

Message from the President and the Office



The EU Clinical Trials Directive has been a hugely destructive piece of legislation for paediatric oncology in Europe. Indeed, it has not only affected our community but has been denounced by the health and medical research community generally. Discussions on the revision of the CTD at EU level have been closely followed by the SIOPE office and Board and we have made it a priority to actively participate in the consultation process. Thanks to many of you for supporting us on this!

Finally, a draft revision of the CTD will be announced next year (likely to be the second quarter of 2012), the first step in the European legislative process. Thus, this is a pivotal time for our community to sustain our advocacy efforts. As President of SIOPE, I have spoken both at a recent event organised by the **European Forum for Good Clinical Practise (EFGCP)** as well as a meeting on **Rare Cancers in the European Parliament** about this 'hot topic', amongst other high-level stakeholder conferences. SIOPE will continue to campaign for better facilitation of our clinical trial work and we urge you to contact your national ministries in the coming months to voice your needs as they will also be involved in the revision decision-making process. We elaborate on our actions on the CTD in more detail in this issue.

In the meantime, as we await this important legislation, we have numerous conferences to look forward to. The **European Multidisciplinary Cancer Congress** takes place this year in Stockholm, Sweden, and many experts from our community will participate in the Paediatric Oncology Track, one of 33 multidisciplinary and multi-professional tracks, which makes this congress unique in many ways. We will have our **General Assembly** here (open to all SIOPE members), where we will announce the results of our recent Board elections, as well as meetings on the EU projects, **ENCCA, Eurocancercoms and PanCareSurfUp**. We also announce the winners of the **2011 SIOPE Lifetime Achievement Awards**, a joint prize this year! I also know that as many of you cannot make it to Auckland for SIOPE, you are considering networking at this event – Per Kogner in Karolinska has also kindly offered the possibility to have side meetings in his institute if we wish! Of course, SIOPE members get a special reduction on this rate.

The anticipated **European Standards of Care for Children with Cancer** project, which is now part of the **European Partnership for Action against Cancer** initiative, will hold a conference in Warsaw, Poland on 20-21 October, 2011,

kindly hosted by the Polish Ministry of Health. This important meeting will attempt to address the disparities that currently exist in caring for our young people with cancer, which can affect their outcome and survival. The particular objective of this meeting, attended by paediatric oncology professionals, parents, patients and policymakers, will be to discuss implementation: what is the best strategy to implement such standards? Can they be integrated into a national cancer plan? What countries are leading in providing optimum care and treatment for children and adolescents with cancer and what are the lessons learned? We look forward to a highly interactive event; for more information contact SIOPE Board Member Jerzy Kowalczyk (jkowalcz(at)dsk.lublin.pl) (please replace [at] with @)

There will also be a **Survivorship Conference** in Dublin, Ireland, part of the PanCare SurfUp project. This event, led by Julianne Byrne from the PanCare consortium, is expected to take place on 26-27 December; more information on this will of course follow shortly.

Finally, a buzz is really building around the **ENCCA** project (European Network for Cancer research in Children and Adolescents). Ivona Brasnjevic, our new Project Manager, has only been with us a short time but has settled in completely to this challenging but exciting new role. We also recently held our ENCCA Executive Committee meeting in Brussels and this has set everything in motion in order to truly integrate the entire community into this project, through the **European Clinical Research Council**. Samira Essiaf in the SIOPE office is busy coordinating a comprehensive contact list so we can engage with all clinical trial and national groups, particularly the newer consortiums in central and Eastern Europe. The **ENCCA General Assembly** takes place in Vienna on 01-02 December 2011 and this will be a great time to look at what has been achieved in less than 12 months, particularly on the dissemination side, where we have presented the project to audiences in ASCO, the European Parliament (twice), the ICCCP European members meeting, Pancare and Pancare SurfUp, the German Paediatric Oncology and Haematology (GPOH) meetings and the CCLG Spring meeting in the UK. We will continue on this endeavour, particularly strong due to our links with the SIOPE office, and look forward to hearing from you on any ideas you have on how we can integrate your group into this network of excellence.

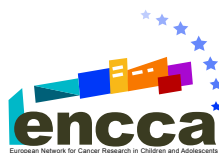
Ruth, Samira and Edel.

SIOPE Europe's Community

Outreach and awareness-building throughout Europe

EU Project Updates

ENCCA Network of Excellence



To achieve the ultimate goal of becoming the 'stepping stone' towards an interactive and sustainable European Institute acting as a paediatric oncology clinical trial facilitating platform, the large and dynamic ENCCA network will deliver 18 work packages over the next 4 years streamlined through 3 main channels of activities embracing all tumours groups: Integrated Activities, Joint Research Activities and Spread of Excellence.

Coordinated by Ruth Ladenstein, MD, our current SIOPE President, ENCCA Project Coordinator and Network of Excellence Manager, the impressive ENCCA consortium is making significant progress.

Recent project developments:

- The ENCCA management team is delighted to inform you about the recent appointment of Ivona Brasnjevic, Project Manager based at the Children's Cancer Research Institute (CCRI) in Vienna.



Ivona Brasnjevic
ENCCA
Project Manager

Ivona is from Belgrade, Serbia and prior to working for Children's Cancer Research Institute in Vienna, Ivona has worked in the field of research and development within biochemical and chemical technology for more than 9 years. Her experience includes:

- A graduate of physical chemistry in Serbia and thereafter a research placement in the Mayo Clinic, in Rochester, Minnesota, US. Subsequently she gained her PhD and PostDoc at Maastricht University in the Netherlands.
- 5 years experience in project and personnel leadership and management in R&D organisations during and after finishing her PhD. Specific project management examples include the NanoBioPharmaceutical (EU-funded FP6) and NanoNeuroTox (EU-funded FP7) consortiums.

Ivona now works as the ENCCA Project Manager in the Children's Cancer Research Institute in Vienna, Austria and her daily work consists of all the technical, financial and administrative tasks related to such a large project.

- Ivona is responsible for the day-to-day technical, financial and administrative management of the project to support tasks leaders.

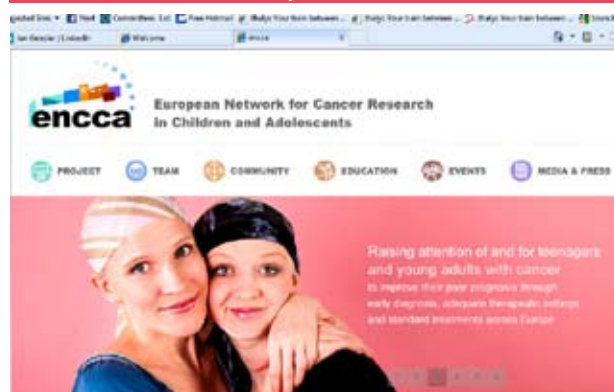
She works in close collaboration with Ruth Ladenstein, Network of Excellence Manager at CCRI and the three Activity Coordinators, respectively, Martin Schrappe for 'Joint Research' at Christian Albrechts-Universitat (CAU),

Kathy Pritchard-Jones for 'Spread of Excellence' at University College London (UCL) and Gilles Vassal for 'Integrating Activities' at Institut Gustave Roussy (IGR). Welcome on board Ivona!

- Launch of ENCCA website!

The ENCCA team are delighted to announce the launch of the ENCCA website. This website features background information on this important network of excellence, including an overview of the partners and deliverables as well as information on relevant upcoming events, educational courses and targeted information on childhood and adolescent cancer for patients, parents, policymakers, the pharmaceutical industry and even the general public. The latest news and press releases will also be uploaded in due course.

