

## Update from the office

Looking back at this time last year, SIOPE has truly moved forward and increased its profile. The only organisation representing paediatric oncology in the European Partnership for Action against Cancer, SIOPE represents the unified voice of the professional paediatric oncology community, responding to a number of important initiatives. Some examples include EMA's call for revisions to the off-patent list of paediatric medicines, the Commission's Public Consultation on the burdensome EU Clinical Trials Directive and an EFGCP survey investigating the current level of consensus on improving the regulatory environment of clinical trials.

Aside from this important policy work, SIOPE continues to promote the centrality of education, aware that such training advancements ultimately contribute to improved treatment and care for young people with cancer. We encourage young professionals to take advantage of the many courses currently on offer, such as the ESO-SIOPE Masterclass, a biennial course with a fantastic faculty that congregates in Rome and of course the ever-popular FLIMS workshop where two young specialists in paediatrics will be sponsored by SIOPE. Finally, there is the good news that ESTRO's first Paediatric Radiology Oncology Society (PROS) course last year was a resounding success. All future educational initiatives will be led by Dr. Dragana Janic from Serbia, recently elected as Chair of the Education and Training Committee.

To conclude, we received some truly exciting news in the last few weeks. The SIOPE-inspired 'ENCCA' proposal to structure clinical research in paediatric and adolescent oncology in Europe through an FP7 Network of Excellence call has been approved! The office would like to congratulate the ENCCA Writing Committee, namely Ruth Ladenstein, Kathy Pritchard-Jones, Martin Schrappe, Gilles Vassal and Riccardo Riccardi and thank them sincerely for their tireless efforts.

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## Message from the President

It doesn't seem very long ago that I wrote my last article for the December issue of the newsletter, yet numerous developments have taken place since then that are likely to positively impact both on SIOPE and European paediatric oncology generally.

The SIOPE-led proposal for the FP7 Network of Excellence, submitted last November, was successful. This is truly excellent news for our community! This project will support us to develop our current informal networks and encourage the construction of a durable, virtual network that will provide the framework for European clinical and translational research in paediatric and adolescent oncology for years to come. This good news was timely as I was able to inform participants of this positive result at the SIOPE-led meeting, the 'Future Strategy for European Clinical Trial Research in Paediatric Oncology, on 17th March in Brussels. This meeting offered Work Package leaders, as well as invited representatives of the clinical trial groups, to acquire a better insight into the planned structure of this challenging project and provide feedback on how they envision their role within it. We also had a brief presentation from Jacques Demotes, Programme Coordinator at ECRIN, who spoke about their current activities.

The months ahead will be demanding, preparing to 'tick the right boxes' for the Commission to ensure this highly-anticipated Network of Excellence can be successful. Of course with a restricted timeline and budget, the creation of the Network can only be a first step and therefore I hope we have the support of the entire professional community to ensure this initiative is sustainable.

I'd also like to inform you that the European Standards of Care for Children with Cancer document is gaining superb attention both from our community and amongst policymakers. With the backing of the Polish Health Ministry we have joined the European Partnership for Action against Cancer, a European Commission initiative, as an Associate Partner and SIOPE is the only organisation representing childhood cancer. We hope to put the Standards in the spotlight during next year's EU Presidency in Poland! We presented this project, amongst other important policy points, to Member of European Parliament, Alojz Peterle recently, and were delighted that he referred specifically to childhood cancer in the draft report to the Parliament on the European Partnership for Action against Cancer.

On another point, I would like to take this opportunity to thank Riccardo Riccardi for his dedication to enhancing educational initiatives for the young paediatric oncology community as Chair of SIOPE's Education and Training Committee. Dragana Janic will take over this position; hailing from Serbia, and with her superb background and expertise, I am confident she will engage in fostering education and training advancement.

Related to this, the SIOPE/ EONS/ ECCO Special Project is in its final stage after three years of funding. This project, which promotes techniques to improve collaboration between doctors and nurses, has been a truly successful initiative and this is due to the excellent efforts by the Project Mentors, led by Faith Gibson. As an outgoing objective, the Special Project team are ensuring the materials collected during the project are accessible and all information will be available shortly on the SIOPE website. I encourage you to have a look at the website, [www.siope.eu](http://www.siope.eu), in the coming months to review these step-by-step guides and identify whether some of the tools used could be suitable to roll-out in your institution. >>>



While it is clear that SIOPE is establishing itself as a key stakeholder in EU cancer policy, this stepping stone is likely to truly transform the landscape of paediatric oncology for years to come.

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

Finally, I very much hope that SIOPE Boston received numerous abstracts from Europe. We look forward to seeing many of you there! SIOPE will host a number of meetings including the General Assembly. You are all welcome to attend this meeting, of which a number of important decisions are likely to be made.

Please do organise your accommodation as soon as possible as this year's congress looks likely to be well-attended and takes place in parallel with a popular Boston regatta!

If you have any ideas on how best we can support you in the coming months, please just let us know!

## SIOPE's Europe's Community



### Outreach and awareness-building throughout Europe EU Clinical Trials Directive Consultation

The European Commission issued a Public Consultation in December 2009 on the EU Clinical Trials Directive (EU CTD) 2001/20/EC, which SIOPE responded to. Paediatrics was explicitly pointed out as an area that should be given special attention. In its response, SIOPE requested immediate efforts to harmonise rule interpretation and create a more simplified process to ensure efficiency.

#### BACKGROUND

The EU Clinical Trials Directive, implemented in 2004, was designed to improve research standards and protect patients. It also aimed to enhance European clinical research competitiveness, revise the ethical approval system for medical trials and improve the standards of new medicines.

However, these new rules have been criticised broadly by researchers, particularly those carrying out investigator-led clinical trials, claiming costs and red tape have greatly increased without bringing any major benefit to patients, researchers or industry.

In order to assess the functioning of the Directive, the European Commission launched a public consultation which ended in January 2010. In this context a series of workshops were organised, under the Road Map Initiative for Clinical Research in Europe, to bring together all of the relevant stakeholders, and to develop a body of recommendations for the European Commission.

A comprehensive Consultation, SIOPE very much hopes that the transfer of the CTD dossier to the Directorate-General of Health and Consumers (DG Sanco) will ensure that the critical responses by the stakeholders are taken into account.

