



SIOPE EUROPE

SIOPE's Quarterly Newsletter

SIOPE News

December 2007 Issue 1

Introducing SIOPE's Quarterly Newsletter

Welcome to the launch issue of SIOPE's (SIOPE Europe) quarterly newsletter: **SIOPE News**.

This first edition presents the new SIOPE Board, the SIOPE office which opened in Brussels in September 2007, as well as some key goals for the term ahead.

SIOPE News will not only serve as a vehicle to update members on current activities but also represents a platform for information exchange between individual members and professional groups.

We hope you enjoy this first issue and would welcome your feedback, comments and/or any suggestions you may have for future content. Please do not hesitate to contact the SIOPE office directly:

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In the meantime, we wish all our Members a very happy and prosperous 2008.

Message from the President



Prof. Kathy Pritchard-Jones
SIOPE President

I do hope you enjoy reading this first SIOPE Newsletter, which shows the progress we have made in the last year to improve our support to our members. We now have a very enthusiastic and experienced team in place in the ECCO office in Brussels. As you will see from their resumés, they are ideally placed to help us establish a platform that will improve harmonisation of clinical trials in paediatric oncology and access to information for health professionals and parents in Europe. One of our first priorities is to work with all the multinational clinical trial groups and national childhood cancer organisations to standardise the way in which we design and execute European multinational clinical trials. Although all of the groups are working very hard in this area, there is still quite a lot of duplication of effort in attempting to solve problems that are encountered time and again in applying the new EU regulations to clinical trials in childhood cancer. We hope that by establishing a clinical trial helpdesk, SIOPE Europe will assist groups in sharing best practice and simplifying procedures. We look forward to working with you all in this area.

Of course, SIOPE is much more than just clinical trials. We continue to support high quality training opportunities for young paediatric oncologists and we hope you will avail yourselves of these and publicise them to everyone in your department. Once the SIOPE website goes live (planned for February 2008), there will be a public access area which will make information on forthcoming training opportunities easily accessible.

Individual membership of SIOPE Europe continues to be restricted to those who sign up as members of SIOPE itself. We all share a common vision for improving treatment for children with cancer both within Europe and worldwide. I would therefore urge you to encourage your colleagues to sign up to membership of SIOPE. We have also recently revised our Statutes to include group membership for SIOPE, namely the multinational clinical trials groups and national childhood cancer organisations who are being asked to join as official members. You will be delighted to know that there continues to be no specific membership fee to belong to SIOPE Europe, though there is a modest fee to be a member of SIOPE itself. We look forward to seeing many of you on board as full members in the future. Please feel free to contact me with your ideas for how SIOPE can best support its members and for any improvement in the plans we are putting in place.

Presenting SIOPE

Presidency

Professor Andrea Biondi (Italy) completed his term as President in September 2007. The SIOPE team would like to thank him for his unparalleled commitment and enthusiasm in directing SIOPE and plotting a roadmap toward the future.

We are delighted to announce that Professor Kathy Pritchard-Jones (UK) was appointed to follow in the footsteps of Andrea as President for the two year term ahead. She has previously been active in directing the SIOPE Clinical Trials Committee.



The SIOPE Board thank Rosalinde Kennis and Astrid Manders from SIOP for all of their administrative support over the years.

Clockwise : Astrid, Rosalinde, Bruce, Kathy, Andrea, Mike, Ruth, Riccardo.

Newly Appointed Board Members, Roles and Responsibilities

■ Dr Bruce Morland (UK) has assumed the role as Treasurer.

■ Dr Ruth Ladenstein (Austria) joined as a Board Member.

■ Prof. Riccardo Riccardi (Italy) has taken over from Dr Willem Kamps (The Netherlands) as Chair of the Education and Training Committee. We take this opportunity to thank Willem for his diligence and drive.

■ Representing the Central and Eastern Europe region, Dr Jerzy R.Kowalczyk (Poland) succeeds Dr Jan Stary (The Czech Republic). We thank Jan for his excellent guidance and contribution.