For more information please visit www.encca.eu.



- **Paediatric Oncology Track including an ENCCA dedicated Session**
24-26 September 2011
- **European Multidisciplinary Cancer Congress - Stockholm, Sweden** ([CLICK HERE FOR THE PROGRAMME](#))
23-27 September 2011
- **Second European Clinical Research Cancer Meeting (ECRC)**, European Multidisciplinary Cancer Congress Stockholm, Sweden.
26 September 2011
The ECRC is planning to finalise the statutes and discuss elected representatives whose roles will be not only to liaise with ENCCA decision-makers but also rally SIOPE on political actions.
- **ENCCA Annual General Assembly**
1-2 December 2011
Vienna, Austria (CCRI Headquarters)

Please help us spread the word on the European Multidisciplinary Cancer Congress! Note that discounted rates apply for SIOPE members and students. We are looking forward to welcoming the paediatric oncology community to this very exciting event! ([CLICK HERE](#))

For further information, please contact the SIOPE office.

SIOPE Board Members present at European Parliament event on Rare Cancers



From l-r: MEP Glenis Willmott, Jan Geissler, Peter Wilkinson, Ruth Ladenstein, MEP Alojz Peterle and Sam White.

Overview of SIOPE's key messages at the Rare Cancers Event

The European Parliament Environment Public Health and Food Safety (ENVI) Committee recently organised a meeting as part of their Health Working Group on 'Rare Cancers: the added value of closer co-operation' on 12 July 2011. Co-chaired by MEPs Glenis Willmott and Alojz Peterle, the workshop debated the special issues people face when diagnosed with rare cancers, a very significant group of whom are children and young people. Several young patients and survivors joined SIOPE Board Members Associate Prof. Ruth Ladenstein (St. Anna's Children Hospital, Austria, SIOPE President and ENCCA Project Coordinator), Prof. David Walker (Children's Brain Tumour Research Centre, UK) and Prof. Gilles Vassal (Institut Gustave Roussy, France and SIOPE President-Elect) to make a plea for more attention for childhood and adolescent cancers.

The three SIOPE Board members were joined by numerous high-level stakeholders active in the field of rare cancers. The meeting itself was organised around two key topics – 'The importance of the special recognition for rare cancers in the revision of the EU Clinical Trials Directive' and 'Improving Radiation Therapies and Drug Development for Rare Cancers'.

The session on the special recognition for rare cancers in the revision of the EU CTD was chaired by Ms. Glenis Willmott, an active MEP in the field of public health in the European Parliament. Aside from Associate Prof. Ladenstein and Prof. Walker, other presented in this session were namely the Director of Health Systems and Products at the European Commission's Directorate General for Health and Consumers (DG Sanco), Dr. Andrej Rys, Prof. Paolo Casali (European Action against Rare Cancers and European Society for Medical Oncology (ESMO)), Jan Geissler (Chronic Myelogenous Leukemia Advocates Network) and Prof. Françoise Meunier (EORTC). We were particularly happy to ensure the patient voice was the central focus of this session, with courageous 14-year old Sam White, a patient of Prof. Walker's in Nottingham. Sam was diagnosed with a brain tumour which imploded and rendered him unconscious.

When diagnosed he was given just an hour to live.

Our focus as paediatricians is driven by our training and working environment in children's hospitals and specialist paediatric departments across Europe and naturally this type of clinical practice brings us into contact with very worried parents advocating for their children. In order to help them understand whether their children are being offered the best available treatment we have to ask ourselves if we offer the optimal treatment for each child. In fact we need to ask ourselves:

- As a parent would you want your ill child treated with drugs, which are licensed or unlicensed for their use?
- As a parent would you want your ill child's doctor to select treatments based upon high quality research evidence or based upon his personal opinion and experience within his/her local health system?

In our cancer practice, most of our drugs are unlicensed for children, despite recent changes to legislation and efforts of the European Medicines Agency (EMA) to try and catch up with the licensing of previously used, but unlicensed drugs as well as the new drugs coming to the market. Most of the drugs are licensed for adults, but their use in younger age groups and in the indications of childhood cancer has not been tested in pharmaceutical development programmes, and hence are considered to be used 'off label'.

Slow progress is being made within the pharmaceutical industry to bring new drugs to the market, but it has still not gone far enough which is frustrating for the European paediatric oncology community. Children in Europe have been denied access to innovative anticancer therapies while in the meantime many truly innovative medicines have been developed for the treatment of adult cancers. Despite the welcomed EU Paediatric Regulation (1901/2006), there are significant delays in the initiation of studies with new drugs in Europe and children are denied access to new potentially effective drugs (as compared to the US where many new drugs are studied in a timely fashion).

KEY CHALLENGES

- The statistical challenge for researchers wishing to study the many different tumour types
- The low priority for children's diseases as a focus for pharmaceutical-led drug development because of the challenge of their commercial justification, the over-emphasised perception of the ethical challenges and their orphan status.

Now 18 months following treatment at the Children's Brain Tumour Research Centre, Sam has defied the experts. Although the brain tumour has left him with some lasting effects, such as memory loss, Sam is back to school and busy highlighting the effects of cancers in teenagers through various activities, in particular speaking about the challenges facing him in his return to education.

Brave Sam drove home the message that while he received the best standard care in his home town of Nottingham and can now share his story, other young patients cannot avail of the same high-level treatment and care in other European countries which can thus affect their outcome.

25-year old Peter Wilkinson was also diagnosed with a brain tumour (pineal Blastoma grade 4) aged 21. Due to a late-diagnosis, the tumour spread down the spine. Despite many challenges physically, including neuropathy, spinal arthritis, fatigue and peripheral vision, he is a superb example of how courageous our young survivors are. Putting a smile on each and every one of the participants at the Parliament using his infamous 'tumour humour', he spoke about the 'Jimmyteens' project, which provide young cancer patients with the opportunity to express themselves creatively. Peter highlighted the fact that just because a cancer is rare should not mean it is forgotten. He encouraged policymakers to ensure further investment in research in the treatment of paediatric cancers to ensure that patients benefit from optimal outcomes in order to survive and live a normal life.

The second part of this meeting dealt with improvements to radiation therapies and drug development for Rare Cancers and was chaired by Mr. Alojz Peterle. Mr. Peterle is a true advocate for cancer and cancer patients in the European Parliament. A cancer survivor, he is Chair of the MAC group (MEPs Against Cancer). Prof. Vassal was joined in this session by Maria-José Vidal-Ragout, Head of the Medical Research Unit at the Directorate General for Research and Innovation, in the European Commission. The other speakers in this session were Dr. Pamela Cohen (Sanofi) and Dr. Stephanie Combs (University Hospital of Heidelberg and ULICE (Union of Light Ion Centres in Europe)).

Inequalities in access to sufficient resources between EU Member States to support the conduct of clinical trials with the current legislative burden as well as the cost of insurance required for Sponsorship.

- The disproportionately negative effect of the EU Clinical Trials Directive (CTD) (2001/20/EC) on the conduct of clinical trials in paediatric oncology where there has been the greatest variability in national interpretation of the Directive. The current bureaucratic workload of trial activation in Europe is much too high for many rare diseases including childhood cancers. This Directive in its current form allows no room for curiosity-driven research in a clinical setting. At this point in time, rather than encouraging innovation, current research funding in paediatric oncology is rather funding insurance companies.

