SIOPE has launched a new subscriber category to provide protected access to all our online benefits. We encourage you to apply for this subscriber status, not only for the

relevant benefits but also to strengthen your link with the SIOPE office and other stakeholders in the field of Paediatric Oncology.

The main benefits from becoming a SIOPE subscriber are as follows:

■ Influence through a Europe-wide paediatric oncology network

SIOPE subscribers represent the driving force in our pan-European effort to raise awareness of the need for and importance of improving treatment and outcomes for children and adolescents with cancer.

SIOPE subscribers will receive regular e-updates on all the very latest within our field, news about SIOPE activities and initiatives, reports about consultations with bodies such as the European Commission and EMEA, as well as funding information from the EU institutions, fellowship opportunities and forthcoming congresses such as the FLIMS workshop on Methods in Clinical Cancer Research, the ESO-SIOPE Masterclass in Paediatric Oncology, and meetings organised by ECCO - the European CanCer Organisation.

To better connect our community as well as foster collaboration, SIOPE subscribers also benefit from exclusive access to the SIOPE subscriber databases including contact information for other subscribers, European Clinical Trials Groups and National Childhood Cancer Organisations.

To build a 'one-stop-shop' in paediatric oncology throughout Europe, our website is undergoing essential phased development which will incorporate exciting new features and sections aimed at responding yet further to the needs of our community.

■ The SIOPE Clinical Trials Information Desk

The SIOPE Clinical Trials Information Desk has been set up to become the reference centre for the latest information surrounding paediatric cancer trials, addressing the associated needs and requirements. It will serve as a common platform to facilitate good trial design, disseminate best practice guidelines and provide access to Good Clinical Practice (GCP) workshops. SIOPE subscribers are granted full access to this information via our subscriber-only sections.

■ Full online access to the European Journal of Cancer (EJC)

SIOPE subscribers have personal online access to the European Journal of Cancer (EJC) included in the subscription fee of 90 euro. For SIOPE subscribers already enjoying such on-line access through their institutional subscription, a reduced SIOPE Subscriber fee is available at 45 Euro.

■ Reduced rates to attend the joint ECCO and ESMO Multidisciplinary Congresses

SIOPE is a Founding Member of ECCO – the European CanCer Organisation. As such, SIOPE subscribers benefit from a reduction of up to 180 Euro (2009 fees) to attend the biennial, joint ECCO-ESMO Multidisciplinary Congresses. For further information please click here (deadline for the early bird booking fee for the 2009 Congress: 31 March 2009).

To become a SIOPE subscriber, please first check whether you have already received log in details to access the website from the SIOPE office (this should have happened automatically if you were a SIOP member resident in Europe who registered before October 2008 (application via the SIOP office in Eindhoven, the Netherlands). If not, please create your account on the SIOPE website first (www.siope.eu>>Members>>Become a Subscriber>>New Subscriber>>Ask for an account), and then login to the online subscription section.



Please note that SIOPE office has sent out an email including login details to access the online subscription system at the end of January 2009 to those who have signed up their membership via the SIOP office in the Netherlands before October 2008.

Please also note that your login to the SIOPE website CANNOT be used to access the SIOPE site due to the differences of management systems.

Please do not hesitate to contact us at: office@siope.eu if you have any questions regarding the above information or have any problems in checking or creating your account on the SIOPE website.

For further information on subscribing to SIOPE or any of the activities and online services, please visit the SIOPE website.

We encourage you to circulate this newsletter within your clinical and research networks to inform your colleagues and collaborators about SIOPE.



News from the SIOPE office: Announcement regarding the new Secretary General



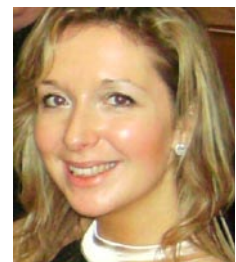
We are pleased to inform you that Ms. Samira Essiaf, the SIOPE scientific coordinator has been appointed and approved by the SIOPE Board to be the new Secretary General of the SIOPE office as of 1 March 2009.

The SIOPE Board would like to thank the current SIOPE Secretary General, Mr. Michel Ballieu, also Chief Executive Officer of the European CanCer Organisation (ECCO) for his support in setting up the SIOPE office and for his ongoing involvement in an advisory role.

The SIOPE Board also would like to congratulate Samira for this recognition of her dedication and personal contribution to the work of SIOPE.

Warm Welcome

We are pleased to announce that Ms. Edel Fitzgerald will be taking up the position of Membership Administrator from 11 February 2009, to replace Jocelyne Wang, who will be leaving the team on 13 February. Edel will be moving from Ireland to Brussels – a relocation about which she is very enthusiastic. With her great communication skills, dynamism and energy, we firmly believe that Edel will be a great addition to the services we provide.



