

Message from the President and the Office



Looking back at the last 12 months, I am delighted with what we have achieved as a community. We have come a long way in helping to increase awareness of the needs of paediatric oncology, particularly at the EU political level. This year our needs were discussed twice in the European Parliament in Brussels and the Polish Ministry of Health hosted a meeting on improving standards of care, in Warsaw in October during the EU Presidency held by Poland. Even the European Medicines Agency (EMA) and key stakeholders from the pharmaceutical industry 'got in on the act', with Ralf Herold from the EMA Paediatric Committee collaborating with SIOPE President-Elect Gilles Vassal to host an event under the Biotherapy Development Association (BDA) umbrella in Canary Wharf in London in early December.

So at all political levels we have been attempting to challenge the regulatory barriers to make our voice heard. This will most certainly continue- very soon, on 07 February 2012, we will have a meeting in the European Parliament hosted by Glenis Willmott, a Member of the European Parliament from the UK and co-chair of the parliamentary Working group on Health, to mark International Childhood Cancer Day (normally 15 February). We hope that many of you will contact your local Member of the European Parliament and encourage them to attend!

I am also very proud of the advances we are making within the European Network for Cancer research in Children and Adolescents (ENCCA). This EU Seventh Framework Programme (FP7) project was launched in January 2011.

The first ENCCA General Assembly took place in Vienna (01-02 December) recently and showed impressive progress within many of the project focus points and these updates can be easily followed on the ENCCA public website (www.encca.eu). The creation of the 'intranet' tool now allows for an easy communication flow amongst partners. We trust ENCCA will have a significant impact on awareness-building for the needs of paediatric oncology in Europe.

A key deliverable has been the creation of ECRC – the European Clinical Research Council for Paediatric Oncology, and interactions and discussions at this level have gone from strength-to-strength, with a particularly successful meeting at the ENCCA General Assembly in Vienna.

We were delighted with the turnout and enthusiasm for the initiative, which now embodies the former SIOPE Clinical Trial Committee and is the future representative body for clinical research in children and adolescents with cancer in Europe. The work being carried out on contract harmonisation has also progressed and we will most certainly require your support on ensuring that the documents we are creating fit your needs and are as comprehensive as possible.

On the educational side, the paediatric track at the European Multidisciplinary Cancer Congress was well-attended, with a number of young paediatric oncologists and experts from the adult field attending our sessions. The debate-style sessions in the paediatric oncology track were particularly interesting and insightful as to how the future of paediatric oncology is perceived. Moreover, the exposure we received was fantastic: as a Founding Member of ECCO- the European CanCer Organisation, SIOPE was very well-profiled at the meeting, which is now the largest congress of its kind in Europe, with 16000 participants this year. We plan to aim higher and advance activities in Amsterdam in 2013.

While Stockholm was a great success, it was with regret that we said 'adieu' to two excellent Board members, Jerzy Kowalczyk and Bruce Morland, who have been hugely committed to carrying out SIOPE's mission and will certainly be missed. I am pleased to advise that the results of the election for new members were close but Henrik Hasle (DK) and Maria Grazia Valsecchi (IT) received the highest points and have accepted to play an important role in our community's future through their membership on the SIOPE Board.

So a lot has clearly been happening and we have even higher expectations of what we can achieve in 2012. Our new SIOPE Treasurer, Martin Schrappe, discusses our exciting plans for membership in this newsletter and we will also have a new staff member joining the SIOPE team in Brussels in 2012 which can allow us to deliver on quality for you, our community.

Let me end by wishing you a peaceful holiday and a happy new year hoping to successfully advance together our paediatric oncology agenda in 2012

Assoc. Professor Ruth Ladenstein (SIOPE President),
Ms Samira Essiaf & Ms Edel Fitzgerald (SIOPE office)



SIOPE Europe's Community

Outreach and awareness-building throughout Europe

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ENCCA General Assembly

Dates: **01-02 December 2011**

Location: **Austrian Trend Hotel Park
Royal Palace, Vienna, Austria**

The European Network for Cancer Research in Children and Adolescents (ENCCA) held its first General Assembly Meeting December 1-2, 2011, at the Austrian Trend Hotel Park Royal Palace in Vienna, Austria.

The meeting was well-attended and all Working Packages were represented, providing an important opportunity for paediatric oncology professionals to meet face-to-face, share results, exchange ideas and build new collaborations. The event was a true "working meeting", with much time dedicated to research planning and discussion of several network-wide cancer research issues (e.g., databasing, population-based cancer registries, the Clinical Trials Directive revision, outreach, etc.).

The annual General Assembly meeting kicked off with Associate Prof. Ruth Ladenstein, ENCCA Project Coordinator, opening the meeting and recalling the most important issues of 2011, looking forward positively and highlighting the planned activities and actions in 2012 (Next ENCCA GA in Brussels, 16 -17 Jan 2013).

December 1st was a day of updates and presentations from each Work Package leader centered on the three activity areas – the Integrating Activities coordinated by Prof. Gilles Vassal, Joint Research Activities by Prof. Martin Schrappe and Spread of Excellence Activities by Prof. Kathy Pritchard-Jones. All sides recognized the significant progress achieved so far in Year 1, while addressing points of concern and ideas for new directions, followed by group discussions and a meeting of the Project Management Committee in the evening.

Key achievements of the ENCCA in Year I include the following points:

- Launch of ENCCA (www.encca.eu) website. The ENCCA webpage provides information about the project, members involved, current activities and events. In addition information is given about Clinical trial issues and survivorship as well press release materials.
- The European Clinical Research Council (ECRC) for paediatric oncology met in Vienna as a back to back meeting of the General Assembly of ENCCA. Discussions covered many topics including informed consent and other legal and ethical aspects related to carrying out clinical trials, as well as advocacy work in the forthcoming proposal by the European Commission for a revision of the EU Clinical Trials Directive. The meeting included an excellent presentation by Dr Pam Kearns on the current MRC/DH/MHRA based risk interpretation in the UK.



From l-r: Samira Essiaf, Secretary General SIOPE and Ivona Brasnjevic, ENCCA Project Manager



From l-r: Prof. Riccardo Ricciardi and Dr Daniela Rizzo (Both from Universita Cattolica del Sacro Cuore- Rome, Italy)



The ENCCA General Assembly participants

- As part of the ENCCA Work Package, 'Quality of Survivorship' and in co-operation with other partners including ICCPO- the International Confederation of Childhood Cancer Parent Organisations, Prof. Haupt has discussed the possibility of creating a "Survivorship passport", a European template of an electronic tool that is to be given to the individual patient at the end of the treatment containing cancer history and therapy information, as well as advice and guidance on patient-specific long-term follow up of possible late-effects.

- In the field of Education and Training, three videos have been developed at the Università Cattolica del Sacro Cuore by Professor Riccardo Riccardi and his team. The videos explain and show the following procedures: lumbar puncture, bone marrow biopsy and bone marrow aspiration.

- The second day of the meeting wrapped things up with a morning of policy session where Ivona Brasnjevic, ENCCA Project Manager, outlined the European Commission contractual rules and regulations of high significance to the ENCCA project, followed

by Working Group meetings led by an interactive methodology in the afternoon. These breakout sessions were highly important as they allowed for a true exchange of ideas and debate on the project deliverables themselves. As this is a large, multi-faceted project, it was decided to group key work packages together as many of the issues and objectives of ENCCA are cross-cutting.