SIOPE hence wishes to draw attention to three particularly critical areas of major importance for the Clinical Trials Directive revision:

- ◆ The definitions of an investigational medical product (IMP) and its enhanced regulatory requirements in rare diseases and paediatric cancer trial settings: we experience a lack commercial interest and hence appropriate drug development. Therefore, the only way to currently treat patients is to utilise drugs in off-label status, which subjects them into IMP status in many Member States with high associated costs of trial governance and insurance rates.

- ◆ The necessity of a refined risk-based approach for paediatric cancer treatments proportionate to the underlying life-threatening disease. Current standard cancer treatments should be considered low-risk trials in spite of the inevitable problem of 'off-label use', an inherited burden accumulated over the last decades. Children should not be excluded from any type of "low administrative burden" regulation just because the drug(s) in question is not licensed for the age group or the indication.

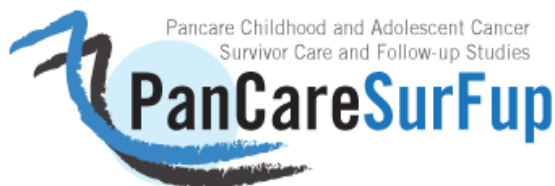
- ◆ The need to challenge the current single sponsor role. Since the majority of paediatric cancer trials are multinational there is a clear need for joint responsibility shared by national sponsors in a co-sponsorship role due to the specific national legal and regulatory settings including ethical committees. We support the co-sponsorship approach governed by a coordinating sponsor and would value recognition of these models throughout the EU.

Projects like the EU-funded Seventh Framework Programme, the European Network for Cancer research in Children and Adolescents will go some distance to address these issues to produce better and safer treatments but there is a need for sustainability of these EU projects. For patients Peter and Sam, projects like the PanCare SurfUp initiative can investigate the long-term effects of the intensive treatment needed by our young patients in Europe.

Ruth Ladenstein, David Walker and Gilles Vassal

Latest News from PanCare SurfUp

PanCare is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer.



SIOPE supports the **dissemination** of the PanCare consortium's EU Seventh Framework Programme project, PanCareSurFup. Coordinated by Prof. Lars Hjorth in the Skåne University Hospital Lund, Sweden, PanCareSurFup aims to collect data on the risks of complications of cancer treatments for children and adolescents.

Here are the latest developments for this project:

- The seventh PanCare meeting, hosted by Dr. Tomas Kepak, was held in Brno 27-29 April 2011.
- PanCareSurFup's website is up and running and provides an overview of the project partners and work packages. Click on www.pancaresurfup.eu to view.
- Work on the Study Protocol for WP's 1-5 has been moving along and expected deliverables are to be finalised in the next few weeks. Thereafter applications for ethical approvals can be sent out from all partners.
- Lars Hjorth will disseminate the project at the forthcoming European Multidisciplinary Cancer Congress in Stockholm during the session, Long-Term Follow-Up in Childhood and Adolescent Cancer on Saturday, 24 September 2011. He will also update the paediatric community on the project at the SIOPE General Assembly on Sunday, 25 September 2011, also during the Congress.

- The PanCareSurFup General Assembly takes place in Amsterdam on 02 October 2011.
- A system for Internal Periodic Reporting is also currently being created within the project.
- A conference, organised by Dr. Julianne Byrne of the consortium will take place on 26 and 27 October in Dublin, Ireland on Survivorship after Childhood Cancer.
- The PanCare Consortium responded to the EU Green Paper consultation on the future of EU research funding, of which SIOPE contributed to. Please [CLICK HERE](#) to view the paper.
- And last but certainly not least, PanCare SurfUp is delighted to welcome it's new Project Manager, Elise Kvarnström. Working with the Coordinator Lars Hjorth and based in the Department of Clinical Sciences in Lund, Elise's background is in languages and communication but for the last nine years she has worked for the two life science networks Medicin Valley Alliance and ScanBalt, and in Lund University as Project Manager. Moreover, Elise has written, administered and disseminated several EU-funded FP6, FP7 and Interreg projects.



The seventh PanCare meeting, hosted by Dr. Tomas Kepak, was held in Brno on 27-29 April 2011

The kick-off meeting of the PanCare SurfUp project was held in Lund, Sweden on 02-04 February 2011.





Young People represented in European Action against Rare Cancers



SIOPE is delighted to be part of the European Action against Rare Cancers representing all children and adolescents with cancer. Here Robert Schaefer, Senior Project Manager for the initiative, discusses the 'raison d'être' for such an initiative.

According to the EU-funded Surveillance of Rare Cancers in Europe project (www.rarecare.eu), there are close to 190 different rare cancer types, some of them so rare that meaningful clinical studies will require global participation. However, rare cancers affect around 4 million people in the European Union alone and represent in total about 22% of all cancer cases, including all cancers in children, diagnosed in the EU-27 each year.

Rare cancers are generally classified in the group of rare diseases, which is defined in the European Union as diseases with a prevalence of fewer than 5 cases out of a population of 10,000. Given that prevalence – the number of patients with the same diagnosis at a given time – is affected by mortality however, it has been proposed by the Surveillance of Rare Cancers in Europe project to consider a definition of rare cancers based on incidence, meaning the number of newly-diagnosed cases per year. According to this, rare cancers are identified as those with an incidence of less than 6 per 100,000 persons per year. Using this definition would help minimise the risk of mistaking a rare cancer (such as testicular cancer), which is frequently cured and thus has a rather high prevalence, for a common cancer, or a frequent cancer (such as small-cell lung cancer), which has a low life expectancy and thus a low prevalence, for a rare cancer.

There is evidence that five-year relative survival rates are worse for rare cancers (47%) than for common cancers (65%) and it has been documented that survival rates differ significantly across Europe (Gatta G., *Lancet Oncology*, 2006).

Like other rare diseases, rare cancers pose particular challenges due to their low frequency, including:

- ◆ late or incorrect diagnosis
- ◆ difficulties finding clinical expertise and accessing appropriate treatments
- ◆ challenges in carrying out clinical studies
- ◆ possible lack of interest to develop new drugs
- ◆ high uncertainty in clinical decision-making
- ◆ scarcity of available registries and tissue banks.

To tackle these challenges, several key stakeholders have decided to join forces in an unprecedented partnership initiative: The European Action Against Rare Cancers (www.rarecancers.eu), which will soon be renamed Rare Cancers Europe. In this partnership, professional societies, cancer and rare disease associations, rare cancer networks and reference centres, professional education and training organisations, patient advocacy groups, and the industry, work together to put rare cancers on the European policy agenda and to implement

39 political recommendations (to view these political recommendations, [CLICK HERE](#)). These address numerous issues :

- ◆ methodological and regulatory barriers in rare cancer care
- ◆ the need for centres of expertise and European reference networks
- ◆ barriers to patients' access to care
- ◆ education of healthcare professionals and
- ◆ access to information on rare cancers.

The 39 recommendations can be summarised under three overarching goals, namely

- 1) to improve the methodology of clinical studies in rare cancers,
- 2) to improve the organisation of health care in rare cancers and
- 3) to improve access of rare cancer patients to new therapies in the EU.

The European Action Against Rare Cancers aims to develop scientific-based platforms, gather scientific findings, educate and raise awareness with target audiences, build consensus among professionals and the patient advocacy community, and advocate recommendations for political and stakeholder implementation. For example, a consensus meeting on the methodology of clinical studies and clinical decision-making in rare cancers will be organised from 9-10 February 2012 in Brussels in order to develop a set of corresponding recommendations and methodological solutions.