The SIOPE Board would like to publicly recognise the huge commitment and personal energy and enthusiasm that Jocelyne invested into the setting up of the SIOPE office. She assumed responsibilities beyond those expected of her and displayed a clear passion to ensure we succeed in our mission to help children with cancer. We wish her every success in her new job and in her future career. Thank you, Jocelyne!

Committee Reports and Roundups

SIOPE Clinical Trials Groups

■ SIOPE Clinical Trials Information Desk

During the last SIOPE Board Strategy Meeting, Professor Ruth Ladenstein (AT) presented the revised working programme for the SIOPE Clinical Trials working groups, after the launch of this initiative during the SIOPE Berlin congress. People were asked to put themselves forward to participate in the development of three main themes:

- Protocol Guidelines Working Group
- Regulations Working Group
- Ethics Working Group

The detailed aims and tasks of these groups was described in the last edition of the SIOPE newsletter. The office will start contacting volunteers soon to organise follow-up activities.

For further information about the SIOPE Clinical Trials Support Desk and its Working Groups or to express an interest in joining these activities, please contact Ms. Samira Essiaf at: samira.essiaf@ecco-org.eu

SIOPE Education and Training

■ Report on the 2nd ESO-SIOPE Masterclass in Paediatric Oncology, 7-13 November 2008 in Ascona, Switzerland

*Professor Riccardo Riccardi, Rome, Italy
Chairman of the SIOPE Education and Training Committee*

The 2nd ESO-SIOPE Masterclass was held on 7-13 November 2008 in Ascona (Switzerland), a picturesque little town on the Swiss side of Lago Maggiore.

“What did we learn today?” This was the question at the end of each course day, although teaching something new to forty very highly motivated paediatric oncologists (age range 26-41 yrs) was not always easy. The Paediatric Oncology Masterclass was structured into plenary lectures focusing on state-of-the-art diagnosis and treatment of Bone Tumors, Central Nervous System Tumors,

Hodgkin's disease, Liver Tumors, Neuroblastoma, Soft Tissue Sarcoma and Wilms tumor.



at a corner of the course venue

An feature was case presentations prepared by all the participants with the involvement of the whole faculty during the discussion. All sessions were closed by the chairman with a summary in order to identify key learning points.

Mike Stevens, Angelika Eggert and myself with the help of a very qualified faculty attempted and were probably successful in giving an update on the clinical management of the most frequent pediatric tumors.

Participants were selected among 76 applications coming from 11 European countries: Austria (1), Belgium (1), Germany (8), Latvia (1), Lithuania (1), The Netherlands (2), Russia (1), Spain (4), Switzerland (3), and UK (6).

Feedback through the course evaluation forms was very positive. Students found that the course met their expectations and developed their skills to deal with real life problems in their current clinical practice.

The ESO secretariat provided excellent organisation of the course and the time spent in Ascona. Thanks are due to Dolores Knupfer and Chatrina Melcher from ESO and Sara Costa from the Neuroblastoma Foundation. SIOPE also provided financial support.

Special thanks are due to Alberto Costa, chairman of the European School of Oncology (ESO) who made this masterclass possible and has already announced that ESO will support a similar event in 2010.

For further information about this course, please visit the SIOPE website at: www.siope.eu (select 'Education' > > 'Course & Training' >> ESO-SIOPE PO Masterclass)



Prof. Kathy Pritchard-Jones during the lecture

Special Editorial: Report on 'the standards in paediatric oncology'

Professor Jerzy R. Kowalczyk, Lublin, Poland, SIOPE Board Member

In May 2008, the SIOPE Board decided to prepare a report on the current status and standards of paediatric cancer units in Europe. This was stimulated by a request from the parents' organisations for an update of the 1991 SIOPE 'Recommendations for the Organisation of a Paediatric Cancer Unit'. After discussions with the SIOPE Board, SIOPE was asked to take on this task.

A questionnaire on the availability of national standards for paediatric oncology/haematology (POH) wards was mailed to representatives of all European countries. We asked the responders to provide us with information on any regulations existing in their countries related to standards for these wards. This should eventually enable us to introduce recommendations for minimal requirements to be fulfilled by paediatric oncology/haematology wards, at least in EU countries.

This could be of importance especially for new member states, since authorities in those countries try to implement new regulations (e.g. limit of working time for physicians) within the limits of their budgets and employment rates.

A total of 25 countries responded (from some countries we have received more than 1 reply), most of them (19) being members of EU and 24 countries have not yet answered our questionnaire. Analysis of the received information showed that only 10 EU countries have specific standards or regulations for POH ward that are already implemented or under discussion with relevant authorities. In fact, only in Germany, Italy, Austria, United Kingdom, Belgium, and Slovakia are the regulations officially recognised not only by the national professional society, but also by the authorities, i.e. by the state's government.



