

Update from the office

While the EU institutions slowed down during the summer, the SIOPE office has been a hub of activity as preparatory work continues on the EU FP7 Network of Excellence ENCCA (European Network of Cancer research in Children and Adolescents) and the European Partnership for Action against Cancer initiative. We are also busy coordinating the paediatric facet of the ongoing Eurocancercoms project, an exciting venture aiming to streamline and professionalise cancer communication and dissemination in the EU. Involving 18 partners from 10 countries, there has been a particular focus upon paediatrics, led by Prof. Richard Sullivan and Prof. Kathy Pritchard-Jones.

Autumn is set to be full of activity also, with many of you joining the community in Boston for SIOPE in October. Keep an eye out for the SIOPE/ EONS/ ECCO Special Project flyer in your delegate bags!

As you may know, we are already preparing for International Childhood Cancer Day on 15th February! In 2011 we expect to host an event in the European Parliament and we also hope to engage with national groups to promote your events. If you are organising an event or an activity to mark this special occasion, contact us now!

Finally, the groundwork is progressing for the Paediatric Track at the 2011 European Multidisciplinary Cancer Congress, taking place next September in Stockholm. The largest congress of its kind in Europe, the Paediatric Track is organised by SIOPE. This comprehensive paediatric track is led by two Chairs, SIOPE President Associate Prof. Ruth Ladenstein and Board Member Prof. Gilles Vassal, who have been working closely to offer the latest cutting edge research and insights from paediatric oncology. This exciting meeting in Stockholm is the ideal forum to obtain a 'state of the art' update on novel anti-cancer therapies and all that is happening, on your doorstep in Europe.

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 @).

Message from the President

Almost twelve months ago, I took up the SIOPE presidential position and undoubtedly I have had a busy but exciting time working closely with both the office and my colleagues from across Europe on the Board. I am delighted now to introduce to you our new Board member, Dragana Janic from Serbia. I hope that Dragana, in her joint position as Chair of our Education and Training Committee, will open the necessary borders to encourage greater interaction with countries based in central and Eastern Europe. I also want to take this opportunity to sincerely thank Kathy Pritchard-Jones and Riccardo Riccardi, who must sadly step down from the Board after many years of dedication to SIOPE Europe. Kathy and Riccardo's commitment since SIOPE's inception has been phenomenal, and without their determination to set up the office in Brussels and lobby on behalf of our young patients, it is unlikely that we would have had the opportunities that face us now, such as ENCCA, the EU-funded Network of Excellence and the European Standards of Care for Children with Cancer project included in the Commission initiative, the European Partnership for Action against Cancer. They will be greatly missed!

All these changes will officially take place at SIOPE's General Assembly in October during SIOPE Boston, of which I hope many of you can join. We expect to have numerous important announcements at the meeting for our members, including the announcement of SIOPE's President-elect.

I also wanted to inform you of two interesting developments that have taken place recently for SIOPE. Firstly, Board members Bruce Morland and David Walker are leading the 'SIOPE Fundraising Committee' which will identify ways to raise money to keep the office up-and-running and also to ensure we can continue our commitment to training and educating junior oncologists by providing grants and fellowships; more details on this are outlined in Bruce's 'Treasurer's Corner'. Secondly, Gilles Vassal and I have been working with the office on ensuring an outstanding programme for the ECCO 16-ESMO 36 Paediatric Track in Stockholm next year. Updates on this dynamic multidisciplinary congress are available on the ECCO website ([CLICK HERE](#)) and I do hope you will encourage your colleagues to submit abstracts and join us in Sweden in September 2011.

Finally, preparations have started for our awareness campaign which we hope to run on an annual basis during the month of February. Commencing in 2011 to mark World Cancer Day (04 February), International Childhood Cancer Day (15 February) and Rare Disease Day (28 February), we will organise an event in the European Parliament and communicate regularly on the various actions taking place at national level. For this we need your support! Please let us know what activities you and your colleagues are doing for International Childhood Cancer so we can promote your actions at EU level.

In the meantime, I look forward to meeting you in Boston!