List of collaborating organisations involved in this initiative:

- The European Society for Medical Oncology (ESMO) (leading the initiative and Secretariat)
- SIOP Europe
- European Organisation for Rare Diseases (Eurordis)
- European Cancer Patient Coalition (ECPC),
- European Organisation for Research and Treatment of Cancer (EORTC)
- Conticanet
- EuroBoNeT
- Association of European Cancer Leagues (ECL)
- Chronic Myeloid Leukaemia Support Group
- International Brain Tumour Alliance (IBTA)
- Orphanet
- Chronic Myeloid Leukaemia Advocates Network
- Fondazione IRCCS Istituto Nazionale dei Tumori
- European Institute of Oncology (IEO)
- European School of Oncology (ESO)
- European Oncology Nursing Society (EONS)
- European Society of Pathology (ESP)
- Novartis Oncology (initiating sponsor and sustaining industry partner)
- Pfizer Oncology (sustaining industry partner)
- Sanofi-Aventis (sustaining industry partner)

The campaign is moreover supported by additional corporate supporters.

Standards of Care

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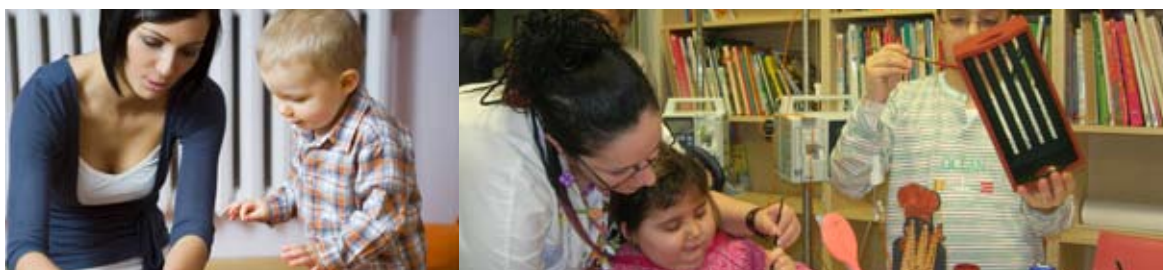
Better outcomes

European Standards of Care for Children with Cancer

Conference organised by the Polish Health Ministry with SIOPE to increase policy and public awareness of the need for the development of standards of care in paediatric oncology in European health system: 20 - 21 October, 2011 in Warsaw, Poland

The European Partnership for Action against Cancer was launched in 2009 after the European Commission published the Communication on Action against Cancer: European Partnership ([CLICK HERE TO VIEW](#)).

This is a unique partnership bringing together stakeholders from the entire cancer continuum in Europe in efforts to share knowledge and expertise to prevent and control the burden of cancer. Encompassing 38 Associated Partners and 90 Collaborating Partners, the European Partnership for Action against Cancer is a large and ambitious project and is a unique disease-specific 'joint action' incorporating all bodies involved in cancer: national health ministries, EU policymakers, regional agencies, professional organisations, patient groups, health NGOs and interest groups and industry.



SIOPE is involved in this initiative 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.

SIOPE Europe represents children and young people with cancer in the initiative. In partnership with the Polish Ministry of Health, SIOPE will disseminate European Standards of Care for Children with Cancer, a consensus document agreed both by patient and parent groups and professionals and in cooperation with the Communication without Barriers Foundation in Poland, on the minimum standards that institutions should have when caring for our young patients. [CLICK HERE TO VIEW](#) the European Standards of Care for Children with Cancer.

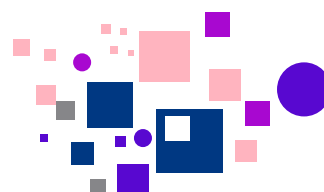
Highlights from the agreed Standards include:

- ⊗ Recommended staffing levels for the paediatric haematology/oncology ward
- ⊗ Components of care in a specialist facility
- ⊗ Delivery of Therapy
- ⊗ Monitoring the late outcomes of cancer
- ⊗ Psychological and Psychosocial Care
- ⊗ The rights of the hospitalised child
- ⊗ The critical role of parents

Deliverables of this part of the European Partnership for Action against Cancer include:

- ⊗ Production and dissemination of the European Standards of Care for Children with Cancer
- ⊗ Survey of Paediatric Oncology units to track the changes observed since the establishment of the standards of care

To find out more, contact the SIOPE office ([office\(at\)siope.eu](mailto:office(at)siope.eu) (please replace (at) with@)).



Oncovideos



Education and Culture DG

Lifelong Learning Programme

Developing Vocational Skills in Oncology through e-Learning is a cross discipline educational resource for young oncologists in Europe who need practice oriented training

Oncovideos is a series of 24 videos demonstrating standard procedures in oncology. Each video features a leading expert from one of the 18 different cancer teaching partner institutions, performing and explaining the particular process involved. Both the topics and experts were selected by the European societies representing each specific oncology discipline: EANO, ESMO, ESSO, ESTRO and SIOPE. ECCO played a key role in coordinating the 18 partner cancer institutions in their development.

The video on Lumbar Puncture will explain in detail how to perform this procedure by combining the procedure filming and tridimensional video clips. The video explains the rationale and the possible complications related to the performance of a lumbar puncture.

The video underlines the importance of the use of deep sedation in performing this painful procedure and the important rules that should be followed in order to avoid any possibility of erroneous intrathecal administration of antineoplastic agents. This could be extremely dangerous when administered by intrathecal route.

In the field of paediatric oncology three videos are developed at the Università Cattolica del Sacro Cuore by Professor Riccardo Riccardi and his team. The videos will explain and show the following procedures: lumbar puncture, bone marrow biopsy and bone marrow aspiration.

Oncovideos is an EU funded project that will be accessible through the Education section of ECCO's website, freely available to all healthcare professionals upon a simple registration process. Launched with four videos last June, the website will be updated on a regular basis so that all 24 videos are made available before the end of 2011. A link will be made from the SIOPE website to the ECCO website.

Promoting better policies for children with Cancer

EU Clinical Trials Directive Concept Paper – response from SIOPE Community

SIOPE has contributed to the consultation of the EU Clinical Trials Directive revision at each stage of the revision process. In May 2011, SIOPE sent a comprehensive response to the Commission 'Concept Paper', allowing the experience of the several European paediatric oncology study groups who launched highly successful multinational clinical trials across the EU to be taken into account. Please find below a summary of the main points of our response.

However the current bureaucratic workload of trial activation in Europe is much too high for many rare diseases including paediatric cancer. Added to this, as a consequence of the rare nature of the disease investigator-led trials suffer from a lack of commercial sponsorship. Thus, many non-commercial organisations are still unwilling to undertake the role of 'sponsor' at a pan-European level for multinational trials in children.

Introduction

Multinational clinical trials are vital to ensure optimal treatment for each young person diagnosed with cancer and to enable further advancement in improving outcomes, in order to sustain the momentum of progress developed over the past 40 years. In the eyes of patients and clinical staff in this field of practice, clinical trials and research are not considered a luxury but rather an essential component of the fight against cancer in young patients.

IMP Definitions (Investigational Medical Product)

Due to lack of commercial interest and thus poor drug development, often the only way to treat patients is to utilise drugs in off-label or off-licence status, many of which already have an off-patent status.

Indeed, the definition of an IMP and its full scope of current implications represent a major burden within academic multi-agent phase III trial settings, as various combinations of licensed, but off-label drugs, are tested

for their efficacy in defined combinations rather than aiming to register a single drug.

Many of these drugs are in use for over 20 years in consecutive trial settings and are the back-bone of many standard treatments for our young patients with cancer. Indeed, standard treatment settings have formed the current success rates for survivorship of childhood cancer patients, with up to 80% compared to previously 10% surviving.