Y any regulations

No no regulations

Member states of EU 19/27 responded, 8 did not

Austria	Y	Germany	Y	Netherlands	N
Belgium	Y	Greece	N	Poland	Y
Bulgaria		Hungary	N	Portugal	
Cyprus	Y	Ireland	N	Romania	
Czech Republic	N	Italy	Y	Slovakia	Y
Denmark		Latvia		Slovenia	N
Estonia		Lithuania	Y	Spain	Y
Finland		Luxemburg	N	Sweden	N
France	Y	Malta	N	United Kingdom	Y

Candidate countries 2/3 responded

Croatia	N	Republic of Macedonia		Turkey	N
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Other European countries 4/19

Albania		Iceland		San Marino	
Andorra		Liechtenstein		Serbia	N
Armenia		Moldova		Switzerland	N
Azerbaijan		Monaco		Ukraine	
Belarus		Montenegro		Vatican City State	
Bosnia / Herzegovina	N	Norway	N		
Georgia		Russia			

In 9 EU countries, 2 candidate and 4 other European countries, no any specific regulations for POH units are reported and in those cases requirements for general paediatric wards are implemented. However, support for the initiative by SIOPE to prepare a document on European recommendations for standards of POH units was expressed by all responders. Thus, it seems reasonable to try to persuade the European Commission to support this.

We are currently going through a detailed process of reviewing the data and documents provided by the six aforementioned countries that have already started government policy for POH units. For example the comprehensive report entitled "Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer" published in 2005 in United Kingdom, describes in great detail how services for children and young people with cancer should be organized, the expected key components for treatment and what patients and families should expect from the health system. The documents from Germany, Austria and Slovakia gave details of requirements for POH facilities, equipment, staff and qualifications. These documents should provide a useful basis to start preparing a common set of

European basic standards for units to be called a POH in different countries. This will set a challenge to ensure that we all comply with the standards which have been set.

To discuss at least some of these issues, the European Conference on Standards of Care in Childhood Cancer is scheduled on May 13 2009, in Warsaw. Medical professionals, parents' organisations, charities and politicians will be invited to participate and we plan to prepare a document to form the basis for wider discussions leading to a final agreed set of basic standards that we should all expect our national health systems to provide for our patients.

I want to express my appreciation and thanks to all responders to the questionnaire for their valuable help in providing us with essential information and also with original documents. I hope, most of you will be also able to participate in the Conference in Warsaw.

For further information about this survey, please visit the SIOPE website at: www.siope.eu (select 'Education' > > 'Standards in Paediatric Oncology')

Report on the SIOPEurope/ EONS/ECCO Special Project

'Collaboration between Nurses and Doctors in Paediatric Oncology'



This ECCO-funded three year project, involving centres in eastern and Western Europe was successfully completed and presented during the nursing programme workshop at the SIOPE conference last October in Berlin. 11 centres (out of 15 that originally started) were able to bring their projects to fruition.

The challenge of overcoming problems related to implementing a change/improvement that requires collaboration between doctors and nurses was met, in spite of the workload of everyday clinical practice, language problems, and the difficulty of maintaining high levels of enthusiasm and commitment for an extended period. Any project requires a phase of consolidation, and in some centres, some extra work. Time is still needed to complete and permanently embed changes in practice. An application for extension of the project for a further year was accepted and we are grateful to ECCO for their continued financial support of the project to allow the completion of local programmes. The final seminar with all participating centres will be held in Berlin on 19 September 2009.

Collaboration is more than working together. It means sharing aims, efforts and requires energy and commitment.

The strategy of using the framework of 'Appreciative Enquiry' -sharing a positive vision, focusing on available resources and not only on problems, and selecting an area for consolidating improvement, was successful and all the groups (even those that stepped down) agreed that it was a positive experience.

To allow others to start a similar experience, an open invitation will be extended to European countries the join the general framework of the project, together with suggestions/instructions on how to implement it – these will be presented prior to ECCO 15, at Berlin on 18 September 2009, in a one day workshop to pairs of doctors and nurses from European centres who would like to run a similar programme in their own country. Long distance support, together with instructions, materials to be used, may also be made available on the web as a training resource to be accessed and downloaded by those outside of European countries.

*Professor Paola Digiulio, Milan, Italy,
Project coordinator*

For further information please contact the SIOPE office at: office@siope.eu

Group photo, taken during the third project seminar, 13-15 June 2008, Prague (CZ)



SIOPE outreach and awareness building throughout Europe

Joint comments by SIOPE and ITCC on the EMEA concept paper regarding the development of a quality guideline on pharmaceutical development of medicines for paediatric use

In November 2008, SIOPE and ITCC sent joint comments on the EMEA concept paper regarding the development of a quality guideline on pharmaceutical development of medicines for paediatric use.