The attendees agreed on the need to insist on concerted action at the national, regional and global levels in order to adequately address the developmental and other challenges that affect the paediatric oncology community.

Thanks to everyone who attended and helped to make the meeting such a great success! For more information, please contact Ivona Brasnjevic at encca@ccri.at.



European Clinical Research Council

Since the last ECRC meeting in February, where the first steps in the creation of the ECRC were taken, many things have been moving forward to structure and set this important Council.

During the 2nd meeting at the European Multidisciplinary Cancer Meeting in Stockholm (Sep 11) the committee brainstormed about the function & structure of the ECRC. All attendees agreed that this Council should act as an independent & sustainable body with an advisory role towards the ENCCA Project Management Team. The ECRC will be the platform for all European National & Clinical Trial groups as a platform for close collaboration with a particular focus on the Paediatric Oncology Trial issues as a unified European voice acting through SIOPE.

A close collaboration with the parent (patients) groups is envisaged. After having called for volunteers, the council was pleased to nominate Dr Bisogno Gianni (Padova, Italy) and Professor Thomas Klingebiel (Frankfurt, Germany), as the two representatives of the ECRC.

On the occasion of the 1st ENCCA General Assembly, ECRC was invited to assist the ENCCA meeting to learn about the project activities and hence held an attached meeting in Vienna on Dec 2-3, 2011. Ruth Ladenstein, host of the event & ENCCA Project Coordinator welcomed the representatives coming from 13 different EU countries each representing either their Clinical Trial Group or National Group.



As SIOPE president and ENCCA Project Coordinator, she highlighted the importance of "2012 as the year of changes" of the Clinical Trial Directive which is currently under revision.

It was a pleasure to see so many interactions from the different Tumour & National groups giving their input and brainstorming during this 2 day meeting in order to set the vision & mission of this council. It was agreed that bylaws for the ECRC are to be drafted to give this council a formal structure allowing to act based on a common vision, mission and rules.

On the second day of the meeting, the main focus was put on the achievements with regard to Sponsor contracts. Mag. Martina Gantschacher from the European Society for Quality in Healthcare (ESQH -Vienna Office - www.esqh.net) gave an overview on the current status of the development of the Sponsor Contracts and discussed the outcome of the survey that was circulated (Jun 2011) amongst the different representatives of the Clinical Trial & National Groups for input on the SIOPE "Contract for Multinational Investigator Driven Clinical Trials". Very interesting was the view on the definition of Informed Consent from a lawyer perspective and from the parent's perspective presented by Sabine Karner (ICCCPO) which created a lot of interaction amongst the attendees. A major part of discussion was devoted to the forthcoming challenge to enhance the paediatric needs within the Clinical trial directive revision: Risk categorisation, definition of investigational medical products as well as insurance needs are the main topics to focus on.

And as a take home message all attendees agreed that is very important to act (together with SIOPE) as **one voice for the paediatric community** towards the politicians in order to make changes feasible on regulatory issues that affect the practises, such as the EU Clinical Trial Directive (CTD).

As an immediate follow up on this topic, Ruth Ladenstein invited all attendees to attend an event in the European Parliament organised by SIOPE on the occasion of **International Childhood Cancer Day** (07 February 2012) **at the European Parliament**, an event where Standards of Care, the EU Clinical Trials Directive and early diagnosis will be addressed with policymakers at EU level.



Professor Nikolaus Forgo, as a partner within the EC FP7 project CONTRACT has joined the group to share their project results and to create synergies with ENCCA activities for the informed consent procedures. As an

expert in privacy of data, he gave an excellent view from the lawyers perspective and explained the meaning of ownership of data from a legal point of view.

Next ECRC Meeting Date to bookmark

We look forward welcoming you at the next ECRC meeting in Brussels (SIOPE office) on Monday 06 February 2012. For more information about the European Clinical Research Council (ECRC) please contact Ms Samira Essiaf.



Participants of the ECRC meeting, Vienna



From l-r: Kathy Pritchard-Jones (UK), Sabine Karner (AT), Maria Valsecchi (IT), Martina Gantschacher (AT), Michel Zwaan (NL)



From l-r: Ruth Ladenstein (AT), Ulrike Potschger (AT), Samira Essiaf (BE), Dieter Körholz (GE), Filomena Pereira (PT), Miriam Wilhelm (GE)

European Standards of Care for Children with Cancer

Report from Conference

Dates: **20-21 October 2011**

Location: **Warsaw, Poland**

SIOPE initiated the European Standards of Care for Children with Cancer project in order to improve the quality of care of children and adolescents with cancer as well as to assess the relevant organisational aspects in paediatric oncology.

We were delighted to partner with the Polish Ministry of Health to host a workshop on the need for such 'Standards of Care' for children and adolescents with cancer across Europe, in October 2011 in Warsaw, Poland, as part of the EU Polish Presidency.



Member of the European Parliament (MEP) Sidonia Jędrzejewska sent a video message supporting the conference.



Professor Jerzy Kowalczyk, Children's Hospital Lublin, Poland



Polish Minister of Health Dr. Eva Kopacz opened the European Standards of Care for Children with Cancer conference, in Warsaw, Poland.

Through the EU-funded 'European Partnership for Action against Cancer' (EPAAC) initiative (<http://www.epaac.eu/>), the Polish Ministry of Health and SIOPE Europe joined forces to disseminate standards that were created by an expert multidisciplinary, multi-professional 'care team' which included paediatric oncologists, nurses, parent and patient advocates, psychologists, physiotherapists, social workers, play therapists and lawyers, at a conference in Poland on 20 and 21 October 2011. Prof. Jerzy Kowalczyk from the Children's University Hospital Lublin in Poland worked closely with the Polish Ministry of Health to invite the 27 EU Member State health ministries to participate in the conference and discuss implementation of such standards at national level, along with members of the European paediatric oncology community and patient and parent groups.

The Polish Minister of Health, Dr. Ewa Kopacz, opened the conference by underlining her support for this important meeting, both within the framework of EPAAC but also the EU Presidency held by Poland. She reiterated Poland's dedication to improving inequalities in Europe and the centrality of child health, which were key priorities of the Presidency. Dr. Kopacz also emphasised the importance of early diagnosis in the treatment of cancer in children. "In the majority of cases, cancer in children is treatable.

At present, two thirds of children and young people have the chance of full recovery, and with some tumours this percentage exceeds 90%. The chances largely depend on the knowledge, experience, and medical intuition of general practitioners, and on early diagnosis," said the Minister.

There was also a video message from Polish Member of the European Parliament, Sidonia Jędrzejewska, who stressed the need for the universal availability of expertise and infrastructure in order for children and adolescents with cancer to receive optimal treatment and care and her commitment to support this initiative. MEP Dr. Jędrzejewska commented after the conference, "The burden of cancer in Europe is very large, and thus we should focus on the education of the medical staff and intensification of scientific research. Equally important is the development of standards in all the EU countries, that ensure both sick and cured people an equal access to medical services as well as the best standard of life after illness. The European Parliament can do a lot here, contributing to the implementation of new, more effective regulations. To view meeting minutes & event summary [CLICK HERE](#).