Mechanisms need to be in place to encourage sponsors to formally share responsibility for trials and identify dynamic ways of addressing pan-European sponsorship of IMP trials (European Science Foundation, 2009, p. 14 - [CLICK HERE](#) to download).

A 'waiver decision process', which can limit the full scope of IMP requirements for drugs in off-label or off-licence use in such rare disease indications should be considered.

Risk-based approaches

SIOPE considers that the major risk comes from the underlying disease: cancer in young people is an aggressive and life-threatening disease; however due to established cancer treatment standards, there has been a fantastic increase in survival rates for young patients. A risk categorisation based on relative risk should be considered as not all childhood cancer trials should automatically be categorised as high-risk if the disease itself is high-risk.

Risk evaluation, such as a 'scoring system' is being considered within the EU-funded Seventh Framework Programme (FP7) project, ENCCA – the European Network for Cancer research in Children and Adolescents. SIOPE and the ENCCA Management team expect to have draft documents available in late autumn to address how to assess risk in childhood and adolescent cancer trials.

Challenging the single sponsor role: **Defined roles for a 'Coordinating Sponsor' and a 'National Sponsor'**

Many barriers affect the running of paediatric trials in relation to sponsorship:

- ◆ The legal and language diversity between Member States
- ◆ The fragmentation in the duties and liabilities of the different Member State trial participants
- ◆ The concern by academic institutions to participate in such a costly and bureaucratic non-commercial trial

The following roles with a defined task profile could be considered to promote sponsorship of academic-led paediatric oncology trials:

Co-ordinating sponsor: the central contact point to be addressed for key trial queries and results hence controlling the integrated data of the whole multinational trial.

National sponsor: the first point-of-contact for country-specific questions and responsible for ensuring conformity at national level of the regulatory and good clinical practice (GCP) issues.

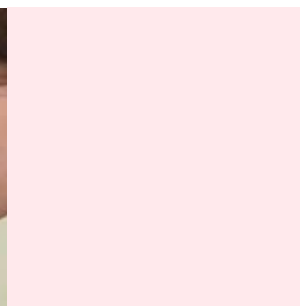
Bureaucracy

Finally, it is essential that the Clinical Trials Directive forges an environment for creating innovative medicines. As red tape is the enemy of creativity, the EU CTD in its current form allows no room for curiosity-driven research in a clinical setting. While the development of personalised medicine is being encouraged, at this point in time current research funding for paediatric oncology is funding insurance companies instead of encouraging innovation. A single submission, with a defined timeline, will greatly reduce the administrative burden.

This response was collated by the SIOP Europe Board and office after extensive consultation with the chairs of the European clinical trial groups and national societies.

To view the Concept Paper, [CLICK HERE](#).

To view the SIOPE response to the Concept Paper, [CLICK HERE](#).



SIOPE Community Reports and Roundups

European Clinical Research Council

Stemming from the SIOPE Clinical Trials Committee, the European Clinical Research Council for paediatric oncology was set up through the EU-funded FP7 project, ENCCA, the European Network for Cancer research in Children and Adolescents.

At our 1st ECRC (European Clinical Research Council for paediatric oncology) meeting, where many European clinical trial groups and national paediatric oncology societies were represented, the importance of the creation of the ECRC, representing all the European Clinical Groups, was stressed out to all attendees. The aim of this council is to have a European level of coordination of paediatric and adolescent cancer clinical research activities as well as developing the capacity to address the many common issues that cannot be solved by each group working in isolation.

IMPORTANT

• Call for two ECRC representatives

As an outcome of our first ECRC meeting a call for nomination for two ECRC representatives has been launched amongst the European clinical trial groups & national paediatric oncology societies to represent the European Clinical Research Council (ECRC) for future interaction with the ENCCA Executive Committee. In case of interest we strongly encourage you to submit your **nomination before the deadline of 05 September 2011** to the SIOPE office.

• Contracts

We are very proud to announce that the first draft templates of the contracts for 'Multinational Investigator-Driven Clinical Trials' have been circulated amongst the EU clinical trial groups and national paediatric oncology societies for an initial review. This first version of these contracts based on a risk analysis has been prepared by Martina Gantschacher (European Society for Quality in Healthcare (ESQH), Vienna, Austria) on the basis of previous European Contracts used by European trial groups and in collaborations with the clinical trial units in the Children's Cancer Research Institute in Vienna and the University of Birmingham as well as with SIOPE as one activity for clinical trial groups within ENCCA.

• Next ECRC meeting

The next ECRC meeting is planned on Monday 26 September 2011 from 17.00 – 18.00 in Room K14 at the Stockholm Congress Centre. We kindly would like to ask you to notify us of any colleagues (European Clinical Trial Chairs and National Paediatric Society Chairs) that did not receive this invitation.

We would like to remind you about our very attractive Paediatric Haemato-Oncology Track at the European Multidisciplinary Cancer Congress in Stockholm, Sweden. [CLICK HERE FOR MORE INFORMATION.](#)

For more information about the ECRC and the 2011 Stockholm Cancer Congress please kindly contact Samira Essiaf at the SIOPE office.



SIOPE Board Member Elections & General Assembly

**SIOPE General Assembly
25th September 2011, 18.15-19.45**

Only a few more weeks to go before we can all meet again at our yearly General Assembly which will be held at the European Multidisciplinary Cancer Congress in Stockholm. Topics such as membership, elections of the new board members, outcomes of the ECRC and updates from the Educational and Training committees will be addressed during, what promises, to be a very important meeting.

Book this meeting in your diary now and benefit of many multidisciplinary tracks!

USE YOUR VOTE FOR YOUR PREFERRED NEW SIOPE BOARD MEMBER

We are very pleased to announce that for the two open position at the SIOPE Board we have received in total four candidates who have been nominated to become a Board Member of SIOPE Europe.

The nominees are

- Henrik Hasle (Denmark)
- Csonger Kiss (Hungary)
- Filippo Spreafico (Italy)
- Maria Grazia Valsecchi (Italy)



The new Board members will be officially announced at the SIOPE General Assembly, Sunday 25 September (18.15 -19.45) taking place at the European Multidisciplinary Cancer Congress in Stockholm (Sweden) of which you are all welcome to attend. For registration to the European Multidisciplinary Cancer Congress and thus the SIOPE General Assembly, [CLICK HERE.](#)

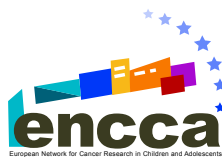
SIOPE Education and Training

The SIOPE Education and Training Committee has again the pleasure to brief you some of the activities SIOPE is involved.

SIOPE was again heavily involved in two training events that took place in late spring: the ITCC-ENCCA training Course held on 25-27 May, 2011, in Rome, Italy and the Joint ECCO-AACR-EORTC-ESMO Workshop on Methods in Clinical Cancer Research held on 18-24 June 2011 in Flims, Switzerland.

As already announced in one of our previous newsletter editions we are continuously working on the " Case Study of the Month project" in order to have a library of case studies which we will share with you in the near future.

We also would like to take the opportunity to launch a call amongst your young oncologists in your institutions to submit case studies.



For the third time the ITCC-ENCCA Training Course devoted to early drug development for paediatric patients with cancer took place.

This intensive course was again a unique opportunity for medical professionals, such as doctors and research nurses in ITCC centres as well non-EU institutions and representatives from the pharmaceutical industry to learn the essentials of early drug development in paediatric oncology from the experts in this highly-specialised field.