The objective of the CTD is reasonable- to standardise the regulation and quality of trials. However, it has had the opposite effect, i.e. a lack of coordination and significant duplication of efforts and resources invested by the clinical trial groups to meet EU CTD requirements. The numerous subtle and at times less subtle interpretations of the CTD cause huge administrative burdens for the sponsoring organisations. With insurance costs increasing a 100-fold and no increase in actual risk between consecutive trials from the same study group, paediatric cancer patients are not offered the maximum opportunity to participate in relevant clinical trials that aim to improve optimal treatment for all children.

It is clear that clinical research should not be considered a luxury but rather a necessary tool to combat the burden of cancer. However, the current bureaucratic workload of trial activation is much too high for the many rare diseases that comprise the childhood cancers. Moreover, the rare nature of the disease results in investigator-led trials due to the lack of commercial sponsorship. Indeed, many non-commercial organisations are still unwilling to undertake the role of sponsor at a pan-European level for multinational trials in children.

In relation to safeguarding the safety of clinical trial participants, SIOPE considers that for children with life-threatening diseases such as cancer, the additional risk of being on a trial is limited if not zero; in fact the outcome is usually better as there is increased adherence to the treatment protocol.

SIOPE Europe deems it necessary to re-draft the EUCTD to dramatically simplify the current regulatory procedures for multinational, non-commercial trials.

Such redrafting must take account of the specific issues raised by clinical research for the benefit of children with life-threatening diseases such as cancer, whose current, suboptimal therapies have significant acute and long-term side effects.

In fact, for paediatric oncology, there is no evidence that children with cancer are better protected than prior to the introduction of the Directive and plenty of evidence of the decline in the number of phase III clinical trials that are available for children. As a result of the Clinical Trials Directive, the paediatric oncology community is facing a period of sometimes a few years where there is no frontline phase III trial open for certain diagnostic groups.

To download SIOPE's contribution to the EU CTD Consultation, just [CLICK HERE](#).

To view all stakeholder responses to the Consultation, just [CLICK HERE](#).

#### NEXT STEPS

Having accepted that the Directive has greatly hampered medical research, the European Commission is currently assessing whether to simplify the existing Directive and tweak it or potentially to introduce a regulation that will aim to harmonise research rules across the 27- Member States.

The Commission is aiming to adopt a legislative proposal on European clinical trials in October 2011.

SIOPE will track the relevant stakeholders' actions in relation to the EU CTD and assess the impact on the European child cancer community. If you would like to contact SIOPE in this regard, please contact the SIOPE office office<at>siope.eu (please replace <at> with @).

## SIOPE's Involvement in EU Projects

### European Partnership for Action against Cancer

SIOPE has been involved in this project since its launch in September. Advising the European Commission about SIOPE's 'Seven Point Plan', we were invited to attend a key stakeholder meeting to discuss the Partnership, an outcome of the Commission's Communication last year, Action against Cancer: European Partnership (To view, please [CLICK HERE](#)).

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

The Partnership is focussed upon four areas:

- Health promotion and prevention;
- Identification and promotion of good practice in cancer-related healthcare;

- A coordinated and collaborative approach to cancer research;
- Health information, and the collection and analysis of comparable data.

As the budget of the Partnership is very limited, SIOPE Europe is expected to concentrate its energies on the pillar, 'A coordinated and collaborative approach to cancer research', promoting the European Standards of Care for Children with Cancer Project in cooperation with the 'Communication without Barriers' Foundation in Poland and the Polish Ministry of Health. Our main objective is to ensure greater public awareness of paediatric oncology in Europe and the many challenges the multiprofessional community faces. We intend to work with numerous Member States, in particular in central and Eastern Europe to bring this initiative to the forefront of cancer policy and ensure Standards of Care for children with cancer are incorporated fully into national cancer plans. This initiative is the result of the European Commission Communication, 'Action against Cancer: European Partnership' which was published earlier this year and was officially launched in September by Commissioner Vassiliou but also EU Commission President Manuel Barroso and HRH Princess Mathilde of Belgium. The Slovenian Ministry, who made the cancer burden a key

priority during their EU Presidency in 2008, will be the leading Member State for this initiative. All identified actions were submitted in the form of a joint action as part of the 2010 Health Call coordinated by EU's Executive Agency for Health and Consumers (EAHC).

The deadline for this submission was the end of March. For further information on the EAHC, please [CLICK HERE](#).

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

## Oncovideos

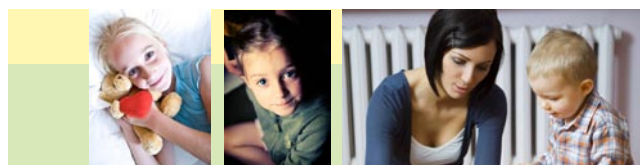
SIOPE is an associated partner in an education project for the development of 24 videos on oncology procedures coordinated by ECCO - the European Cancer Organisation and funded by the European Commission's Leonardo da Vinci Programme, part of the European Education and Training Life-long Learning initiative.

SIOPE's role is led by Prof. Riccardo Riccardi of the Catholic University of the Sacred Heart in Rome, Italy. His interest in educational activities is wide-ranging, as the past the Chair of SIOPE's Education and Training Committee as well as part of the faculty at the ever-popular FLIMS Workshop, coupled with his key contributions to numerous educational courses and

programmes, such as the paediatric track at the ECCO 15-ESMO 34 Multidisciplinary Congress and the ESO-SIOPE Masterclass.

Last October his institution hosted the highly successful ITCC Training Days, a course devoted to early drug development in paediatric patients with cancer. Prof. Riccardo will be supported by fellow Board member Prof. David Walker from Nottingham, who has kindly taken on the role of SIOPE's Liaison Officer to the coordinator ECCO.

The project is set to kick-off soon and these important educational videos will be posted on the ECCO website with links to SIOPE's website, [www.siope.eu](http://www.siope.eu).



## EUROCANCERCOMS

SIOPE is delighted to be part of the FP7-funded project, EUROCANCERCOMS, an exciting project that aims to streamline and professionalise cancer communication and dissemination in the EU. A two-year co-ordinating action (CA) funded under the EU programme, 'Science in Society', it involves 18 working partners from 10 countries.