Solutions were discussed on how to ensure all young people with cancer have access to the best available diagnostics, treatment and healthcare:

● **The state of paediatric oncology in Europe:** SIOPE President Assoc. Prof. Ruth Ladenstein outlined the current challenges in Europe and suggested possible solutions. The ability to perform academic clinical trials in paediatric cancer is paramount to guarantee to each child the best possible cure. She underlined the need for a risk based approach allowing to lower the regulatory burden.

● **Sharing Best Practice:** Prof. Martin Schrappe from the University Medical Center Schleswig-Holstein, in Kiel, Germany is part of an international consortium of experts specialising in leukaemia and outlined how they achieved huge successes in curing patients with this disease. To date, population-based clinical trials in childhood leukaemia have provided the best available treatment and quality-assured clinical care. Outcome improvement normally relates to a combination of the quality of protocol as well as improved supportive care. Important aspects such as the ration of doctors to nurses, the access to specialists, the number of beds, on-call availability and psychosocial support for the patient and family can substantially improve outcomes for young leukaemia patients. Parent of childhood cancer survivor Elzbieta Pomaska from Poland provided examples of the campaigns she was involved in, including a highly successful campaign on the need for better 'early diagnosis'.

● **Professional Partnerships:** Professor Alexander Karatchunskiy from the Research Institute of Paediatric Haematology in Moscow, Russia, presented the treatment data of childhood ALL in Russia and explained that he gained a lot of knowledge from international groups particularly Germany. This information-exchange and support on 'lessons learned' ensured he could achieve concrete success, while also modifying in order to fit to the national cultural context of Russia.

● **The important role of patient/ parent advocates:** Participants heard from numerous patient/ parent advocate representatives: ICCCPO – the International Confederation of Childhood Cancer Parent Organisations, Jimmyteens.tv in the UK, PAVEL and Little People in Romania and the Communication without Barriers Foundation in Poland all provided presentations both on achievements to date and their commitment not only to help SIOPE improve standards but also how they are excellent partners in advocacy and can play a major role to improve conditions.

● **Knowledge Exchange:** There are several EU initiatives currently taking place which were presented by the project coordinators at this conference – ENCCA (the European Network for Cancer research in Children and Adolescents) PanCare and PanCare SurFup, EPAAC and Eurochip amongst others. Momentum is clearly building and opportunities are regularly appearing to raise awareness of the needs of children and young people with cancer but information dissemination needs to continue.

● **Translation and dissemination of European Standards of Care for Children with Cancer:**

This 'consensus' document has been translated into multiple languages and has already helped both professional and parent/ patient groups to advocate for improved standards.

● **Dissemination of the standards** is also encouraged. Of course the content of the document is 'standardised' and can be modified according to the national perspective and culture but it may be useful as a reference point for national health ministries when creating or updating their national cancer plans.



Children in Poland should be treated with the best available treatment protocol



Poland still faces huge challenges in treating children with cancer. Dr. Walentyna Balwierz from the Jagiellonian University Medical College, raised her concerns as a paediatric oncologist and pleaded for urgent changes to the regulatory system to help her provide the best standards to patients.

In her presentation, she outlined that until 2006 only Ethics Committee approval was required to conduct clinical trials in Poland. But since 2006, many additional requirements were introduced by the EU CTD (EU Directive 2000/2001/2005) and due to the bureaucratic procedures now incurred by the paediatric oncology community in Poland, only one clinical trial, the EuroNet-PHL-C1 Protocol, to treat Morbus Hodgkin Lymphoma, has been implemented.

Aside from the EU CTD, the situation has become even more complicated. In April 2011, new pharmaceutical regulations were brought into law in Poland – clinical trials are also covered in this law. As the Polish law now clearly states that the sponsor of a clinical trial has to cover all expenditures related to the clinical trial a new huge hurdle was created by this interpretation of the EU CTD rendering participation in academic trials practically impossible. Treatment costs are not covered any longer by the national health system for patients on a trial but need to be taken on by the official sponsor (university) of the trial. Academic trials in paediatric oncology are offering best care treatment approaches in a controlled setting including new treatment advances. Hence, if a university in Poland would accept the sponsor role for a clinical trial as in other EU countries it needs to provide diagnostic and all medication costs. This practically stops the initiation of any academic trial in Poland since clearly universities do not have the financial resources to cover all treatment expenditures. Treating children with cancer outside of academic clinical trial guidance and data reporting may lower survival chances by up to 30%. In addition no access to new and innovative treatment can be granted. An example given is an antibody treatment available for high risk Neuroblastoma since 4 years which may improve survival by up to 20%. However, this innovative treatment is withheld from children in Poland for these regulatory reasons.

The Polish academic community is missing opportunities to participate in multinational European trials to ensure best diagnosis, treatment and care. Dr Balwierz' take-home message was that should the situation not change immediately not only academic research in Poland is put into question but more importantly the cure of Polish children with cancer is under threat. The Polish paediatric oncology community hence urges the Polish government to take immediate action to revise the new Polish pharmaceutical regulation to allow Polish children to benefit from the participation in academic trials as part of a best possible standard of care strategy.



Mrs Dagmara Korbasinska of the Polish Ministry announced that the standards of care will be reviewed by a team of experts in order to make such standards legally binding; thus it will be obligatory for all clinics in Poland treating young patients with cancer to meet such standards of care. This was warmly welcomed by participants

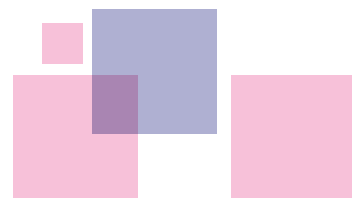
Dr. Josep Borrás of the Spanish Health Ministry advised that a new cancer strategy is being implemented in Spain and considered that the European Standards of Care for Children with Cancer document can help as a guiding document when including information on paediatric oncology.

In Conclusion:

Significant progress has been made since the last conference in 2009 which catapulted this project and partnership between paediatric oncologists, patients, parents, nurses, psychologists, counsellors, play therapists and physiotherapists. Numerous presenters indicated that standards in their country and or unit had improved in recent years which should be commended

At the 1st meeting there were no policymakers and when looking to the event, taking place within the EU Presidency of Poland and hosted by the Ministry of Health, at least 15 representatives of national ministries were represented. There is still a long way to go however improvements are being made, although slower than anticipated. As more translations of the standards are made, further lobbying activities at local and national level can take place.

However, Dr. Balwierz's presentation and her 'call for action' indicated the seriousness of the situation in Poland.



PanCare and SIOPE meet EU political leaders in Brussels

SIOPE was delighted to join members of the PanCare consortium on their visit to Brussels in October. This included high-level meetings with the Cabinet of the EU Commissioner for Research and Innovation, Maire Geoghegan-Quinn – here we met John Bell, Head of the Cabinet and Patricia O'Reilly who is responsible for health research and had a very positive meeting to discuss the key challenges facing both patients (and those who care for them) and survivors. We also met a Member of the European Parliament from Ireland, Mairéad McGuinness, who works primarily on parliamentary dossiers related to agriculture, the environment and disability and health issues. SIOPE invited her to a meeting to mark International Childhood Cancer Day in the European Parliament, on 07 February 2012, and very much hope she can attend.