The 13th edition of the joint ECCO-AACR-EORTC-ESMO workshop, also known as the Flims workshop was again a very successful and high-level meeting. From the 80 selected young oncologists we had three paediatric oncologists participating, of which 2 were supported by a SIOPE fellowship grant. In our next newsletter, you can read their testimonies on their experience of this unique and intensive workshop on Clinical Research Methods tucked away in the Swiss mountains.

For more information on the SIOPE Education and Training activities, please kindly contact Samira Essiaf at the SIOPE office.



Students with faculty members at FLIMS, tucked away in the Swiss mountains!

Special Features

Chronic Myeloid Leukaemia in paediatric patients: iCMLf and CML Advocates Network join forces on this ultra-rare cancer



In 2001, at the age of 28 years, Jan Geissler was diagnosed with Chronic Myeloid Leukemia (CML). In 2002 he founded the online patient community Leukamie-Online/ LeukaNET, today one of the most frequented online platforms for leukaemia patients in the German-speaking internet. Since then he has become a true patient advocate, co-founder of the CML Advocates Network and Communications Manager of the International CML Foundations amongst numerous other roles. Here he provides an overview of CML in paediatric patients and newly-launched web resources for paediatric CML

Chronic Myeloid Leukaemia in paediatric patients: iCMLf and CML Advocates Network join forces on this ultra-rare cancer.

In general, acute leukaemias are most prevalent in children and are therefore often referred to as “childhood leukaemias”.

The chronic forms of these leukaemias, including Chronic Myeloid Leukemia (CML), are seen almost solely in adults. With the average age of diagnosis of CML being around 60 in western countries, CML in children is considered an ultra-rare condition. Incidence is unknown but estimations are that this cancer accounts for less than 3% of all childhood leukaemias and less than 10% of all CML cases including adults. For so far unknown reasons, incidence is suspected to be higher in developing countries.

Long-term survival of paediatric patients with CML receiving hematopoietic stem cell transplantation has been reported between 60-75%, but is also associated with significant morbidity. New tyrosine kinase inhibitors (TKI) offer potential for turning this leukaemia into a chronic disease, reducing the risk of therapy-associated morbidity and mortality significantly. However, due to the low incidence, most CML data with these drugs are derived from adult studies only. Specific issues in children and adolescents with CML include the uncertainty about long-term effects of TKI therapy, challenges of adherence to therapy, fertility and family planning issues, as well as psycho-oncology.

As CML in children is so rare, collaboration between researchers and patient groups across national borders is all the more important. The “CML Advocates Network”, the international platform of patient groups supporting patients and relatives suffering from Chronic Myeloid Leukemia, and the “International CML Foundation”, initiated by leading hematologists, has joined forces to support physicians, researchers and patients.

The project, launched on International Childhood Cancer Day on 15 February 2011, encompasses a range of activities to support collaboration as well as sharing of experience and best practice.

The newly launched web resource on paediatric CML is available on both the iCMLf's and the CML Advocates Network's websites and contains a comprehensive overview of scientific publications and ongoing trials in paediatric CML, links to patient organisations supporting young CML patients, an online discussion forum for physicians. In addition, teleconferences give paediatricians additional opportunities to share data and experiences.

“As the coordinator of a number of clinical trials in paediatric CML, I know well how important it is to share best practice between those that treat young patients with CML. I am very supportive of this initiative and wish both organisations great success”, says Prof. Meinolf Suttrop, Division of Paediatric Haematology and Oncology, Department of Paediatrics, University Hospital Carl Gustav Carus, Dresden, Germany.



Prof. Meinolf Suttrop, Division of Paediatric Haematology and Oncology, Department of Paediatrics, University Hospital Carl Gustav Carus, Dresden, Germany.

“We perceive a need for communications between paediatricians treating children and adolescents with CML. At the same time, parents feel uncertain about how young CML patients can be managed in the best way. Joining forces between the iCMLf, connecting physicians, and the CML Advocates Network, connecting

patient advocates, is a perfect match”, says Jan Geissler who is both a CML patient, a co-founder of the CML Advocates Network and the manager of the paediatric project at the iCMLf.

“Five years ago, my youngest son just turned 9 years old when he was diagnosed with CML”, says Rod Padua, president of the patient organisation ‘Touched By Max Philippines’. “We are grateful that the international community is now collaborating to improve care of this very rare childhood leukaemia”, he adds.

For more information check out the websites:

<http://junior.cmladvocates.net>

<http://cml-foundation.org/pediatric>



RareCare initiative The Burden of Rare Cancers in Europe



Prof. Gemma Gatta, coordinator of the EU-funded Rarecare project, is part of the European Partnership for Action against Cancer and the European Action against Rare Cancers, similar to SIOPE. At their meeting in Treviso, Italy in June 2009, Dr. Gianni Bisogno attended representing SIOP Europe. Here now is brief summary on this project and key outcomes, which finished in 2010.

programme of DG Health and Consumers and PHEA programme, RARECARE also contributed among other projects to the creation of networks of action for rare diseases. The Fondazione IRCCS Istituto Nazionale dei Tumori (Milan, Italy) is the leading organisation and more than 15 European institutions and organisations participated in the project as associated or collaborating partners.

The Surveillance of Rare Cancers in Europe project, or ‘RARECARE’ estimated the burden of rare cancers in Europe. Its aim was to provide an operational definition of “rare cancer” and a list of cancers meeting that definition. The project also provided cancer burden indicators (incidence, survival, prevalence and mortality), based on population-based cancer registry data, on rare cancers across Europe.

The Surveillance of Rare Cancers in Europe project (funded by the European Commission) aimed at providing a definition of “rare cancer”, a list of cancers and rare cancer burden indicators, based on population-based cancer registry data, across Europe.

In addition RARECARE assessed the quality and comparability of rare cancer data between cancer registries. The project developed strategies for the diffusion of information among all the key players involved in Europe-wide surveillance on and treatment of rare cancers (clinicians, patients, health planners and researchers).

An international consensus group agreed that incidence is the most appropriate indicator for measuring rare cancers frequency and set the threshold for rarity at 6/100,000/year. The list of rare cancers was based on the International Classification of Diseases for Oncology (ICD-O 3rd edition) and it was hierarchically structured in 2 layers based on various combinations of ICD-O morphology and topography codes: layer (1) families of tumours (relevant for the health care organisation) and layer (2) tumours clinically meaningful (relevant for clinical decision making and research).

Co-funded by the European Commission from 01/04/2007 to 31/03/2010 through it's the Public Health

Conclusions of the RARECARE project:

The RARECARE project, on the basis of population-based cancer registries data provided an operative definition of rare cancer, a list of tumour entities from which is possible to select rare entities and the most important epidemiologic indicators (incidence, prevalence and survival) of rare tumours in Europe. The consortium proposed a definition of rare cancer based on incidence and developed a list of rare entities, using an incidence threshold of 6/100.000. However, they also acknowledges the importance of prevalence for health planning purposes; therefore this important measure was provided for all the tumour entities included in the

rare cancer list. No important differences were found in identifying rare tumours on the basis of the incidence rate as opposed to the European definition of rare diseases based on prevalence.

To view the RARECARE website, [CLICK HERE](#).

To view a list of the rare cancers, as confirmed by RARECARE, [CLICK HERE](#).

To view SIOPE Member Prof. Gianni Bisogno's presentation on paediatric cancers at a RARECARE meeting in 2009, [CLICK HERE](#).

IPHOUM Congress Letter from the IPHOUM Chair

Please join us in Edinburgh at the Royal College of Physicians on 3rd and 4th May 2012.

Dr. Angela Thomas, Chair of 2012's IPHOUM Congress in Edinburgh, gives us a taste of what is to be expected at this exciting meeting.