2010





SIOPE's Europe's Community

Outreach and awareness-building throughout Europe

E-Health

e-Health is a hot topic at EU level. One of the health priorities of Spain's EU Presidency and an overarching discussion for the 'Trio' Presidency of Spain, Belgium and Hungary, the European Commission has placed emphasis for many years on the importance of potentially life-saving communication and technology tools like telemedicine and innovative personal health systems. e-Health encompasses a huge range of electronic and digital tools that can be leveraged by the healthcare sector to connect stakeholders and enhance healthcare and care-delivery systems.

In 2004, the Commission adopted the e-Health action plan, a comprehensive plan that covers everything from electronic prescriptions and health cards to new information systems that reduce waiting times and errors, in an effort to create an EU 'European e-Health Area' and facilitate a more harmonious and complementary European approach to eHealth. The e-Health Action Plan has set a number of targets to be rolled out by 2010. To view the European Commission's e-Health Action Plan, [CLICK HERE](#).

e-Health is also one of the priorities of the EU's i2010 programme to boost innovation and jobs and aims to provide user-friendly and interoperable information systems for patients and health professionals across Europe. To find out more about the EU's i2010 programme, [CLICK HERE](#).

Moreover, e-Health is one of the EU's first six Lead Market Initiatives (LMI), due the numerous market growth opportunities of this sector. This move makes e-Health a strategic priority: working closely with Member States and industry, the European Commission creates action plans for the 6 Lead Markets to facilitate the introduction of new products or services onto the market (the other LMIs are: sustainable construction, protective textiles, bio-based products, recycling and renewable materials).

Indeed, the emergence of an 'e-Health industry' has the potential to become the third largest industry in the health sector after the pharmaceutical industry and the medical device and imaging industry. Naturally this potentially lucrative area has ensured that industry and civil society have actively engaged with policymakers on e-Health. However, the question of data protection in the e-Health debate continues, and a key challenge will be to address the significant concern by consumers that their medical records could be mislaid or be used for commercial gain. A key challenge will be to create confidence amongst European citizens that their medical records will not be shared.

With the new Commission placing innovation at the heart of its agenda, e-Health is expected to be even more important. In March of this year at the 8th Ministerial e-Health Conference in Barcelona, EU health ministers signed a Declaration on e-Health outlining the '2020 Vision for' providing key objectives to be reached in the next ten years. To view more on this call for greater Member State coordination in eHealth, [CLICK HERE](#).



SIOPE and E-Health

A 'Survivorship' Passport: Tracking Health throughout Europe

The SIOPE-led Network of Excellence, ENCCA, the European Network of Cancer research in Children and Adolescents, will create strong and important links to the newly-created PancareSurFup project, also financed by the EU's Seventh Framework Programme. An interesting concept in relation to e-Health led by Prof. Riccardo Haupt of the Giannina Gaslini Institute, is the creation of a 'Survivorship Passport'. As part of the ENCCA Work Package, 'Quality of Survivorship' and in co-operation with other partners including ICCCO- the International Confederation of Childhood Cancer Parent Organisations, Prof. Haupt is assessing the possibility of creating a European template of an electronic tool that will contain comprehensive information on the medical history of a cancer survivor. This 'passport', will provide a detailed and up-to-date description of the tumour type, stage and related risk factors, as well as key information on the cumulative doses of chemotherapy and radiotherapy and any major surgical procedures.

In addition, through close collaboration with Prof. Lars Hjorth and the PanCareSurFup consortium, suggestions on follow-up procedure are likely to also be available on this electronic 'passport', as reflected in the guidelines on follow-up to be developed by PanCareSurFup.

Partnering with IT companies to ensure an innovative and efficient resource highlighting treatment exposure and medical background, it is hoped that the Survivorship passport will be available in multiple European languages; however the challenge is as always to carry out such a project with major budget limitations.