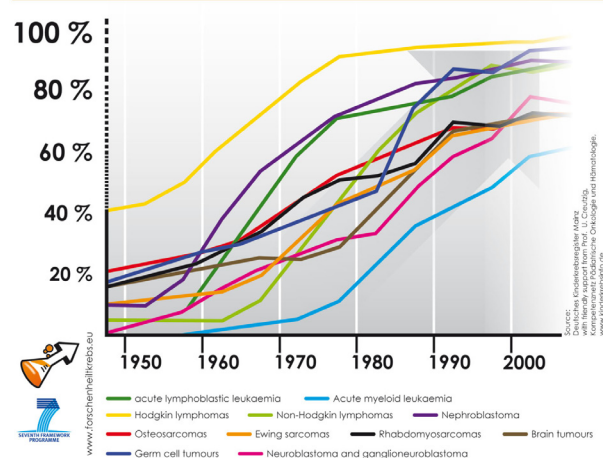


PanCare and SIOPE visit the European Parliament: from l-r PanCareSurFup Coordinator Prof. Lars Hjorth, Dr. Julianne Byrne from the Boyne Research Institute, Member of the European Parliament Mairéad McGuinness, PanCare SurFup Project Manager Elise Kvarnstrom and SIOPE Membership and Public Affairs Coordinator Edel Fitzgerald.

SIOPE Joins Forces with other medical organisation calling for major changes to the EU Clinical Trials Directive

As the Scientific Community eagerly anticipates the proposal by the European Commission to Directive 2001/20/EC, SIOPE has been linking with other organisations and consortiums to ensure we are well-represented. Coordinated by Cancer Research UK, below is an extract from a 'Joint Statement' that has received full backing by ECCO- the European CanCer Organisation, EORTC- the European Organisation for the Research and Treatment of Cancer, the Academy of Medical Sciences and the Medical Research Council in the UK, the British Heart Foundation and ESMO, the European Society for Medical Oncology, and SIOPE of course, amongst others. To view the Joint Statement, [click here](#).

Survival Rates of Children and Young Adults Suffering from Cancer



Extract from 'Revision of the EU Clinical Trials Directive: A joint statement from non-commercial and commercial organisations'

What do we want to improve?

We would like to see revision to the Directive and the accompanying guidance in the following areas:

Risk-based approach: A proportionate approach to the assessment and regulatory requirements of clinical trials examining the safety or efficacy of medical products should be introduced, ideally with the onus on the Sponsor to justify the assessment.

This should take into account a number of factors including the extent of prior knowledge and experience with the Investigational Medicinal Product (IMP) and the patient population involved.

Greater clarity on the scope of the Directive: It is essential that the scope of the Directive is clarified to ensure it is limited to trials examining the safety and efficacy of medicinal products as originally intended and that it is applied in the same way across Member States.

The lack of clarity of the definitions included in the Directive contributes to its inconsistent implementation across Member States (see case studies 3 and 4). Where the regulatory requirements are unclear there is evidence that those undertaking trials go above and beyond the requirements to ensure that they are compliant. The definitions that are in the Directive should be revised to ensure the scope of the Directive is clear and that studies are treated consistently across Member States

Authorisation and assessment of clinical trials: We are broadly supportive of the approach outlined in the recent concept paper from the Commission on having a single 'EU portal' for submitting documentation for multinational trials. It could reduce the administrative burden of multiple submissions at the time of initial application as well as streamline amendment and clinical study reporting. However, we would like to see a full impact assessment to be reassured that this proposal would not lead to increased cost or approval times. We are supportive of the principle behind the proposal for a 'coordinated assessment procedure' (CAP) and specifically support the option whereby the assessment is undertaken by a lead 'Reporting Member State'. However, until there is more detail as to how this would operate in practice, it is difficult to be strongly supportive of the proposal. Such detail should include how a proportionate approach would be harmonised across Member States. Without this information, it is difficult to appraise whether this would lead to improvements in setting up multinational studies.

Simplified approval and monitoring requirements: The Directive sets out specific requirements for safety reporting for clinical trials including reporting all suspected unexpected serious adverse reactions (SUSARs) to the National Competent Authority (e.g. the MHRA in the UK), the main research ethics committee and the national competent authorities of any other Member State where the trial is being conducted. Sponsors are also required to submit an annual safety report to both the National Competent Authority and relevant ethics committees. These arrangements lead to unnecessary duplication, without enhancing patient safety.



The Commission's concept paper has not identified how these requirements could be revised and we would like greater clarity on how these arrangements could be simplified.

Clearer, more detailed guidance: We would welcome clearer and more detailed guidance in a number of areas to improve understanding of the Directive. For example, the recent guidance on the current requirements for reporting suspected adverse serious adverse reactions (SUSARs) was welcomed. Nevertheless, in addition to this, there is a need for additional clarification on other issues, such as what constitutes a 'substantial amendment' to a study protocol.

Inclusion in the CTD for academic sponsors: We agree with the appraisal outlined in the Commission's concept paper that clinical trials by 'academic/non-commercial sponsors' should not be excluded from the scope of the Directive.

Latest News from PanCare SurfUp



Survivorship after Cancer during Childhood and Adolescence Conference, Ireland

Samira Essiaf and Edel Fitzgerald attended this important awareness-building conference on survivorship after paediatric cancer, in Dublin on 26 November, representing both SIOPE Europe and the ENCCA project. Attended primarily by survivors and their families, this event was organised as part of dissemination for the EU-funded Seventh Framework Programme project, PanCare SurFup – PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies. SIOPE is an Associate Partner in this project, involved in dissemination. Here conference organiser, Julie Byrne of the Boyne Research Institute in Ireland, provides an overview of the event, which included a speech by Member of the European Parliament (MEP) Nessa Childers.



From l-r, CEO of the Irish Cancer Society John McCormack, conference organiser Julie Byrne and Member of the European Parliament, Nessa Childers.

Participants kick-starting the 'No Smoking' campaign for survivors Description

From l-r, PanCare SurFup Coordinator Prof. Lars Hjorth, Member of the European Parliament Nessa Childers, Irish Cancer Registry Director Prof. Harry Comber and PanCare SurFup Work Package Leader for Dissemination Prof. Momcilo Jankovic.

This conference was held on 26 November, 2011 in the Croke Park Conference Centre, Dublin from 10 am to 4 pm. It was organised by the Boyne Research Institute, Drogheda, Ireland, in association with PanCareSurFup's Work Package 7 (WP7), and the Irish Cancer Society. Co-sponsoring organisations were the Children's Medical & Research Foundation of Our Lady's Children's Hospital, Crumlin, Dublin, Novartis Ireland and Bristol-Myers Squibb Ireland.

The conference targeted survivors and their families and also, specialists, general practitioners, nurses and other health professionals. Registration was free. A total of 111 guests attended; about 70% were survivors and family members.