As Chair of the 13th International Paediatric Haematology and Oncology Update Meeting, it gives me great pleasure to announce the dates of our next Conference.

The aim of the Conference has always been to provide biennial updates on key topics in our speciality, delivered by world-class experts. We always allow plenty of discussion time within the programme in order to encourage interaction between the audience and the speakers. For the last few Update Meetings, we have also accepted submitted abstracts for poster presentation.

Now, the Conference has become very well established in the meetings calendar and has become a very friendly forum where colleagues from across the world meet, share knowledge and experience and relax in the beautiful city of Edinburgh.

The Conference is attended by nurses, doctors, pharmacists and professionals allied to medicine, as well as trainees from any country.

Our 2012 conference programme will shortly be available on our website – www.iphoum.com and you can register your interest now, to receive more information as it becomes available. Again this promises to be an excellent educational event and interest is high. 20 State-of-the Art Lectures by leading international experts across the 2 days of the Conference provides the opportunity to gain top-quality and time-efficient updates on paediatric haematology and oncology.

The programme even features a debate entitled "Is it worth crossing the Atlantic for treatment?" and we expect a be interactive discussion with the audience. We have also organised a lovely Gala Dinner at the Scotsman Hotel. The Hotel will offer us a very elegant backdrop to an evening of good food, music, convivial company and excellent views of Edinburgh.

Whilst the economic climate means that we live in uncertain times, one thing is for sure: this well-established Update Meeting is always relevant, always popular and always highly educational. Do join us for the next in our Series.

Please visit our website for further information and to register your interest.

Our Conference Secretariat remains at your disposal for any queries that you may have in relation to our Conference. Please contact them via our website.

Dr Angela Thomas
Chair, Organising Committee

For more information, check out the website, www.iphoum.com



ECCO
16



ESMO
36

The European
Multidisciplinary Cancer Congress
Integrating basic & translational science,
surgery, radiotherapy, medical oncology & care
STOCKHOLM, 23-27 SEPTEMBER 2011

ESTRO
30

European Multidisciplinary Cancer Congress 2011

Integrating basic & translational science, surgery, radiotherapy, medical oncology & care
The European Multidisciplinary Cancer Congress will be held at Stockholmsmässan, the Stockholm International Fairs & Congress Centre, from 23-27 September 2011.

VIEW THE ADVANCED PROGRAMME HERE

Building on the great successes of Congresses past, this year 16th ECCO, 36th ESMO, 30th ESTRO Congresses will come together to form the European Multidisciplinary Cancer Congresses, organised in partnership with the essential contribution of all ECCO's other Founding Members - ESSO, EACR, EONS and SIOPE. Further, as the Congress tagline 'Integrating basic & translational science, surgery, radiotherapy, medical oncology & care' suggests, the uniqueness of this Congress lies in the multidisciplinary and multi-professional scope, appeal and draw.

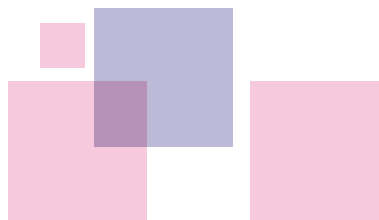
This joint European Congress promises a record attendance of scientists, clinicians, doctors, nurses, patient advocates, policy makers and care givers drawn through an even stronger, all encompassing comprehensive programme of excellence. Incorporating an expansive range of core themes, the programme will deliver the latest advances and insight in scientific and clinical research, patient management and practice through a balance and blend of plenary sessions, teaching lectures, educational symposia, workshops, proffered paper sessions and so much more.

Paediatric Oncology at the European Multidisciplinary Cancer Congress 2011

SIOPE has led the way in finalising the programme and speakers for the paediatric oncology track. Indeed key opinion-leaders and experts have designed this important paediatric agenda: SIOPE President, Ruth Ladenstein (AT) and SIOPE President-Elect, Gilles Vassal (FR) are the Track Chairs, and the experts are truly pan-European: Christian Carrie (FR), Mark Gaze (UK), Lars J. Hjorth (SE), Riccardo Riccardi (IT), Umberto Ricardi (IT) and Martin Schrappe (DE).

REGISTER HERE NOW!

We are delighted to announce that ENCCA- the European Network for Cancer research in Children and Adolescents and PanCare SurfUp will feature in the paediatric track, along with tumour-specific sessions – including brain, medulloblastoma and ewing sarcoma. The paediatric oncology community also have the opportunity to attend any of the other 33 tracks. Indeed for 2011 there are five new tracks including oncotechnology, and of course you have the potential to meet key EU cancer policymakers at the sessions of the Oncopolicy Track. The Patient Advocacy/ Ethics Track and the Oncology Nursing Track are all fully integrated into the scientific programme; indeed we are delighted that ICCCP – the International Confederation of Childhood Cancer Parent Organisations have contributed to the Patient Advocacy/ Ethics Track for this congress as a Programme Expert which has been hugely influential! Topics in the Patient Track include Ethical Learnings from Paediatric Cancer Research and Ethical Dilemmas in the Management of Teenage Cancer Patients.



We saw many of you in Berlin in 2009... See you in Stockholm in 2011 for the Congress in Europe for all those working in cancer !





Our Award winners in Stockholm

At the last Congress in 2009, Prof. Helmut Gadner from the Children's Cancer Research Institute (CCRI) in Vienna, Austria, won the SIOPE award, a recognition of an academic's contribution to paediatric oncology. At this year's Congress in September, another award will be bestowed – in fact the 2011 Lifetime Achievement Award is special this year: it's a joint award given to two outstanding experts in the field of childhood and adolescent oncology. HINT: from France and from Germany, these two eminent clinicians celebrate a successful partnership in paediatric oncology, progressing clinical research in non-Hodgkin Lymphoma... Find out who are the winners in Stockholm!

News bites

ecancerHub

A new and exciting communication platform (ecancerHub) for the oncology community has just been launched. Stemming from the Eurocancercoms project, of which SIOPE is a partner, ecancerHub addresses the needs of European and Global audiences and delivers an interactive online tool for the latest information from the oncology world and a number of 'sector' firsts – custom search, tools directory, map integration and more...[CLICK HERE FOR MORE INFORMATION.](#)

How to Address Inequalities and Implement Standards of Care

Indicate your interest to join the high-level meeting of the EU Polish Presidency on European Standards of Care for Children with Cancer by contacting the SIOPE office as soon as possible. This meeting will involve significant interaction with participants to ensure a working plan is established on implementation of the European Standards of Care consensus document. This event takes place on 20-21 October 2011.

2011 ESTRO-PROS-SIOPE Paediatric Oncology Radiation Course

Following 2009's success, ESTRO (European Society for Radiation and Oncology) will once again organise a course on paediatric oncology, in partnership with SIOPE and PROS (Paediatric Radiation Oncology Society) in Brussels, Belgium from 01-03 December 2011.

The course is meant for trainees and specialists in Radiation Oncology interested in the field of Paediatric Radiation Oncology. Please spread the word about this course. NOTE: the early fee deadline is 05 September. Contact Chiara at ESTRO for more details ([chiara.gasparotto\(at\)estro.org](mailto:chiara.gasparotto@estro.org) (please replace (at) with @)).

ENCCA six months later...

The EU- FP7 project dedicated to the creation of a sustainable Paediatric and Adolescent Oncology Clinical Trial common platform for clinical and translational research in childhood and adolescent cancer, recently made a head start on activities.