To find out more about the Survivorship Passport, please contact Prof. Haupt, at riccardohaupt@ospedale-gaslini.ge.it (please replace <at> with @). or by phone: +39.010.5636.423

Generating Debate through EUROCANCERCOMS

SIOPE is participating in EUROCANCERCOMS, a project that aims to understand and develop the next generation of e-tools and e-information for patients, their families and healthcare professionals. A two-year co-ordinating action (CA) funded under the EU programme, 'Science in Society', it involves 18 working partners from 10 countries.

In collaboration with Prof. Richard Sullivan of the Kings College London and the European Institute of Oncology Milan, and SIOPE Board Member Prof. Kathy Pritchard-Jones, Professor of Paediatric Oncology and Programme Director for Cancer, UCL Partners, 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. Tasks include the coordination of a survey on policy issues related to paediatric oncology as well as an executive summary of Prof. Richard 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.

One of SIOPE's objectives for Eurocancercoms is to form a true 'country-by-country' analysis of the policy challenges that affect the paediatric oncology community. Therefore, the office contacted key experts of childhood cancer at national level in Europe to gather this intelligence. Through this survey it is expected to (a) provide accurate data and expertise to policymakers and (b) decide the best way to support e-cancer communication within the paediatric oncology community.

"The response by national leads to the policy questionnaire and country mapping has been superb and the whole of the EUROCANCERCOMS team are very grateful. The next steps are to build a specific survey for healthcare professionals and patients as well as their families to capture the key approaches to gathering information on the web, the best websites and the sorts of applications / web tools that people find useful. This will be the last bug chunk and once we have this then we will feed back the results to the community, launch a full report on our findings, and, most importantly use this information to develop the EUROCANCERCOMS web portal to integrate key information, sites and tools for everyone." – Prof. Richard Sullivan

SIOPE would like to take this opportunity to thank all of you who were contacted and provided such comprehensive information to this survey.

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

For more information on SIOPE's role, please contact the office directly (office@siope.eu (please replace <at> with @)).



ENCCA, European Network for Cancer Research in Children and Adolescents

The FP7 Health call to structure clinical research in paediatric and adolescent oncology indicates that the advocacy work of SIOPE and other related stakeholders to raise awareness of the many challenges facing the paediatric oncology community has gained the attention of EU policy-makers. 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', coordinated by Associate Prof. Ruth Ladenstein based in CCRI, Austria, 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 main objective of this project is to restructure knowledge-sharing through the integration of the whole chain of stakeholders and to support the acceleration of the development of innovative therapeutic strategies for children and adolescents with cancer. ENCCA's goals include:

- 1. 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

- 2. Promote innovative methodology and designs for clinical trials, as well as their implementation and integration to address the specific needs in rare diseases

- 3. Initiate harmonised therapeutic strategies by increasing significantly access to knowledge and technologies on paediatric tumour biology and interactions between tumour and host.

- 4. Improve substantially the quality of life of children and adolescents with cancer, in particular the long-term side-effects of current and future treatments

- 5. 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 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.

Latest news on ENCCA

The negotiation phase has been successful and we are aiming for a

project start date of January, 2011 with a kick-off meeting scheduled for 14 January in Brussels. We also aim to establish the European Clinical Research Council (ECRC) which will integrate the heads of the clinical trial groups and national groups in Europe in February, 2011, again in Brussels. Details of these meetings will be provided during the SIOPE General Assembly at SIOP Boston on 23 October, 2010.

The ENCCA Writing Committee, namely Associate Prof. Ruth Ladenstein, Prof. Gilles Vassal, Prof. Kathy Pritchard-Jones, Prof. Schrappe, the SIOPE office and ALMA Consulting Group have been busy in recent months creating the all-important management structure to ensure ENCCA will be successful, inclusive and sustainable. For example, three Activity Coordinators will manage various Work Packages, i.e. Prof. Pritchard-Jones will lead the 'Integrating Activities', Prof. Schrappe will lead the 'Joint Research Activities' and Prof. Vassal will lead on the 'Spread of Excellence'. Associate Prof. Ladenstein will, as Project Coordinator, bring together all these activities and be the key contact with the European Commission. SIOPE will lead on dissemination of the results of the project.