■ We also thank Dr Kjeld Schmiegelow and Dr Giorgio Perilongo who left the Board last year.

As recently announced by SIOP International, SIOPE is currently calling for nominations for a new President-Elect. We consider these to be exciting times to serve on the SIOPE Board and we therefore hope that you will consider putting yourself forward to contribute to the present and more importantly, the future of our Society.

For further information and to register your interest please contact Jocelyne Wang.

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Final nominations, including support by 2 members and a CV must be received by **31 March 2008**.

SIOPE - Brussels Bound

SIOPE's new office is based at ECCO – the European Cancer Organisation in Brussels. The two recently appointed officers - Samira Essiaf and Jocelyne Wang - will focus on extending SIOPE's outreach through raising awareness on and around its activities and initiatives among EU policymakers and other European organisations.

Samira and Jocelyne will also be responsible for working on strategies and projects aimed at the future development of SIOPE.

Profiling your SIOPE Staff



SIOPE Scientific
Coordinator

Samira Essiaf

After graduating in Biology, I embarked upon my career 9 years ago when I joined the world of clinical trials working at a central lab as an Intercontinental Project Manager. During this time I was responsible for communicating all central lab business and affairs to the European facility as well as disseminating news to the various Intercontinental laboratories in Australia, India, Israel, Singapore and South Africa.

In addition to my role as Intercontinental Project Manager I led the teaching of the Pharmaceutical Assistants Program at the Paramedisch Instituut in Mechelen for 5 years.

Professional duties aside, I am also highly dedicated to my volunteer work for Plan International which works toward a world in which all children can achieve their full potential in societies that respect and defend individual rights and dignity.

I am delighted to be part of SIOPE and look forward to working for you all to deliver on SIOPE's key goals and objectives.

Jocelyne Wang

With my master diplomas in European Studies and European Public Administration from the Katholieke Universiteit Leuven, I began my career five years ago in the field of public affairs working for several research and lobbying groups in Brussels as a Junior Researcher and Coordinator.



SIOPE
Administrator

Main duties included writing analyses for lobbying activities addressing EU policy-makers, enhancing external communication aimed at the members from the EU 27 (such as developing newsletters and websites) and contributing to strategic processes.

I am also learning German which I really enjoy. In addition to my work and studies, I am involved in various World Vision projects to help improve the day-to-day lives of underprivileged children.

It is an honor to be part of SIOPE and I really look forward to contributing to the future development of the Society.

Moving SIOPE Forward

We are currently developing a work plan to be implemented throughout 2008. One key goal will be to structuralise office activities and devise strategies for future initiatives.

Core objectives outlined in SIOPE's work plan include:

- The setting up of an organisational framework for all SIOPE internal affairs.
- Development and expansion of external relations.
- Establishment of a clinical trials help desk.
- The enhancement and development of education, teaching and fellowship programmes.
- Introduction of a web based/electronic communications toolkit. It is thanks to the sterling efforts of former Board Member, Dr Kjeld Schmiegelow (Denmark) that SIOPE will be ready to launch its official website in February 2008.

SIOPE: Driving Collaboration

SIOPE is currently expanding relations with other European entities such as the European Organisation for Research and Treatment of Cancer (EORTC) as well as organisations representing parents.

Building relations and strengthening ties with EU policy-makers will also represent an essential area for SIOPE activity and focus in the future.

Dr Faith Gibson - SIOPE Course Steward

In collaboration with the European Oncology Nursing Society (EONS) with the support of ECCO – the European Cancer Organisation, SIOPE facilitates collaboration between doctors and nurses in European pediatric oncology through the organisation of intensive residential courses.

Under the leadership of Dr. Faith Gibson, three two-day intensive courses have been organised for 2006-2008 to promote two-way dialogue and debate surrounding theoretical aspects of issues encountered in clinical practice. The conversation ideally culminates in the planning of concrete measures to be implemented at the respective units under the supervision of the corresponding mentors.