Speakers were primarily drawn from PanCareSurFup and included Lars Hjorth, Mike Hawkins, Momcilo Jankovic, Elvira van Dalen and Gill Levitt. Other speakers included Alex Brownsdon, Harry Comber,

director of the Irish Cancer Registry, Michael Capra, paediatric oncologist at Our Lady's Children's Hospital, Crumlin, John McCormack, CEO of the Irish Cancer Society, and representatives from CanTeen Ireland, Barretstown Castle and ICCPO (Gerlind Bode).

The keynote speaker was Irish MEP Nessa Childers, who reminded survivors not to even think about smoking, and to take control of their health.

A survey of those who attended showed a high level of satisfaction with the conference, the speakers and the arrangements. Most rated all elements on the survey as „Excellent“. BRI staff are currently analysing the data from the surveys. A final report will be placed on the conference website – www.ccs2011.ie. The website carries the full programme and the presentations from each speaker. Numerous photos from the event can be viewed on <http://www.facebook.com/BoyneResearch>, as well as on the conference website.

SIOPE Community Reports and Roundups

SIOPE Board

A heartfelt 'Thank You'!

The SIOPE Board and office sincerely thank Dr. Bruce Morland and Prof. Jerzy Kowalczyk for their dedication as members of the Board of Directors. Their input has been instrumental in ensuring SIOPE is profiled as the pan-European organisation dedicated to promoting optimal standards of care for children and young people with cancer.



Dr Bruce Morland – Assoc. Prof Ruth Ladenstein – Prof. Jerzy Kowalczyk

Welcome Henrik and Maria Grazia!

The SIOPE Board warmly welcomes Profs. Henrik Hasle and Maria Grazia Valsecchi as new members of the Board of Directors.



Henrik Hasle received his MD from Odense University in Denmark in 1987, and carried out specialised training in epidemiology, haematology and paediatrics including a research fellowship in paediatric oncology. Since 2000, Hasle has worked as

a consultant and Associate Professor at the University Hospital Skeljby in Aarhus, Denmark and since 2009 is a Professor in paediatric haematology and oncology.

Prof. Hasle is author of more than 140 journal articles, primarily dealing with myeloid leukaemia and genetic predisposition to cancer.

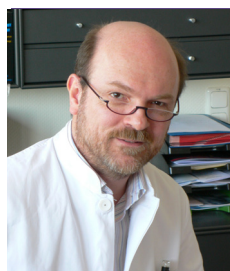
Henrik Hasle is the founder and former chairman of the European working group on Childhood MDS (EWOG-MDS); he has also held the chairman position for the Nordic Society of Paediatric Haematology and Oncology (NOPHO) leukaemia-lymphoma and the AML groups, and is a member of the editorial board of the journal *Pediatric Blood and Cancer*.



Maria Grazia Valsecchi is a Professor of Medical Statistics at the Department of Clinical Medicine and Prevention in the University of Milano-Bicocca since 2001. She carried out her studies in Mathematics at the University of Milan and completed an MSc in Biostatistics at the University

of Washington in the United States. Prof. Valsecchi is interested in the methodology for controlled clinical trials, survival analysis, prognostic modelling and clinical epidemiology. She is the author of 130 scientific papers and published a book on survival analysis (Wiley 1995). Her field of applied research lies mainly in childhood onco-hematology.

Prof. Valsecchi held the position of Associate Editor of *Statistics in Medicine and Biometrics* and she has been very active in International Societies and has been promoting activities in the International Biometric Society (IBS) – the Italian Region. At a recent meeting in June 2011, Maria Grazia Valsecchi was elected IBS Council Member. From 2003-2004 she was President of the International Society for Clinical Biostatistics and she is currently President-Elect of the IBS- Italian Region.



New SIOPE Treasurer

The SIOPE Board and office is delighted to announce that Prof. Martin Schrappe has agreed to take on the challenging role of Treasurer for SIOPE Europe. We kindly thank him for committing to this important task, and look forward to working with him closely.

SIOPE Education & Training Committee: Chair: Prof. Dragana Janic



The Education and Training Committee (ETC) had the pleasure to meet during the European Multidisciplinary Cancer Congress in Stockholm in September where new strategies of the SIOPE ETC have been discussed in order to meet the needs of the young and experts in the paediatric oncology community. One of the main outcomes of this meeting is to expand the ETC with more experts as well as young paediatric oncologists. Therefore the ETC will launch in 2012 a call for nominations to join this expanding committee.

In the meantime we will still keep you informed about all the educational workshops and available (e-) courses that are in the interests of the community, as well as information on scholarship and grants, including the opportunity to attend the Films 14 workshop (June 2012) in Switzerland, the Elective Course (July 2012) taking place in Belgium and Poland and the SIOP 2012 Congress (Oct 2012) in London.

SIOPE General Assembly 2011

It was a pleasure to see so many SIOPE members not only attending the General Assembly but also actively taking part in the discussions on different paediatric and other oncology topics within the various scientific sessions, debates and the SIOPE society session.

After a warm welcome by the SIOPE President Ruth Ladenstein, the members received an update on the SIOPE political agenda (presented by President Assoc. Prof. Ruth Ladenstein and SIOPE Public Affairs Coordinator Edel Fitzgerald) as well as the involvement of SIOPE in several EU projects such as ENCCA (by Ruth Ladenstein), PanCareSurfup (by Prof. Lars Hjorth) and the finalisation of the (2 year) Eurocancercoms project and its final outcomes (by Prof. Richard Sullivan).

Moreover, the SIOPE Board presented a potential new approach to SIOPE membership (fee) as an outcome of two membership surveys (one on membership in general and the second focussed mainly on National Group membership) that were conducted to move forward on this issue and in particular to take into account the current need for action to ensure sustainability for the SIOPE office's financial resources. As an outcome, SIOPE members agreed on a proposal which will result in a change in the SIOPE statutes. The final agreement on this new approach will be voted during the next SIOPE General Assembly in London (October 2012).

As a take-home message of the SIOPE General Assembly Assoc. Professor Ruth Ladenstein underlined the importance of acting together in order to make sure our voice is heard and that changes can be implemented through our common advocacy work on the EU level.

Next SIOPE General Assembly in London!



We look forward seeing you at the next SIOPE General Assembly taking place at the SIOP 2012 congress in London (5-8 Oct 2012). For more information about the SIOPE General Assembly, please contact Ms Samira Essiaf at the SIOPE office.



Prof. Jerzy Kowalczyk (PL)

Prof. Richard Sullivan (UK)

Our Community Profiled

Interview with ICCCPO



From l-r: Anita Kienesberger and Sabine Karner

Better outcomes and survival for children and adolescents with cancer is only achieved through a multidisciplinary and multi-professional team working together, with the patient and their family at the centre. The Network of Excellence, ENCCA (European Network for Cancer research in Children and Adolescents) incorporates all the stakeholders involved in paediatric oncology including parent and patient groups, through the participation of ICCCPO – the International Confederation of Childhood Cancer Parent Organisations.

In the first of a series of interviews with key personalities from our community, we ask Anita Kienesberger (AK) and Sabine Karner (SK) of ICCCPO – The International Confederation of Childhood Cancer Parent Organisations - some questions on their life:

How did you get involved with ICCCPO?