Learn more about this project at the ECRC – European Clinical Research Council meeting, in Stockholm during the European Multidisciplinary Cancer Congress AND at the ENCCA website, <http://www.encca.eu> !

Visit Karolinska!

Per Kogner of the Karolinska Institute warmly welcomes the SIOPE community to avail of the facilities in his institute during the European Multidisciplinary Cancer Congress. If you would like to have side meetings in the fantastic surroundings of the Karolinska Institute in September during the Congress, please contact the SIOPE office as soon as possible.

Treasurers Corner



I firstly would like to thank all of you who responded to the request to complete our survey on membership fees. We had 85 replies which was very gratifying. Fortunately the vast majority agreed that continuation of membership fees should be supported, clearly without this mandate we would be in an even more precarious position! We asked you about three possible options for membership fees, individual (as currently exists), institution or national. Interestingly there was no clear leader between these options and each of course has its various merits and disadvantages.

The members of the SIOPE Board will be looking into these issues in the coming weeks to determine if one option should move forward or whether a choice of options might also work depending on circumstances in each country. However we do need to bear in mind that our constitution will require us to define exactly what we mean by "members" irrespective of the future structuring of fees. We will feedback in time for the SIOPE General Assembly held at the European Multidisciplinary Cancer Congress meeting (previously ECCO) in Stockholm in September. We hope to see many of you there ([PLEASE CLICK HERE FOR MORE DETAILS](#)).

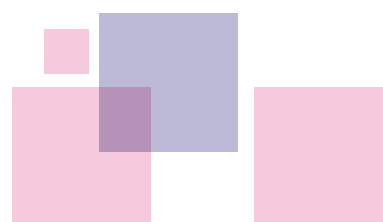
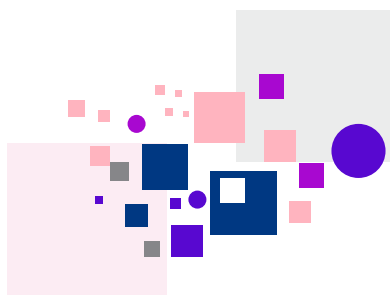
We also received very useful feedback on a number of aspects of SIOPE activity and the relationship between SIOPE and its continental partners. May people remain confused as to the exact remit of SIOPE, particularly around the role it has in the clinical trials arena. The ENCCA project gives us the opportunity to establish clearer models of collaborative working in Europe and I believe that defining the future role of SIOPE within this framework is essential to our future.

The links between SIOPE and SIOPE and other continental branches was again something that people raised in their feedback. There is perhaps a sense of lack of alignment between the organisations in terms of their objectives. What is clear is that the various continental branches have very different requirements. This is understandable, but perhaps we and SIOPE have not always made those distinctions clear. I know that Gabi Calaminus, in her role as SIOPE President, is very keen that Boards of SIOPE and SIOPE work in partnership to reinforce and develop a more unified approach for the future.

Finally I will be stepping down from the SIOPE Board and my role as Treasurer at the Congress in Stockholm in September. Please remember to Register for this meeting, the largest congress of its kind in Europe. With comprehensive paediatric oncology, drug development, industry and oncology tracks amongst others, it makes a very significant contribution to our funding as each SIOPE registrant counts towards our share of the profit! As I will not be able to go to the SIOPE congress in New Zealand, I will be using this opportunity to network with my colleagues in paediatric oncology in Europe.

Finally my thanks go to all the Board Members I have served with and the staff at the ECCO/SIOPE offices in Brussels without whom nothing would ever happen!

Bruce Morland



Upcoming Events

Joint ECCO 16 - 36th ESMO Multidisciplinary Congress
23 - 27 September 2011
Stockholm, Sweden.
<http://www.ecco-org.eu/Conferences-and-Events/ECCO-16-ESMO-36/page.aspx/217>

Joint DIA/EFGCP/EMA Paediatrics Forum 2011
The paediatric regulation in its 5th year: Transition from toddler to school age
26 - 27 September 2011
De Vere Venues Canary Wharf, London, UK
Organised by DIA in partnership with EFGCP and EMA
http://www.efgcp.be/Conference_details.asp

2011 Oncopolicy Forum, European Multidisciplinary Cancer Congress
26 - 27 September 2011
Stockholm, Sweden
<http://www.ecco-org.eu/Public-affairs/Oncopolicy/Oncopolicy-Forum-2011/page.aspx/2917>

Conference on Prescribing without Evidence
27 September 2011
Wolfson Theater, Royal College of Physicians London, United Kingdom
<http://www.efgcp.be/Downloads/Prescribing%20without%20evidence%2027-09-2011.pdf>

3rd European Symposium on Late Complications after Childhood Cancer
29 - 30 September 2011
De Rode Hoed, Amsterdam, the Netherlands
www.eslccc.org

8th Pancare Network Meeting
01 - 02 October 2011
De Rode Hoed, Amsterdam, the Netherlands
<http://www.pancaresurfup.eu/>

PanCare SurfUp General Assembly
02 October, 2011
De Rode Hoed, Amsterdam, the Netherlands
<http://www.pancaresurfup.eu/>

European Health Forum Gastein
05 - 08 October, 2011
Gastein, Austria
<http://www.ehfg.org/>

SIOPEN Annual General Assembly
UCL Institute of Child Health, London, UK
12-14 October, 2011
<http://www.siopen-london.org.uk/index.html>

EACR-Anticancer Agents Research Congress
13 - 16 October 2011
Zeynep Golf Resort-Antalya, Turkey
<http://www.aarm2011.org/>

European Standards of Care for Children with Cancer conference
European Partnership for Action against Cancer organised by the Polish Ministry of Health, SIOP Europe and the Communication without Barriers Foundation
20 - 21 October 2011
Warsaw Poland
Contact SIOPE for more details

SIOP 2011 – 43rd Congress of the International Society of Paediatric Oncology
26 - 30 October 2011
Auckland, New Zealand
<http://www.siop2011.com/>

Eurocourse Cancer Control Summit
23 - 24 November 2011
Brussels Belgium
www.eurocourse.org

Survivorship after Childhood Cancer
26 - 27 November 2011
Dublin Ireland
<http://www.pancaresurfup.eu/>

ESTRO Paediatric Radiation Oncology
1 - 3 December 2011
Brussels, Belgium,
<http://www.estro-education.org/courses/Pages/Brussels2011Paediatrics.aspx>

EFGCP Annual Conference 2012 on Informed Consent – How Less could be More: Effecting a paradigm shift so we do inform participants
24 - 25 January 2012
Brussels, Belgium
<http://www.efgcp.be/Events.asp?TimeRef=1&L1=10&L2=1>

1st Up Close and Personalized, International Congress on Personalized Medicine
2 - 5 February 2012
Florence, Italy

44th Congress of the International Society of Paediatric Cancer (SIOP)
5 - 8 October 2012
Barbican Centre, London, United Kingdom
<http://www.siop2012.org/>

European Action against Rare Cancers meeting
09 -10 February 2012
Brussels Belgium
<http://www.rarecancers.eu/>

4th ESO-SIOP Europe Masterclass in Paediatric Oncology
24 - 30 November 2012
Castel Gandolfo (Rome), Italy
<http://www.eso.net/events-2.html>

Excellence in Oncology 2nd edition
International Union Against Cancer (UICC) and the International Journal of Cancer
23 - 25 February 2012
Istanbul, Turkey
<http://www.excellence-in-oncology.org/>

8th EONS Spring Convention
26 - 27 April 2012
Valencia, Spain
<http://www.ecco-org.eu/Conferences-and-Events/EONS-8/page.aspx/2218>



About US



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.



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

www.siope.eu

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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