SIOPE is involved in the Working Party, Project Data, which assesses and analyses barriers and recommends solutions for optimal dissemination of cancer data from translational research, clinical trials and epidemiologic studies. Professor Richard Sullivan, who is overall Project Manager of Eurocancercoms, works with SIOPE to carry out a number of its tasks. Discussing the project, he pointed out, "EUROCANCERCOMS is one of the key

European projects to understand and develop the next generation of e-tools and e-information for patients, their families and healthcare professionals. It provides the paediatric community with a superb opportunity to really map out their web needs and be involved in the generation of new tools and content to support their cancer journey." The SIOPE office will work with Sullivan to deliver a number of tasks including the coordination of a survey on issues affecting paediatric oncology as well as an executive summary of Sullivan's bibliometric study on funding and outputs of paediatric oncology research and the research levels, from clinical to basic research, of published paediatric oncology papers.

Information on this dynamic project is available on the official website, [www.eurocancercoms.eu](http://www.eurocancercoms.eu).

# ENCCA, European Network for Cancer research in Children and Adolescents

The provision of a call to structure clinical research in paediatric and adolescent oncology within the EU's Seventh Framework Programme indicates that the advocacy work of SIOPE and other related stakeholders to raise awareness of the many challenges facing the paediatric oncology community, is finally gaining the attention of EU policymakers. Thank you for your support of SIOPE and the Brussels office. We are delighted to announce that the proposal for the creation of a European Network for Cancer research in Children and Adolescents (ENCCA) submitted under the FP7 Health topic, HEALTH.2010.2.4.1-3: Structuring clinical research in paediatric and adolescent oncology in Europe, last November was successful!

This 'network of excellence', 'the European Network for Cancer Research in Children and Adolescents', expects to network and integrate the different tumour groups in order to define and run a global strategy in Europe for the development of new drugs and biology-driven therapeutic strategies. The project is coordinated by SIOPE President, Ruth Ladenstein and her team at the Children's Cancer Research Institute in Vienna, Austria. Three SIOPE Board members make the ENCCA Management Support Team, coordinating the various areas of focus, namely Kathy Pritchard-Jones (Integrating Activities), Martin Schrappe (Joint Research Activities) and Gilles Vassal (Spread of Excellence Activities).

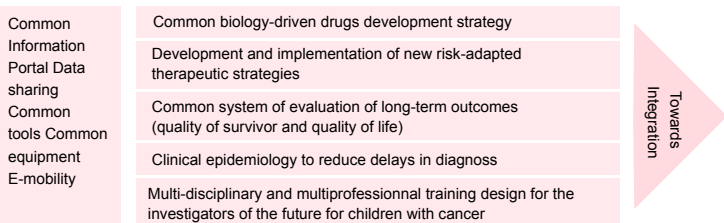
The main objective of this project is to restructure knowledge-sharing through the integration of the whole chain of stakeholders (epidemiologists, biologists, clinicians, drug developers, statisticians, industry, imaging developers and IT partners in electronic health records, parents and ethical and regulatory authorities) and to support the acceleration of the development of innovative therapeutic strategies for children and adolescents with cancer.

ENCCA's goals include:

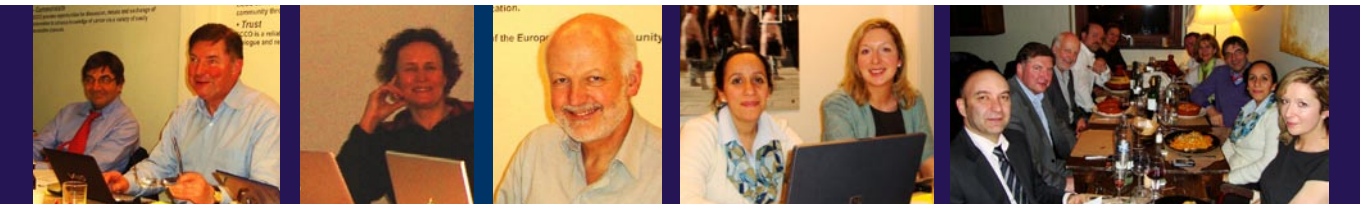
- Structure and integrate, on a sustainable basis and at a European scale, clinical and translational research in children and young people with cancer by proposing a European Strategy for Clinical and Translational Research in paediatric and adolescent oncology
- Promote innovative methodology and designs for clinical trials, as well as their implementation and integration to address the specific needs in rare diseases
- Initiate harmonised therapeutic strategies by increasing significantly access to knowledge and technologies on paediatric tumour biology and interactions between tumour and host.
- Improve substantially the quality of life of children and adolescents with cancer, in particular the long-term side-effects of current and future treatments
- Propose common ethical definitions of issues and solutions adapted to national and cultural requirements, while monitoring ethical issues in the implementation of the European agenda in clinical research.

It is our sincere ambition to work with all Clinical Trial Groups in the future and to make the most of this FP7 grant as a stepping stone towards an interactive and sustainable European Network that will facilitate running trials on the European level and foster the integration of European research tasks. We have foreseen structures within ENCCA that allow us to work very closely with the clinical trials groups as well as National Oncology groups. We trust that ENCCA will facilitate follow-up funding for the multitude of areas that we were unable to cover in the current funded call.

We envision ENCCA as a dynamic and open network that will eventually benefit the entire paediatric oncology community in Europe.



**NEXT STEPS:**  
The negotiation period with the European Commission is currently in progress and we expect this to continue until autumn, with 2011 being the major kick-off of the ENCCA project. Watch this space!



# Committee Reports and Roundups



Photos l-r: clinical trial chairs and ENCCA participants, R. Ladenstein and J. Demotes, the ENCCA Coordinator and the Management Support Team, further participants of the meeting at the UCL in Brussels.