AK: Since 2001 I'm the Managing Director of the Austrian Childhood Cancer Organisation, which is a member of ICCCPO since 1997. From the first conference I attended I was impressed by how enthusiastic ICCCPO and its members are and its important work to achieve their aims under their vision, "We Care, We Share". For six years I have been ICCCPO Board Member and I am responsible for European agendas.

SK: Since 2006 I'm involved in the work of the Austrian Survivors Group, which is an active group particularly supporting childhood cancer patients with a mentoring project. Members of the group also organise different activities and meetings for long-term survivors (LTS). It is interesting that survivors who attended ICCCPO meetings always come back with new ideas and motivation to work within this field. They have inspired me to get more and more involved, and thus since 2011 I have the honour to work as a project worker within ENCCA for ICCCPO.

Describe a typical working day at the ICCCPO office.

AK and SK: Here is some background information which is necessary to mention: officially, the ICCCPO secretariat is located at VOKK's office in the Netherlands. Within ENCCA however, the Austrian Childhood Cancer Organisation has become as a sub-office of ICCCPO and supports the ICCCPO office in the Netherlands. Our ICCCPO secretariat has a constant communication to the 141 ICCCPO member groups from all around the world.

You are working in an oncology and haematology 'research' project. What encouraged you to focus on this area?

AK and SK: For ICCCPO it is important to be involved in oncology and haematology research projects to give parents and patients a voice.

You are currently in an EU-funded FP7 project with SIOPE, ENCCA. Can you briefly describe your role in this project?

AK and SK: ICCCPO is the project partner who represents the opinion and vision of parents and patients and we focus on the needs of their support groups. Essentially, we ensure that the voice of national parent and patient groups is heard and strengthened within ENCCA.

ENCCA is an ambitious project: what kinds of challenges do you envisage?

AK and SK: One challenge will be the implementation of the "Survivorship Passport". Every European LTS should have access to this tool which includes a summary of treatment and a check-list of long-term follow-up screenings (treatment received and instructions on what and when to do follow-up).

Another key challenge we envisage in our participation in the ENCCA project is the need to raise awareness on a national level of health policy issues of childhood cancer patients and to work hand-in-hand with the physicians to improve the national health policy.

This network of excellence is expected to continue in some form after EU-funding is complete. How do you see ENCCA being sustainable?

AK and SK: We are just able to focus on the parent and patient support groups: To us it is important to strengthen the profile of ICCCPO in Europe, to support parents and survivor groups on a national and regional level and to become active on a health policy level. Working on a National Health Care Plan together with physicians could make the work sustainable. The PAC (Parents and Patients Advocacy Committee) created within this project should be a sustainable institution within Europe after ENCCA.

How do you relax? Any hobbies?

AK: After a busy working day my way to relax is having a bath with my bath duck. I like reading books, hiking and I love going to the cinema.

SK: My hobbies are quite similar to Anita's. I like reading, hiking and walking, especially (Nordic) walking, which is walking with special walking sticks. Another hobby is beating drums and discovering new cities. Not forgetting to meet friends and LTS, chatting, enjoying life and organising Survivors activities.

Describe one of your proudest moments/ an achievement you are particularly proud of.

AK: One very important moment for me was when I got my general qualification for university entrance at the age of 35 by evening classes; this was a major achievement considering it was on top of my day job as an intensive care nurse.

SK: One achievement I'm proud of was the time I finished my studies of political science. For me it was not to be taken for granted to study and now I have the possibility to work for an international organisation.

Special Features

2011 SIOPE Achievement Awards

The SIOPE Board was unanimous in its decision to award for the first time a joint prize, to Profs. Catherine Patte and Alfred Reiter for their dedication and scientific and clinical excellence in enhancing the treatment and care of children with cancer in Europe.

The progress and advances that they fostered, particularly through their clinical research in the childhood cancer disease, non-Hodgkin Lymphoma, have been, and continue to be, outstanding and internationally recognised. Indeed, their contribution to this field is considered as a major driving force for the dramatic increase in the survival rate of young patients with NHL both at European level and at the international arena. With this in mind, the SIOPE Board was keen to recognise the significance of their joint ambition to surpass standards and promote innovation in paediatric oncology.

The SIOPE Lifetime Achievement Award is a biennial award granted to distinguished personalities from the European paediatric oncology community during the ECCO (European Cancer Organisation)-led congress. In 2009, during the ECCO 15-34th ESMO Multidisciplinary Congress in Berlin, Prof. Helmut Gadner, based in the Children's Cancer Research Institute in Vienna, Austria, was recognised by the



The SIOPE Lifetime Achievement Award- winners with SIOPE Board members, Ruth Ladenstein, Martin Schrappe and Gilles Vassal.

The SIOPE Lifetime Achievement Award- winners Profs. Alfred Reiter and Catherine Patte after their award lecture at the European Multidisciplinary Cancer Congress in Stockholm in September 2011

SIOPE community for his eminent work in the field of Langerhan's Cell Histiocytosis (LCL).

This year, the Board agreed to jointly recognise both Prof. Catherine Patte of the Institut Gustave Roussy, France, and Prof. Alfred Reiter, of the Children's University Hospital, Giessen, Germany, for their groundbreaking advances in paediatric oncology as well as their important and fruitful collaboration during the past decades. The Board concluded that this relentless work for the heterogeneous group of diseases labelled as NHL helped to lay the foundation and empower the subsequent generation to build a solid network for childhood and adolescent lymphoma, as well as enhance research opportunities and high-quality treatment.

The 2011 SIOPE Lifetime Achievement Award ceremony took place at the European Multidisciplinary Cancer Congress in Stockholm, Sweden during a special SIOPE Society Session where both Patte and Reiter had an award lecture and the community was able to thank them personally for their longstanding commitment to our young cancer patients.

SIOPE's Rising Star

At the European Multidisciplinary Cancer Congress, SIOPE gave Dr. Nathalie Gaspar, a junior paediatric oncologist, with the 'SIOPE Rising Star' award.

Dr. Nathalie Gaspar is a French paediatric oncologist who received her PhD in 2010 after three years of research on HSP90 as a target in paediatric brain tumours in Paul Workman's lab at the Institute for Cancer Research, in London, UK. She was also one of two paediatric oncology students supported by a SIOPE fellowship to attend the 2010 'FLIMS' workshop – Methods in Clinical Cancer Research- a prestigious educational workshop to facilitate cancer research in Europe by enabling young researchers to learn from top experts how to design effective therapeutic clinical trials.

Dr. Gaspar is currently working at the Institut Gustave Roussy in France, where she specialises in treating adolescents and runs the Adolescents and Young Adults programme within the adult oncology ward.

There is no doubt that in the future Dr. Gaspar will be a major player in the SIOPE community helping to progress treatment for this vulnerable group.