Please click here to view the comments submitted to EMEA in November 2008.

For further information about the joint SIOPE/ITCC response to this consultation, please visit the SIOPE website at: www.siope.eu (select 'SIOPE-EU' >> 'Advocacy Activities' >> 'Revised off-patent PD medicines priority list').

SIOPE and the World Cancer Day



To mark World Cancer Day, Wednesday 4 February 2009, ECCO – the European Cancer Organisation conducted a special interview with our President, Professor Kathy Pritchard-Jones to speak on child health, in particular, how the seeds of a healthy adult lifestyle are laid in childhood. The theme of this year's World Cancer Day, is 'I love my healthy active childhood' and aims to inform children about the increased risks of adult cancer associated with obesity and lack of exercise (smoking was tackled last year). This campaign aims to motivate governments to empower children to make their own healthy lifestyle choices, to prevent cancers in adulthood.

The interview consequently triggered widespread media attention including a live interview on BBC World News as well as the following coverage in both lay and scientific media:

- **BBC online:** Obese cancer 'explosion' warning, 4 February 2009
- **Daily Mail, UK:** The children eating their way to cancer: Expert warns of obesity timebomb, 4 February 2009
- **ecancermedicalsience:** World Cancer Day: President of the European Society for Paediatric Oncology says more needs to be done to tackle children's unhealthy life-styles, 4 February 2009
- **dmedicina.com (Spain):** Niños y supervivientes, nuevos retos para la futura oncología, 4 February 2009
- **NRK, Oslo:** Advarer mot tikkende kreftbombe, 4 February 2009
- **Pakwatan (Pakistan):** Obese cancer 'explosion' warning, 4 February 2009
- **Onmedica:** Obesity cancers predicted to rise in young people, 4 February 2009

- **Stop.hu, Hungary:** Ne engedjük gyermekeinket elhízni, mert rákot kaphatnak!, 4 February 2009
- **Medical News Today:** World Cancer Day: President of The European Society For Paediatric Oncology Says More Needs To Be Done To Tackle Children's Unhealthy Life-styles, 4 February 2009

SIOPE appreciates the efforts of ECCO in promoting child health as an important topic among all the other issues raised during World Cancer Day.

Dates to bookmark

■ European School of Oncology in co-operation with Cure4Kids e-grandround on retinoblastoma in developing countries: How telemedicine may help GR44, 16 April 2009 at 18h15 -19h00 CET (Central European Time)

Expert: Guillermo Chantada, Hospital Garrahan, Buenos Aires, Argentina

Discussant: Francois Doz, Institut Curie, Paris, France

E-grandround are sessions held live on the internet that offer the opportunity to online participants to interact with the Expert and the Discussant by submitting text questions. Questions are received by the Discussant and are addressed by the Expert during the session itself. The recorded version of the e-grandround will remain available on the website for further 6 months.

CME accreditation (ACOE and PRA) is in progress. CME evaluation and multiple-choice test will be accessible at the end of the session and the certificate of attendance is released electronically.

Please [CLICK HERE](#) to register. The registration is free of charge but required.

■ The 22nd Annual Conference of the European Musculo-Skeletal Oncology Society (EMSOS) and the 10th Symposium of the EMSOS Nurses & Allied Health Professionals Group, 14 - 15 May 2009 in Stuttgart, Germany.

For further information, please [CLICK HERE](#). (Sessions on Treatment of bone sarcoma in adolescents and young adults; Paediatric soft tissue sarcoma, Rare bone & soft tissue tumours; Long-term outcomes; European collaborative projects. Additional training course on bone tumours on 13 May 2009 free of charge to nurses and junior doctors who register for the EMSOS meeting.)

■ The 3rd International Symposium on Childhood, Adolescent and Young Adult Non-Hodgkin's Lymphoma, 11-13 June 2009 in Frankfurt, Germany.

For further information, please [CLICK HERE](#).

■ **The 11th ECCO-AACR-ASCO Workshop “Methods in Clinical Cancer Research, 20-26 June 2009 in Flims, Switzerland.**

For further information, please [CLICK HERE](#).
Application deadline: Friday, 13 February 2009

■ **Advances in Neuroblastoma Research, 23-25 June 2010 in Stockholm, Sweden.**

For further information, please [CLICK HERE](#).

■ **The Joint 15th Congress of the European Cancer Organisation and 34th Congress of the European Society for Medical Oncology, 20-24 September 2009 in Berlin, Germany.**

For further information, please [CLICK HERE](#).

■ **The 41st SIOP Congress, 5-9 October 2009 in Sao Paulo, Brazil.**

For further information, please [CLICK HERE](#).