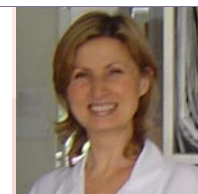
## Future Strategy for Clinical Trial Research in Paediatric Oncology

On 17th March, SIOPE President and ENCCA project coordinator, Ass. Prof. Ruth Ladenstein invited the representatives from the European paediatric clinical trial groups to assemble in the UCL University in Brussels to discuss the Future Strategy for Clinical Trial Research in Paediatric Oncology. Invitees included not only work package leaders of the proposed ENCCA project (European Network for Cancer Research in Children and Adolescents) but also heads of SIOP Europe's clinical trial groups. The meeting was organised around three main areas of focus: integrating activities chaired by Prof. Kathy Pritchard-Jones, joint research activities by Prof. Martin Schrappe and the spread of excellence of clinical research chaired by Prof. Gilles Vassal.

An interesting debate on how to structure and advance clinical trial research in paediatric oncology, the day was focussed upon how to progress through the anticipated ENCCA project, the European Network for Cancer research in Children and Adolescents.

Jacques Demotes-Mainard from the European Clinical Research Infrastructures Network (ECRIN) also presented, highlighting ECRIN's pan-European infrastructure for clinical research in any disease area.

## SIOPE's new Education and Training Committee Chair, Dragana Janic



SIOPE warmly welcomes Prof. Dragana Janic to the position of the Chair of the Education and Training Committee (ETC). One of SIOPE's priorities is to promote educational and training initiatives not just for the younger community but also ongoing training for practitioners and activities are envisioned within the ETC.

Janic has already provided a comprehensive analysis of the status of paediatric haematology and oncology education and training in Eastern Europe at the last ETC meeting in Berlin last year and a comprehensive report on her findings is available in the December edition of the SIOPE newsletter ([CLICK HERE](#) to view the report).

Paediatric oncology is a well-defined paediatric sub-specialty in Europe. Outside of a few countries, the recognition of paediatric oncology and haematology as well as the implementation of related educational and training activity remains limited throughout Europe; The lower survival rate (from 10 to 20%) of children with cancer observed in some European countries may be at least in part related to lack of adequate training and educational programmes.

A Professor of Paediatrics and Head of the Department of Haematology and Oncology at the University Children's Hospital in Belgrade, Serbia, her breadth of experience and keen interest in addressing the current disparities between European countries is bound to accelerate SIOPE in its endeavours to increase education and training activities.

## Thank You Riccardo Riccardi



SIOPE wishes to sincerely thank Prof. Riccardo Riccardi for his dedication to the education and training of the young paediatric oncology community as Chair of SIOPE's Education and Training Committee.

As Director of the Institute of Paediatrics, Head of the Division of Paediatric Oncology at the Catholic University of Rome and key expert for research activity in paediatric oncology, Prof. Riccardi brought a breadth of experience to the Education and Training Committee. Indeed his enthusiasm to share his knowledge from his role as Past Coordinator of the biennial ESO-SIOPE Masterclass, regular Faculty Member of the FLIMS Workshops and Member of the Executive Committee of the European Consortium of ITCC is greatly appreciated by both the SIOPE Board and the Education and Training Committee.

An expert in the field of clinical pharmacology of antineoplastic drugs in children, Riccardi remains involved in SIOPE activities as a SIOPE Board Member until September, 2009.



## ECCO / SIOPE / EONS Special Projects

### The end of an era



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



SIOPE/ EONS/ ECCO Special Project Mentor, Prof. Paolo di Giulio provides the final report on this highly successful three-year project.

The SIOPE/ EONS/ ECCO Special Projects on collaboration between doctors and nurses is now completed and the end of a project is the occasion for assessing the results achieved and obtaining a final feedback from participants.

A first important result was the fact that most centres managed to work for three years, to attend to the annual

meeting and to complete a project: this is not so common neither is it something that can be taken for granted. Initial commitment and enthusiasm are too often overwhelmed by busy routines.

The results of the efforts were good: they were shared and presented at a public session (ECCO 15-ESMO 34 Multidisciplinary Congress in Berlin in 2009). Considering that no extra external resources were allocated to participants, this is indeed another very good result.

The next challenge is to allow others to run similar programmes in other countries and to render materials produced and the strategies used available for those not involved in the international group. To avoid other groups starting from scratch, the mentors agreed with participants to develop web-based materials, easily available to everybody interested.

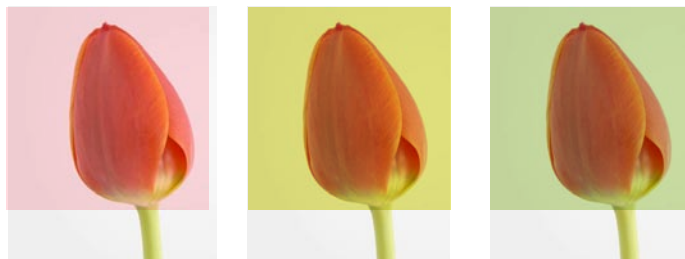
While a toolkit of instructions on how to use a PC is easy to develop, a toolkit for creating an experience that is more than one course due to the transmission of contents, methods, long-distance support and personal efforts, could be more complex. Flyers have been developed and distributed in delegate bags at upcoming conferences in 2010 (EONS Spring Convention in April and SIOP Boston in October) to inform everybody of this opportunity.

The development of the toolkit is offered to future mentors of similar courses who take advantage from the suggestions received by participants of the seminar in Berlin in 2009, on what can be improved.

The most appreciated aspect of the project was the opportunity to share experiences with other countries: this was considered a very enriching experience and for some countries site visits at the beginning of the project could have helped to better shape what to do.

Although an impression (but a shared impression is more than a feeling), participants felt that the collaboration between doctors and nurses increased because they learnt (improved their capacity) to see a problem from each other's point of view. One of the challenges of future projects will be to find "harder" tangible indicators of collaboration.

An article will be submitted to an international journal to share this unique experience and suggest that the project be replicated not only in the field of paediatric oncology field but also in other clinical areas.



## Thank you to MENTOR TEAM

SIOPE would like to warmly thank the Special Projects team for their dedication to this project namely:

- Faith Gibson
- Martin English
- Paolo di Giulio
- Momcilo Jankovic
- Alison Arnfield

SIOPE also appreciates the support of EONS and its representative Danny Kelly for his co-operation and advice during the project.