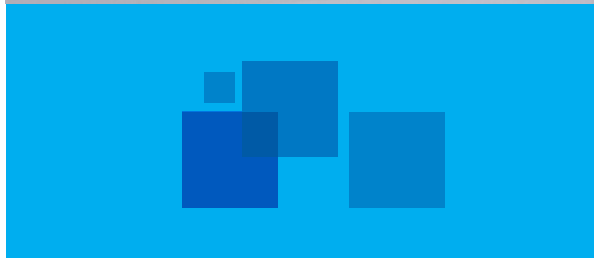
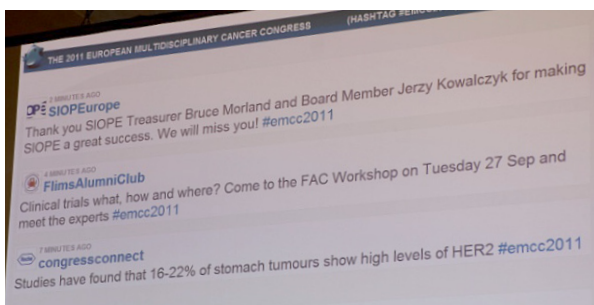


Images from European Multidisciplinary Cancer Congress Stockholm, Sweden, 2011



The ENCCA Musketeers disseminating the EU-funded FP7 project in Stockholm! (From l-r: Ruth Landestein (AT), SIOPE President & ENCCA Project Coordinator, Gilles Vassal (FR): Integrating Activities Coordinator, Martin Schrappe (GE): Joint Research Activities Coordinator, Kathy Pritchard-Jones (UK): Spread of Excellence Activities Coordinator.

Below more memories from Stockholm, including SIOPE Board Member David Walker providing a presentation for the Patient-Ethics Track.



Paediatric, Adolescent, Wild-type & Syndromic GIST



A new UK initiative for rare GIST cancer in Young people



Having children overwhelms you with feelings of joy. Despite months of preparation there is nothing that you have ever done before that can match these wonderful feelings. If your child is diagnosed with cancer there is nothing that has ever happened before that can prepare you for the overwhelming devastation and despair that you feel. To discover that there is no cure for your child's cancer, there is no specialist group with expertise in your country and that the only research into their disease is thousands of miles away in another land makes you feel very alone.

This is how we felt in January 2010 when our 15 year old daughter Eve was diagnosed with Paediatric Wild-type GIST.

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Overnight our lives changed

To combat this attack on our lives we have formed a specialist clinical focus group consisting parents, GIST Support UK and some very special doctors, led by Dr Ramesh Bulusu of Addenbrookes hospital in Cambridge.

Our initial reaction was to seek help from a brilliant team of doctors at the NIH in the USA where they have set up a clinic for Paediatric & Wild-type GIST.

We also came into contact with a fantastic patient support group in the UK called GIST Support UK. They helped us to gain some perspective and gave us hope. They introduced us to other paediatric GIST patients and parents in the UK.

PAWS-GIST

Our group is called PAWS-GIST (Paediatric, Adolescent, Wild-type & Syndromic GIST (Gastro Intestinal Stromal Tumour)) and our aim is to improve treatment and care for this group of patients in the UK and ultimately to find a cure.

We currently know of at least 8 Paediatric GIST cases in the UK, most have Wild-type GIST. There are many more, older patients with Wild-type GIST in the UK, whose lives are similar to those of our children. All have questions and fears that are not easily answered and we are hoping that in collaboration with doctors in America & Europe we will find answers and evolve treatments that will benefit our children and other PAWS-GIST cases in the future.

We are raising funds for research and have many mountains to climb, not least, finding experts who are willing to start research projects.

The current situation

When these rare tumours are removed from patients in the UK they are not being used to optimum effect for research to find a cure. We would like to have a clearly defined protocol in the UK to optimise their use for research.

Dr Bulusu recently attended The National Institutes of Health in Washington DC. Having returned to the UK he has pointed out how very important it is that we gain "Specialist Commissioning Status" for this rare condition.

Most UK doctors have not heard of GIST so it is often misdiagnosed, resulting in unsatisfactory patient management & variable treatment. There is insufficient knowledge in the UK of this rare and complex disease and it requires highly specialist treatment.

We aim to raise awareness and create a situation where PAWS-GIST patients are automatically referred to a specialist centre. We hope to collaborate with GIST patient groups and doctors in Europe.

Paediatric oncologist from Italy, Dr. Gianni Bisogno has set up a group dealing with particularly rare paediatric cancers, such as GIST. Here he provides some information on the group.

Rare Cancer in children, as other uncommon disease, presents to doctors and patients additional challenges to the ones posed by the disease itself. Lack of interest from the scientific, economic and political community; lack of funds; lack of colleagues to work with, have greatly compromised the possibility to conduct meaningful clinical and biological research. This is the case of GIST, a definitely very rare cancer in pediatric age (approximately 0.02 per million children below the age of 14 years). The discovery of new effective drugs in adults have allowed to better characterize GIST also in children. The most important finding is represented by the fact that gene expression profile of pediatric GIST may be distinct from the one typical of adult GIST. Once again tumours typical of adults may behave differently when occurring in paediatric age.

In 2008 a cooperative group denominated EXPeRT – European Cooperative Study Group for Paediatric Rare Tumours has been founded with the aim to empower research on very rare tumours including pediatric GIST, by promoting collaboration between the founder national groups: Italy, France, United Kingdom, Poland and Germany. Additional countries have expressed their interest to collaborate with EXPeRT.

To perform research on rare tumours will require an enormous and prolonged effort as results may be visible only in the long term. We do not expect that EXPeRT will radically change the scenario but at least it will be able to bring this problem to the attention of the medical community.

Our Mission

- registration of all UK PAWS-GIST patients/data collection
- mutational testing as standard
- growing wild type GIST cells "in vitro"
- specialist commissioning status
- minimum doctor's data set before seeing patients
- human tissue, biopsy & blood sample management
- specialist PAWS-GIST treatment clinics
- inclusion of Paediatric GIST patients in clinical trials
- breaking down barriers
- research to achieve better outcomes
- a cure

More information on GIST is available through:

<http://www.gistsupport.org/treatments-for-gist.php>

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JUNE
2011**



Flims Workshop 2011 - SIOPE Fellows

The ECCO-AACR-EORTC-ESMO Workshop on Methods in Clinical Cancer Research, better known as the 'Flims' Workshop, is an educational programme that introduces junior clinical oncologists in any oncology subspecialty to the principles of good clinical trial design. The ultimate goal: to develop a robust, expanding base of well-trained clinical researchers by providing them with the training they need to conduct better clinical/translational trial designs. Within a week attendees elaborate a full clinical trial protocol under expert guidance in their proposed and approved topics.



Dr. André O. van Bueren from the University Medical Center Hamburg-Eppendorf in Germany was awarded a SIOPE fellowship to attend the highly prestigious ECCO-AACR-EORTC-ESMO Workshop - "Methods in Clinical Cancer Research" that took place in Flims, Switzerland on 18 - 24 June 2011. Here he provides an overview of his experience in the wonderful Swiss mountains.

I am extremely grateful that I have been selected to receive personalised financial support (Fellowship Grant recipient) from SIOPE to participate at the ECCO-AACR-EORTC-ESMO Workshop in Flims 2011, Switzerland, the country where I am from.

The workshop was extremely well organised and located at Flims, a very nice place in Switzerland, providing an excellent atmosphere to work very efficient. Some time was reserved for lectures, given by excellent faculty members, providing the fellows the important knowledge with regards of clinical trials in a rapid manner. In the protocol development session, fellows were coached very efficient (8 fellows, 4 faculty member).