As outlined, the European Clinical Research Council will represent a key stakeholder in ENCCA as it incorporates important decisionmakers in paediatric oncology.

Parents and patients also have an important role to play and will be integrated in ENCCA

through ICCCPÖ (ÖKKH) as a partner and the Parents/Patients Advocacy Committee (PAC) in the project. An Ethics Advisory Committee (EAC) will also be established, composed of external experts and parents/patients representatives, not only in charge of ensuring

respect of fundamental ethical principles but also to evoke continuous attention to aspects of ethical handling. Moreover, industry stakeholders will be integrated through the creation of a Club of Industrial Interest and a Scientific Advisory Group will be founded consisting of key experts

from multiple scientific backgrounds of excellence who can be consulted for strategic questions related to this large network of excellence.

For more information on ENCCA please contact the SIOPE office directly.



Childhood Cancer Awareness Month

Commencing from 2011, numerous activities to promote childhood cancer awareness at EU level will be rolled out during the month of February. Actions include a meeting at the European Parliament in Brussels, Belgium, hosted by Slovenian Member of the European Parliament, Mr. Alojz Peterle.

The SIOPE Board members are actively involved in the creation of the programme for the meeting and are keen to have the patient perspective and participation at the event. SIOPE will liaise with groups at local level in Benelux to ensure they are included. A section of the photo exhibition of young cancer patients will also be featured, thanks to the organisation from Luxembourg, 'Een Haerz fir kriibskank Kanner' (A Heart for Children with Cancer).

SIOPE's deliverables for the Eurocancercoms project (www.eurocancercoms.eu) are also expected to be completed in the month of February and of course we will closely link in with the activities of other organisations to mark World Cancer Day (04 February), International Childhood Cancer Day (15 February) and Rare Disease Day (28 February).



But SIOPE also needs your help to promote childhood cancer awareness! If you and/or your national groups are organising activities in your country, we want to hear from you! Contact the SIOPE office now to see how we can help promote your event to the paediatric oncology community as well as key decision-makers in Europe.

Committee Reports and Roundups

SIOPE Education and Training Committee



SIOPE is delighted to introduce the newly-appointed Education and Training Committee Chair, Prof. Dragana Janic from Serbia. Here she provides an overview of SIOPE's recent educational activities.

An important activity of the SIOPE ETC is involvement in joint courses with other organisations offering education in paediatric oncology and/or assistance in promotion of such events. Our aim is to increase the availability of high-quality training courses in paediatric haematology and oncology for European trainees and to incorporate

them eventually as future training activities in a paediatric haematology/oncology curriculum.

Two training events took place in late spring 2010: the ESO-SIOPE Masterclass, held on June 12-18, 2010 in Castel Gandolfo, Italy and the Joint ECCO-AACR-EORTC-ESMO Workshop on Methods in Clinical Cancer



ESO-SIOPE Masterclass, Castel Gandolfo, Italy 12-18 June 2010

Research held on June 19-25 in Flims, Switzerland. SIOPE was deeply involved in both events and supported them with fellowships as well as direct contribution to the courses faculties.

The 3rd ESO-SIOPE Masterclass was organised by the European School of Oncology (ESO) in close collaboration with SIOPE. The course was structured around plenary lectures focusing on state-of-the-art diagnosis and treatment of Bone Tumours, Central Nervous System Tumours, Neuroblastoma, Soft Tissue Sarcoma, Liver Tumour, New Drugs Development and Wilm's Tumour. The case presentations, which were prepared by all the participants with the involvement of the whole faculty, added real value to the discussion. All sessions were closed by the chairman with a summary in order to answer questions related to the specific tumours. There were 39 participants selected among applications coming from 11 European countries: Austria, Czech Republic, Denmark, Germany, Greece, Italy, Spain, The Netherlands, Turkey, UK and Yemen. It was a very interesting interactive course that was highly-rated by the students.

The 12th joint ECCO-AACR-EORTC-ESMO Workshop on Methods in Clinical Cancer Research has been successfully held on June 19-25 in Flims, Switzerland with the goal to provide junior clinical oncologists the tools they need to conduct clinical trials presenting them the full spectrum of challenges in clinical research, from

conventional antineoplastic agents and multidisciplinary treatment regimen to gene therapy.