Finally, we wish to take this opportunity to thank ECCO – European CanCer Organisation; without their support the project could not have taken place.

For more information on this Special Project [CLICK HERE](#).



# Report from ESTRO Paediatric Radiation Oncology

Brussels, Belgium 3 – 5 December 2009

Course Directors:

- Rolf Dieter Kortmann, *Radiation Oncologist*,  
University of Leipzig (DE)
- Umberto Ricardi, *Radiation Oncologist*,  
University of Turin (IT)

SIOPE Board member Professor David Walker was involved in the organisation of an ESTRO (European Society for Therapeutic Radiation and Oncology) Paediatric Radiation Oncology event in December of last year. The first of its kind, this course exceeded expectations in attendance. Two participants of the course, Yasmin Lassen and Akmal Safwat, outline how beneficial the course was for them.

Paediatric Radiation Oncology is difficult. The considerations that have to be taken into account when planning a radiation field for a child are multiple and considerably different from those of adults. Radiation is given at a vulnerable period of growth and development. Carefully planned and optimally executed radiation therapy can make the difference between a long healthy life and prolonged suffering as a result of deformity and late complications. The challenges are enormous because the stakes are so very high.

It is therefore surprising that in many parts of the world paediatric radiation oncology is seldom taught as an independent subject during the formal training of radiation oncologists.

Our initial training as “Radiation Oncologists” in Egypt (Akmal) and Switzerland (Yasmin) is a testimony to this sad state of affairs. Moreover, when we ended up later on practicing oncology in a third country (Denmark), we found this omission to be the rule rather than the exception. Until the Paediatric Radiation Oncology Society (PROS) was formed in 2003, those of us with a particular interest in paediatric radiation oncology had no forum where we could exchange our daily experiences and consult international experts.

It was therefore with great enthusiasm that we attended the first ESTRO/PROS course in Paediatric Radiation Oncology organised by the course directors Rolf Dieter Kortmann and Umberto Ricardi. This took place in Brussels in December 2009 and we were delighted that the programme exceeded all our expectations.



Yasmin Lassen and Akmal Safwat took part in the first ESTRO Paediatric Radiation and Oncology event last December

Long before the course itself, we received teaching material and “homework” in the form of cases on which we had to draw different targets and organs at risk. This signalled the dedication and serious attitude of the organisers and meant that the discussions in the course workshops were lively, at a high level and addressed all the essential and relevant topics.

The subjects for the lectures were well chosen and balanced. Essentially, the course covered four topics: Hodgkin’s Diseases, Ewing Sarcoma, Medulloblastoma and Ependymoma and was taught over three days. The subjects were covered in detail, ranging from histopathological aspects, imaging, radiation dose planning, treatment results, ongoing international trials and acute and long term toxicity. All the faculty members, Christian Carrie, Karin Dieckmann, Carolyn Freeman, Wolfgang Hirsch, Roger Taylor, Beate Timmermann and David Walker are highly regarded experts in their field and there was always plenty of time for questions from the audience, discussions and the exchange of ideas, all of which made for a very interactive programme.

Unfortunately, David Walker had an accident just before the course started and couldn’t attend, but nevertheless his colleagues guided us through his topics and his slides were made available to us.

One of the big advantages of the course was the special attention given to the role of diagnostic radiology, which is an important subject that is usually forgotten or not given the focus it deserves. The wealth of knowledge and the large number of images shown by Wolfgang Hirsch was impressive and much appreciated.

Beate Timmermann’s lecture on proton therapy was first class and her experience was enlightening as it gave a much needed insight into a difficult and highly specialised subject.

Target delineation and dose planning were discussed in smaller groups on a workshop basis with case examples from the four subjects. This part of the course was full of hands on exercises, tips and tricks for daily practice.

Short breaks between the lectures allowed for plenty of networking opportunities with other radiation oncologists interested in paediatric oncology. Altogether there were 62 participants from 23 countries with a varied level of experience and because the course had been structured in a nice balanced way, everybody was able to benefit considerably from all that was on offer. As a special bonus, course participants received free membership of PROS for a year. This enabled those attending to join in case discussions in the PROS forum after the course had finished.

The hotel was pleasant and centrally located and was suitably equipped for the purpose. Brussels itself looked very charming with all its Christmas decorations. The course dinner was in a very nice restaurant in the city centre where we were served delicious Belgian food followed by music and dancing.

We would like to thank the course directors and the entire faculty for this long awaited and very inspiring training experience in paediatric radiation oncology. Special thanks goes to Chiara Gasparotto, the very kind and wonderful local ESTRO organiser.

We are looking forward to Paediatric Radiation Oncology (Part II)....

Source: ESTRO newsletter, Spring issue 2010

## Special Features

### Rare Disease Day

Eurordis, the European Organisation for Rare Diseases, this year organised an awareness-raising workshop for Rare Disease Day, in Brussels on 1st March focussing upon the topic, 'Bridging Patients and Researchers'. The event, co-organised with E-RARE in partnership with the European Commission, Orphanet and EuroPlan, brought together 100 participants from 15 countries including numerous prestigious speakers, with the primary objective to ensure that rare diseases remains high on the EU political agenda, and in particular to ensure that funding is sustained and indeed targeted to the diseases that need the greatest attention. The event was opened by Robert Madelin, former Director-General for Health and Consumers in the Commission.

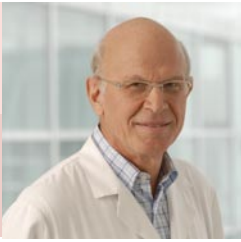
Addressing the gap between patients and researchers is essential to further better results in rare diseases. The scattering of patients, knowledge and action across Europe is currently not efficient to secure the attention of policymakers and facilitate scientific advancement.



Manuel Posada of the Instituto de Salud Carlos III, Spain who spoke about the E-Rare Network and Volker Straub, Coordinator of the Treat NMD project, Newcastle University at the Rare Disease Day European Workshop in Brussels.

SIOP Europe recognises the importance of partnering researchers with patients, linking with ICCCP, the International Confederation of Childhood Cancer Patient Organisations, as well as national childhood cancer group.