14 Centres from 12 countries have been selected and are currently working on projects that have been jointly devised by doctors and nurses to build on local practices.



SIOPE: Bringing hope to children with cancer

Committee Reports and Roundups

SIOPE Clinical Trials Committee Updating the activities

One of SIOPE's key objectives for 2008 will be to develop a clinical trials support desk to respond to the needs of paediatric oncologists.

Further to a highly successful Committee meeting held on 15 October 2007, several action points have been agreed upon for which the Brussels office will be responsible for carrying out in 2008:

- Analyse and report on the requirements of clinical trial groups as well as national organisations for children with cancer.
- The development of a common platform for trial design, best practice guidelines and Good Clinical Practice (GCP) trainings.
- Maintenance of the member database and updates on the European activities.
- Add URL links to relevant ECCO - European Cancer Organisation initiatives of interest.
- To help position paediatrics high on the agenda at scientific events and meetings in terms of prominence within programmes.
- Lobbying at the EU institution level.

For Members who may wish to contribute to this project or share their expertise please kindly contact Samira Essiaf at:

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For all EU regulatory enquiries and information, please contact Jocelyne Wang at:

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SIOPE's Education & Training Committee



Under the expert leadership of Dr Riccardo Riccardi, the Society will continue to support, develop and advance European training opportunities for young paediatric haemato-oncologists.

The next committee meeting is to be held in March 2008.

Prof. Riccardo Riccardi
Chair of SIOPE Education
& Training Committee.

SIOPE outreach and awareness building throughout Europe

The European Medicines Agency (EMA) and the European Commission

Over the past year, SIOPE has issued its response regarding official documentation relating to childhood cancer.

For example, we succeeded in influencing the EMA Priority Drugs List, which will be considered for funding projects under the FP7 Call on off-patent medicines in children.

SIOPE was represented at an important discussion meeting, 3 October 2007 (London, UK) upon the request of European Commissioners. Hosted by EMA, the main objective was to analyse the impact of the EU Clinical Trials Directive (EUCTD) on clinical trials in Europe.

It has been widely recognised that there are ongoing problems with the implementation of the EUCTD Europe-wide – a situation which is impeding certain areas of clinical research. SIOPE successfully highlighted that such obstacles have had a disproportionately negative impact on paediatric clinical trials in cancer.

A full report from the meeting has recently been published on the EMA website at: www.emea.europa.eu (select 'meetings and events')

Fully downloadable material includes a well illustrated presentation given by Stefan Bielack (Germany) representing non-commercial sponsors such as the European and Osteosarcoma Study Group (EURAMOS), as well as documentation submitted by SIOPE. We highly recommend that you read the closing remarks of the meeting which were presented by the European Commissioner, Georgette Lalis (page 46-50 of the report).

Her comments clearly demonstrate that the Commission has recognised the vast differences of opinion existing between the regulators and those involved in carrying out clinical trials, where the problems arise and from where the future solutions should be sought.

Solutions are proposed within the context of the existing legal framework but also considering revisions and/or replacements. For the latter to occur, considerable public consultation would need to take place involving us all – individually, nationally and collectively at the SIOPE level.

We will soon be setting up a clinical trials help desk to keep all our Members informed about the very latest news, developments and announcements.

Dates to Bookmark

The 10th Annual ECCO-AACR-ASCO Workshop on Methods in Clinical Cancer Research, 21-27 June 2008, Flims, Switzerland.

Jointly organised by ECCO – the European Cancer Organisation, the AACR and ASCO, this forthcoming workshop marks a decade of providing European junior clinical oncologists with unparalleled opportunity to learn the essentials of clinical trial design.

The specially crafted programme will incorporate protocol development sessions, small group discussion sessions, lectures and panel discussions facilitated by renowned experts within the field, as well as one-on-one sessions for individual coaching and education.

To view the programme and send an application prior to the submission deadline of **15 February 2008**, visit: www.ecco-org.eu (select 'Congresses and Conferences' > 'FLIMS 10').