The idea of this meeting is to allow young oncologists with the support of a highly-qualified faculty (medical oncologists, statisticians) for each group of attendees to write and complete in five days a clinical protocol for cancer patients. Originally, this course was primarily targeted at medical oncologists but in the last three years SIOPE has encouraged the participation of paediatric oncologists also.

In the coming years, the approval by the European Commission of a grant dedicated to the development of a Network of Excellence in paediatric oncology in which SIOPE is deeply involved, ENCCA – the European Network for Cancer Research in Children and Adolescents, will be essential for the implementation of clinical programmes in paediatric oncology and the availability of additional training courses throughout Europe.

The SIOPE Education and Training Committee is aware that the national educational programmes for paediatric haematology and oncology are greatly influenced by the socio-economical situation. In this respect, future efforts of the ETC should be directed towards analysing the situation in Europe both in EU and non-EU countries in order to be able to give guidance on paediatric haematology and oncology training.



ECCO/ SIOPE/ EONS Special Projects

Doctor-nurse collaboration resource materials now available online

We are delighted to announce that the web materials on 'Partnership to improve care: a doctor-nurse collaboration' will shortly be available online! Click on the SIOPE website, www.siope.eu to view all the materials.

A huge 'Thank You' to all the Project Mentors of the SIOPE/ EONS/ ECCO Special Project team, namely Prof. Faith Gibson, Dr. Martin English, Dr. Momcilo Jankovic, Dr. Paola di Giulio, Alison Arnfield and of course Dr. Danny Kelly from EONS. Thanks too to ECCO- without their support none of this would be possible!



SIOPE General Assembly: All Members Welcome!

This year's Annual General Assembly takes place at the SIOPE Boston Conference in the John B. Hynes Memorial Convention Center in Boston Massachusetts. With topics such as the ENCCA Network of Excellence, SIOPE Board Member elections and information on the European Standards of Care for Children with Cancer event hosted by the Polish Ministry of Health next year, it is sure to be a very important meeting! Book this meeting in your diary now.

SIOPE Annual General Assembly

Saturday, 23 October 2010
16.00 – 17.30
Room 107

Special Features

FLIMS 12

12th joint ECCO-AACR-EORTC-ESMO Workshop 'Methods in Clinical Cancer Research' Waldhaus Flims, Switzerland, 19 – 25 June 2010

One of the primary objectives of SIOPE is to support and facilitate scientific, medical, professional and educational co-operation across Europe. In particular, we are keen to provide fellowship opportunities to young oncologists and in particular the hugely popular and competitive 'FLIMS' Workshop, Methods in Clinical Research. Taking place annually in Waldhaus Flims in Switzerland, this year we offered two SIOPE fellowships to participate in the 12th Joint ECCO-AACR-EORTC-ESMO intensive workshop. Dr. Ladislav Krol from the Faculty Hospital Motol in the Czech Republic and Dr. Natalie Gaspar from the Institut Gustave Roussy were selected to avail of these grants; here they give some feedback on their experience.



Dr. Ladislav Krol

Dr. Ladislav Krol

The workshop "Methods on Clinical Cancer Research", which is annually held in Flims, Switzerland, is designed to involve young clinicians in a clinical research and development of clinical trials. I was one of the selected participants this year and I would like to describe in a few words my extraordinary experience.

At the beginning, it was hard for me to imagine that it is possible to create a feasible clinical trial within 1 week in addition to the busy schedule of the workshop which consisted of many lectures covering topics from clinical trial design to the legal importance of regulatory issues in establishing and conducting clinical trials, protocol development groups meetings and small discussion groups.

The workshop has a great concept – organisers took more than 80 trainees and almost 40 faculty members to a superb hotel in the Swiss Alps. This hotel provides all the needs for such a workshop and of course was far away from the hustle and bustle of everyday life, nestled in the Swiss mountains. It allowed us to concern ourselves with the main goal – to transform our clinical trial concepts to feasible protocols. Our commitment has been high since the completion of individual pieces of the protocols had strict deadlines. This has led to several sleepless nights that we spent in front of our computers. The enthusiasm and great advice of all faculty members helped us a lot to overcome the fatigue and continue with our work.