Related to this, rare disease stakeholders were able to nominate for their favourite researcher to the Rare Disease Research Hall of Fame! SIOPE included Professor Helmut Gadner, winner of last year's SIOPE Lifetime Achievement award. Based in St. Anna's Children's Hospital in Vienna, Austria, Prof. Gadner is dedicated to advancing paediatric cancer research, initiating the first multicentre prospective standardised protocol for the treatment of disseminated Langerhans Cell Histiocytosis (LCH). Gadner became a driving force in increasing international cooperation in the field of LCH, and subsequently was appointed to chair the first randomized international clinical trial LCH-I.



Helmut Gadner, winner of SIOPE's Lifetime Achievement Award 2009 and listed in the Rare Disease Research Hall of Fame.

More than 3,000 LCH Patients have been enrolled onto one of the LCH studies. The LCH-study Reference Center in Vienna, is acknowledged worldwide as leading the expertise in treating LCH and continually improving LCH therapy options. The work for the next study, LCH IV is in progress and Gadner will be a Senior Advisor.

To view the full list of nominations for the Rare Disease Research Hall of Fame, [CLICK HERE](#).

To find out more about Rare Disease Day and what activities took place at both local and global level, [CLICK HERE](#).

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

World Cancer Day (04th February), International Childhood Cancer Day (15th February) and Rare Disease Day (28th February) all take place during the month of February: all key dates in the SIOPE Calendar. With this in mind, SIOPE expects to coordinate a high-impact awareness campaign of the challenges faced by those suffering from paediatric cancer.

For further information on the 'February Awareness Month' in 2011 please contact the SIOPE office ([office@siope.eu](mailto:office@siope.eu)).

If you are organising activities for International Childhood Cancer Day, we would particularly like to hear from you!

Related to rare diseases, SIOPE warmly welcomes the establishment of the EXpert Group- the European Cooperative Study Group for Paediatric Rare Tumours. To contact Dr. Gianni Bisogno and his colleagues in EXpert, please email [office\(at\)siope.eu](mailto:office(at)siope.eu) (please replace (at) with @).



## Katie's Garden

SIOPE is delighted to offer interested parties the opportunity to download a book recently produced for young children affected by cancer on our website. This beautiful story tells the true tale of a little girl named Katie and her brave and imaginative outlook on life. At two years of age, Katie developed Wilms' tumour. Here her mother Fiona Adams outlines the motivation for the creation of the book.

Our beautiful daughter Katie was diagnosed with bilateral Wilms' tumours at the age of 23 months in 2002. (Katie is now 9 years old and very well.)

Like most parents we often read to her, and I immediately started to look for a colourful story book about children with cancer to share with her. I felt that reading a book like that would help her to understand what was happening to her and perhaps help to "normalise" her experiences.



There were already a number of helpful books available, but they were all aimed at older children. For a child of Katie's age, I felt that many of them contained unnecessary detail and had "busy", complicated pages. I felt that a book for a pre-schooler like Katie needed to be simple, bright and positive.

Several years on, Katie was in remission and I started to have contact with the UK charity Wilms at Home, a support group for families affected by Wilms' tumours. I agreed to write a review article for their newsletter about books available to help children through their cancer journeys. Once again, I failed to find anything that I felt was really suitable for supporting pre-school children with cancer.





I decided to take up the challenge myself, and to produce the book I wished had been available when Katie was ill. I enlisted the help of two friends, talented at writing and drawing respectively. We worked very closely together on the story line, medical information, details of illustrations etc.

Wilms' at Home saw the need and potential for this book and supported me at every stage. The book was proof-read by a variety of different people, including pre-school workers, teachers, a school nurse, a hospital play therapist and also SIOPE Board Member Prof. Kathy Pritchard-Jones. Funding from Wilms at Home and the local Rotary Club has enabled me to cover the printing costs of the first edition and to distribute the book free of charge.



Our simple, colourful, honest yet cheerful book has been very well received, not just by those it was primarily produced for, families affected by cancer, but also by paediatric oncology health professionals, teachers, and parents of children with conditions like hemihypertrophy and Beckwith-Wiedemann Syndrome, whose children are of course at an increased risk of developing Wilms' tumours or hepatoblastoma. The book is also having an educational role in helping siblings and friends of those affected by childhood cancer.



The fantastic response to the book has been a great encouragement to me. Our book is obviously filling a hole in literature provision in this area and helping many children. It is very satisfying to have this positive result springing from our precious Katie's illness.

Katie's Garden is available as a pdf download on the SIOPE website and copies of the book itself can be obtained free of charge from myself at s\_f\_adams[at]talktalk.net (please replace [at] with @).

## jimmyteens.tv

### Sharing cancer experiences creatively

SIOPE Board Member, Professor David Walker, actively engages with the jimmyteens.tv project, a delightful concept that allows young people affected by cancer to creatively share their experiences through video diary, animation, documentary and drama.



Currently gaining a phenomenal 50,000 visitor hits on their website, [www.jimmyteens.tv](http://www.jimmyteens.tv), annually and employing eleven young people, at both part-time and full-time capacity, this innovative initiative which began in 2005, is now active in seventeen hospitals throughout the UK. Sponsored by the UK's Teenage Cancer Trust, Jimmyteens.tv provides teenagers and young adults with the opportunity to diarise their emotional journey, often dealing with their illness through a unique and even humorous perspective as only a young person can!

Many members of the Jimmyteens team are in fact former patients who realised the hugely positive impact a 'home-made' video can have. Peter Wilkinson was diagnosed with pineal blastoma at 21. Now 23 and employed by Jimmyteens he recognises how it helped him to deal with cancer. "Being able to be myself on films and have the

lighter edge to it gave me the chance to express myself which in turn has helped my self esteem and get things off of my chest which during and after treatment is very helpful to myself and also to my partner."

Prof. Walker's institution, the Children's Brain Tumour Research Centre, in Nottingham UK has established links with Jimmyteens.tv and he has been involved in a number of their initiatives. "As a doctor I have witnessed the dramatic transformation of individuals' psychological state through recording their experience and presenting it on this website. One particular story stands out, that of Joe Moir (Nottingham) who chose in the last weeks of his life to tell his story of dealing with his cancer. His unique insight as an individual allowed him to explain what was important for him at each stage of diagnosis and treatment. This witness statement has lessons for us all."