The stimulating discussion within the small groups was of great value. During the evenings, there was time to work on the protocol. Importantly, the faculty members were always around to speak with (meet-your-expert session), and were very keen to work together with fellows almost all night.

Everybody could feel the excitement of faculty members and fellows for clinical trials and research. There was also time to socialize and to speak with each other. I personally met extremely many faculty members and fellows with outstanding expertise, and I am convinced that people will keep in touch, exchange their research activity, and we will most probable also collaborate in the future together.

There was a special spirit in Flims, people were motivated, and therefore it was just exciting and fun to work together. I would like to express my sincere gratitude to the faculty members, the organizing committee, the other fellows, and to the sponsors and partners. I am looking forward to similar workshops in the future within the SIOPE or other societies.

André O. von Bueren (Protocol development subject: Metastatic Medulloblastoma)



Dr. Giuseppe Barone from the Institute of Child Health in Great Ormond Street Hospital was also awarded a SIOPE Fellowship to attend the well-known 'FLIMS' workshop. Here is his account of his experience.

Last year I was chosen to attend the joint the joint ECCO-AACR-ASCO Workshop on Methods in Clinical Cancer Research 2011—known also simply as 'the Flims Workshop' supported by a SIOPE grant. I left my duties for an entire week, off to a small village in Switzerland with the hard task to write up an entire clinical protocol. Quite a tough agenda full of lectures nad meetings for an almost impossible task.

I felt the passion of all the attendants and tutors since I first arrived. We were all speaking the same language...and it was not only English...but clinical cancer research.

All the major topics and issues that could be possibly encountered while writing a protocol in the daily practice were covered by a series of lectures: ethical, statistical, practical and legal considerations. Nevertheless the most interactive part was still the work in the small protocol development groups where learning from (and helping) one another. Discussions that continued also during coffee-breaks and after-dinners.

As a paediatric oncologist the interaction with colleagues working with adults and surgeons was enriching and productive, and learned that looking at things with a different prospective could be helpful but at the same time I found out differences that characterize these two worlds, adults and children.

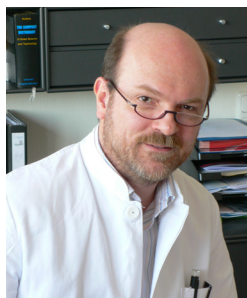
Extremely helpful and weirdly unusual was the possibility to work side by side with a statistician specifically trained at working on clinical trials. Statistics became a friend in a couple of days and I could really enjoy and appreciate our discussion.

At the end of the week the hardest task was completed and the protocol was given to the faculty along with the short title ... an easy way to remember it when it will be presented at the next relevant international meeting.

An attractive and tempting venue for one of the most productive learning experience for a young paediatric oncologists, supported by excellent IT facilities and surrounded by very knowledgeable colleagues and tutors, that is my experience of FLIMS 2011.

Giuseppe Barone (Protocol development subject: Relapsed High Risk Neuroblastoma)

Treasurer's Corner



I am happy to write to you in this position for the first time. I appreciate the confidence, and I hope to succeed in preserving SIOPE's financial stability. There are challenging tasks ahead, among them the issues of future SIOPE membership and membership fees, which is of significant importance for us. Let me thank Bruce Morland for his

work in this position to date. Also I would like to thank Michel Ballieu and Thierry Hoppe for their support through the ECCO office.

Under the direction of the SIOPE President, the SIOPE Board has explored with the Chairs of several European National Societies different strategies on membership and have suggested the possibility to create a new membership model by following the examples of other ECCO Founding Member societies: The basis of membership and fees to SIOPE would be based on the respective national societies rather than on an individual membership, i.e. in our case, on the European National Paediatric Oncology Societies bringing their current members to SIOPE. Currently an amount of 20€ per member within a society is under discussion and would be a basis to calculate the society contribution. These fees would be gathered by national societies along with their national contributions or other funding streams at the discretion of each society. In those countries in which a national society is missing, individual institutions may be able to pay SIOPE membership fees for the doctors and scientists employed there and the institutional fee will be in proportion to the national contributions. Of course, some details still need to be worked out but it was clear that it is positively regarded generally.

The new SIOPE membership will have political implications with regard to our visibility and representation but will also offer and improve reach-out opportunity to the European paediatric oncology community which is currently largely under-represented based on previous member models. It is a reality that currently information does not always reach the right people, such as on educational and training possibilities, which we hope in the future will reach the relevant people through social media.

Bruce Morland has already launched on behalf of the SIOPE Board the open discussion on membership at the SIOPE General Assembly in Stockholm during the European Multidisciplinary Cancer Congress in September 2011.

The subsequent open discussion made clear that increased membership will carry multiple advantages for all stakeholders and ideally will create a real European voice for the paediatric oncology community. It was recognised that a broad membership has the potential to make SIOPE the one major voice relating to all paediatric oncology matters in Europe. The launch of ENCCA certainly gave this move a strong boost, but will require a sustainable structure after the funding period is over. The vision is that SIOPE could comprise that structure.

In the meantime, the Society for Pediatric Oncology and Hematology in Germany (GPOH) has unequivocally voted in support of a national SIOPE membership. Other large national groups have also signalled their approval.

The SIOPE Board has also decided that a new Fundraising Committee with David Walker, Edel Fitzgerald and the Treasurer will explore additional ways to increase funding for SIOPE.

[Martin Schrappe](#) on behalf of the SIOPE Board



News bites

Headsmart

SIOPE is partnering with ICCCPO, the International Confederation of Childhood Cancer Parent Organisations, to kick-start a campaign on the early diagnosis of brain tumours. The successful UK campaign, Headsmart, is expected to be rolled out in a number of European countries through a collaboration between the SIOPE Brain Tumour group and the national parent groups, with support from SIOPE and ICCCPO. Led by SIOPE Board Member Prof. David Walker, a meeting is planned on 06 February 2012 in Brussels to brainstorm on how this can be achieved. Contact the SIOPE office to find out more.

International Childhood Cancer Day 2012

Member of the European Parliament (MEP) Glennis Willmott will kindly host a meeting in the European Parliament in Brussels on 7th February 2012 to mark International Childhood Cancer Day. This is the second meeting of-its-kind and SIOPE delighted to once again have this opportunity. For information on the policy meeting, please contact the SIOPE office.

Standards now in Multiple Languages

The European Standards of Care for Children with Cancer, part of the European Partnership for Action against Cancer initiative (www.epaac.eu) are now available for download in 6 languages – English, Greek, Portuguese, Spanish, Serbian and Polish, with more translations expected in 2012! To view, [CLICK HERE](#).



Season's Greetings to you and your family

From the SIOPE Office and Board

About US



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

www.siope.eu

Working to ensure the best possible care and outcomes for all children and young people with cancer in Europe SIOPE focuses on making a difference and improving the quality of life of young cancer patients.

To do this, SIOPE supports the pooling of initiatives and expertise of multidisciplinary stakeholders in paediatric oncology, building their common experience into a positive force and creating a brighter future for young people with cancer.

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

To view previous newsletters go to www.siope.eu

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

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