David Walker is now working closely with the collaborators of Jimmy Teens, Mosaic North, on the production of a series of DVD's entitled 'The Developing Brain in Neuro-oncology: The teenage and Young Adult Frontier'.

At present, the Jimmyteens website holds over 600 films made by young people, their families and professionals with new films being added daily.

To discover this resourceful and inspiring website, just click on [www.jimmyteens.tv](http://www.jimmyteens.tv).



**SIOPE is keen to build links with childhood cancer support organisations. In this newsletter edition we profile the dynamic 'Dynamo Club' in Italy.**

Momcilo Jankovic from the University of Bicocca, Milan, is a mentor in the SIOPE/EONS/ECCO Special Project and also happens to be Head of the Medical Staff of Dynamo Camp, an innovative 'recreational therapy camp' for children and young people suffering from serious or chronic illnesses.

The trauma of a chronic illness for a young person goes without saying. The Dynamo Camp aims to give back the lost childhood to a young person with an illness such as cancer, even for a short, but magical experience. Located in the midst of a World Wildlife Federation (WWF) Nature Reserve in the heart of Tuscany, Dynamo Camp is the first Italian camp specifically designed to for children suffering from serious or chronic illness.

Post-hospitalisation, the Camp offers a range of fun, free and interactive activities for young people from 7 to 17 years of age.

The vibrant and action-packed programme designed for the kids is based on the 'Recreational Therapy' model.

Each activity can be seen as a constructive and non-competitive personal CHALLENGE. The youngsters are allowed to CHOOSE their own pace and how far they wish to go, for example whether they feel like performing on stage or prefer to help out behind the scenes.

Each goal is achieved through their individual commitment and with the COLLABORATION of the group. The children encourage each other to work as a team and through their enthusiasm and the supervision of qualified staff, achieve SUCCESS. Straight after the activity, either in group discussion or more privately, e.g. writing their diaries, the children have a chance to REFLECT on the goals they have attained, how they achieved them and the meaning of their success. This step-by-step process leads to the DISCOVERY that they can do doing things they didn't think they were capable of, focusing on their abilities rather than their disabilities to rebuild their self-esteem and self confidence.

Naturally the Dynamo Camp experience is above all FUN!! Every aspect of the programme is designed to be exciting and fun so that the youngsters are eager to step up to new challenges, to succeed, to reflect on what they have achieved and discover their enormous potential.



In Italy, more than 10,000 children contract serious or chronic illnesses annually, often undergoing invasive therapies with long-term hospitalisation. Dynamo Camp offers children with illnesses like cancer the opportunity to share an unforgettable experience, one of collaboration and mutual support, with other youngsters in similar circumstances.

The Dynamo Camp is part of the 'Hole in the Wall Camps Association, the leader of a family of camps worldwide dedicated to helping children with serious and life-threatening medical conditions. Founded by Paul Newman over two decades ago with the idea that no child should have to compromise their childhood because of a serious illness, the Association today oversees eleven full member camps in eight countries,

including l'Envol in France, Bátor Tábor in Hungary, Barretstown in Ireland and Over the Wall in the UK. seven new camps in various stages of development, and five Global Partnership Initiatives in Africa and Asia. ([www.holeinthewallcamps.org](http://www.holeinthewallcamps.org)).

Some thoughts from a lucky Dynamo Camper:

### *If I Were a Wizard...*

*If I were a wizard I would have a long and grey beard, a long conical hat the same colour as my tunic, with shining stars. I would wave my stick up and down, right and left, I would be full of knowledge. I would pass through the clouds and walk on the waters. In case of drought I would bring rain and make the trees grow, I would stop nastiness; I would have radar to show me the way, to distinguish bad and good people. I would go across the time; I would touch the stars and stop environmental catastrophes. I would stop the death of an innocent person; I would control adults and force them to give young people more freedom. I would bury hate and create love, I would destroy the wars and let the World live in peace! This kind of magic has already been done at Dynamo Camp.*

For more information on Dynamo Camps, check out their website, [www.dynamocamps.org](http://www.dynamocamps.org) or email [info\[at\]dynamocamp.org](mailto:info[at]dynamocamp.org) (please replace [at] with @).

## Treasurer's Corner



This newsletter features our brand new 'Treasurer's Corner' where I will be giving information on the financial activities of SIOPE.

We are very pleased to announce that as one of the six founding members of ECCO, the European CanCer Organisation, (for more information, [CLICK HERE](#)) we have been granted €243.226.

Thanks to this Grant we are able to maintain the activities of our Brussels office as well as numerous other tasks ...

- Educational award supporting the 3rd ESO-SIOPE Masterclass in Paediatric Oncology taking place from 12-18 June 2010 in Italy

- The support of 2 SIOPE fellows for the Flims 12 Workshop (Methods in Clinical Cancer Research Workshop) taking place from 19-25 June 2010 in Switzerland

- Supporting numerous fellows in order to provide them with the opportunity to attend ECCO 16-ESMO 36 Congress, the largest multidisciplinary oncology congress of its kind in Europe, taking place from 23-27 September, 2011 in Sweden.

The Grant from ECCO is an important source of income for us but unfortunately does not cover all of our running costs and aspirations to develop the work of SIOPE. We are therefore continuing to investigate new avenues of funding. In the meantime the preparations of the paediatric track for the next ECCO 16-ESMO 36 congress, taking place in

Stockholm, have started. Therefore we kindly would like to take this opportunity to encourage you to book the ECCO 16-ESMO 36 Conference dates, 23-27 September, in your 2011 diary!

Bruce Morland

## Profile of SIOPE Staff members

The SIOPE Europe office is based in Brussels, Belgium and consists of two part-time staff, Samira Essiaf and Edel Fitzgerald.

Samira Essiaf is the Secretary General of SIOPE. Her skillset is wide-ranging and includes extensive experience in clinical trial management:



Edel Fitzgerald works on Membership and Public Affairs for SIOPE. She has significant experience working in public policy administration roles:

- Previous positions include Clinical Trials Central laboratories (LabCorp & Esoterix, EU headquarters) involving the set-up and follow-up of different clinical trials studies from Phase 1 - Phase 4; start-up of the Pharmaceutical Assistant Degree at the KTA Institute in Belgium and teaching several Pharmaceutical Assistant-related courses
- Comprehensive experience in the creation of scientific programmes of congresses/ conferences in her present function as Scientific Manager for ECCO-the European CanCer Organisation
- Broad knowledge of Clinical Trials, general management and project management
- Languages: Dutch, English, French, Moroccan, Classical Arab & Spanish
- Education: Bachelor in Biology, Masters in Biochemistry, Scientific Teacher degree & Pharmaceutical Assistant degree.
- Previous roles include positions in numerous semi-state bodies (Department of the Environment, Northern Ireland Civil Service; German-Irish Chamber of Industry and Commerce; Bord Bia-the Irish Food Board; Dublin Tourism)
- Comprehensive background in public policy administration; marketing and communication expertise as well as event management (Events Manager in German trade commission to Ireland); office management, project management, report-writing
- Extensive knowledge of EU public affairs including through her current role in ECCO- the European CanCer Organisation
- Languages: English, German and French
- Education: M.A. European Integration and Public Policy, Queen's University Belfast; CRAC Insight into Management Certificate, Queen's University, Belfast; Certificate in Marketing Practice, Marketing Institute of Ireland, Dublin; B.A. Law and European Studies, University of Limerick degree.

# Newsbites

## SIOPE meets MEP Alojz Peterle at the European Parliament



Hildrun Sundseth from the European Institute of Women's Health joined SIOPE President Ruth Ladenstein and staff member Edel Fitzgerald at a meeting in the European Parliament in Brussels to discuss with the Slovenian Member of the Parliament, Alojz Peterle SIOPE's policy objectives for 2010-2011. Mr. Peterle is the Rapporteur for the Parliamentary report on the Commission Communication, Action against Cancer, a European Partnership. In the report he outlined the necessity to give specific attention to paediatric cancer due to the many challenges children and adolescents with cancer face. To find out more about the European Parliament, [CLICK HERE](#).

## February Awareness Month

In 2011, SIOPE expects to launch a wide-reaching campaign raising awareness on the many challenges faced by patients of childhood cancer and those who treat them.

February is a key timeframe to actively campaign on the many issues surrounding these rare cancers, with World Cancer Day (04th February), International Childhood Cancer Day (15th February) and Rare Disease Day (28th February) all take place during the month, all key dates in the SIOPE Calendar. If you are marking International Childhood Cancer Day in your country, we want to hear from you! Please contact us by emailing office<at>siope.eu (please replace <at> with @).

## SIOPE offers two FLIMS fellowships

SIOPE received numerous applications in response to the call for proposals for the FLIMS 12 Workshop "Methods on Clinical Cancer Research", 19-25 June 2010, Flims, Switzerland.

This annual intensive workshop provides the opportunity to European junior clinical oncologists in any clinical research specialty area to learn the essentials of clinical trial design.

The goals of this workshop include:

- Introduce junior clinical oncologists in any oncology subspecialty to the principles of good clinical design
- Expose junior clinical oncologist to the full spectrum of challenges in clinical research
- Develop a cadre of well-trained, experienced researchers whose expertise will foster better clinical trial designs

We are very pleased to announce that three applicants were selected to participate this year to the 12th edition of this excellent high-quality workshop. From the three selected participants we have two of whom have been awarded a SIOPE Scholarship for FLIMS:

\*\*\* Dr Krol Ladislav from *Motol Hospital, Czech Republic*

\*\*\* Dr Nathalie Gaspar from *Institut Gustave Rouissy, France*

Congratulations to both applicants!

## ESO-SIOPE Masterclass

3rd Masterclass in Paediatric Oncology

12-18th June, 2010

Castel Gandolfo (Rome), Italy

This clinically-oriented educational programme has been designed for young paediatric oncologists who wish to improve their skills in clinical management of common childhood tumours. With a truly pan-European faculty, this dynamic course will provide practice-oriented training while the teaching sessions will focus on the application of the most recent research findings to clinical practice.



# Upcoming Events

The 11th International Conference on the Long-Term Complications of Treatment of Children and Adolescents with Cancer takes place on 11-12 June, 2010 in Williamsburg, Virginia, US. For further information contact Dr. Daniel Green (daniel.green<at>stjude.org (please replace <at> with @).

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

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

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The 4th World Congress of International Federation of Head and Neck Oncologic Societies (IFHNOS) takes place from 15-19 June, 2010 in Seoul, Korea. Click on the website [www.ifhnos2010.org](http://www.ifhnos2010.org) for more information.

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

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

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The 26th International Pediatric Association Congress of Pediatrics takes place from 05-09 August, 2010 in Johannesburg, South Africa. For more information, click on <http://www2.kenes.com/IPA/Pages/home.aspx>.

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The Children's Oncology Group Meeting (COG) takes place from 21-25 September, 2010 in Dallas, USA. For more information, check out [www.childrensoncologygroup.net](http://www.childrensoncologygroup.net).

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

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The 21st Annual Meeting of the International BFM Study Group will be held from 02-04 October in the Maritim Pine Beach Resort & Convention Centre, Antalya, Turkey. For further information, please click on the website, <http://www.ibfm2010.org/>.

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The 7th Bi-Annual Childhood Leukaemia Symposium will take place from 04-06 October in the Maritim Pine Beach Resort & Convention Centre, Antalya, Turkey. For further information, please click on the website, <http://www.ibfm2010.org/>.

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

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

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SIOP 2010- the 42nd Congress of the International Society for Paediatric Oncology takes place from 21-24 October, 2010 in Boston, USA. Further information is available here, <http://www.siopboston2010.com/>.

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The American Society of Hematology (ASH) Annual Meeting takes place from 04-07 December 2010 in Orlando, Florida. To find out more, check out the website, <http://www.hematology.org/>.

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The First International Symposium on Childhood, Adolescent and Young Adult Hodgkin Lymphoma (1-ISCAYAHL) takes place from 12-14th May, 2011 in Washington DC, USA May 12-14, 2011. To find out more, [CLICK HERE](#)

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# About SIOPE



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

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

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