And finally, we all uploaded our protocols to the workshop server successfully. >>>

I would especially like to thank Lillian L. Siu, Peter Naredi, Riccardo Riccardi and Sally Stenning and all my colleagues from Protocol Development Group 2 for the great time.

I am very glad I was able to attend this prestigious workshop. It was a great opportunity to meet the leaders in the field of clinical research, speak to them and gain valuable advice. All of this would not be possible without the support from SIOPE Europe.

*Dr. Ladislav Krol
Department of Pediatric Hematology and Oncology
University 2nd Faculty of Medicine and University Hospital Motol
Czech Republic*

Dr. Nathalie Gaspar

I have been delighted to participate in the joint ECCO-AACR-EORTC-ESMO Workshop on "Methods in Clinical Cancer Research" 2010. The interactions with experts on clinical drug development from all over the world, their incredible availability to answer all your questions and share their expertise, are of great value to build and improve fellows protocol. The variety of the fellows present (e.g. medical oncologists, surgeons, radiotherapists, pediatric oncologists) and the variety of protocols presented (e.g. phases I to III, quality of life) have opened my mind and improved my understanding of clinical trial construction.



Dr. Nathalie Gaspar

The discussions on my protocol and on other's protocols are unique.

Paediatric oncology is a small world and as a paediatric oncologist I clearly appreciate the interactions with the wider world of adult oncology. This workshop was an incredible experience, a really intensive week but fantastic and of great educational value, held in a wonderful and peaceful place which favours this hard work and human interactions. I really thank SIOPE Europe to have selected me as a fellowship grant recipient and have permitted me to participate in such an experience.



*Dr. Nathalie Gaspar
Institute Gustave Roussy
Villejuif, France*

Newsbites

See you at SIOPE Boston

See you at SIOPE's General Assembly in SIOPE Boston, 21-24 October!! Our General Assembly will be held during the SIOPE Boston conference so we hope you can join us. Check your delegate bag at SIOPE Boston for information on the SIOPE/ EONS/ ECCO Special Project Online Resources now available on 'Partnership to improve care'.

SIOPE's Annual General Assembly and Reception takes place on Saturday, 23rd October at 16.00.

All Members are warmly welcome

Bookmark Stockholm!

Book your dates for the European Multi-disciplinary Cancer Congress from 23-27 September 2011! This highly successful biennial meeting takes place next year in Stockholm, Sweden! SIOPE will hold its General Assembly as well as give the next SIOPE Award as chosen by the SIOPE Board. Last year, the distinguished clinician, Prof. Helmut Gadner, won the award for his dedication to childhood cancer throughout his career. For more information on this event, check out the ECCO website [HERE](#).



Bátor Tábör

As part of SIOPEurope's aim to bridge the gap between professionals, parents, patients and policymakers, we profile various successful patient initiatives at EU level. This time we turn to Hungary, where Hatvan, a small town 60km from Budapest, is a haven for children whose lives have been interrupted by a serious illness, primarily cancer. This sanctuary of therapeutic recreation is called Bátor Tábör or 'Camp of Courage'.

Hungary's 'Camp of Courage' each year welcomes over 500 campers from Central and Eastern Europe living with cancer as well as other illnesses such as diabetes or haemophilia. Linking in with more than 60 paediatric specialised centres (of which 13 are paediatric oncology centres in Slovakia, Czech Republic, Poland and Romania), Bátor Tábör allows children to take part in activities that they would otherwise never have a chance to enjoy. Since its opening in 2001, over 3000 campers have availed of activity programmes which include rowing, horseback-riding, archery, arts and crafts as well as dancing, music and acting. Accommodation is available in modern and wheelchair-accessible cottages that accommodate 70 children and over 90 volunteers and facilities include a canoe lake, an artificial football field, a sports hall, riding stables and a media studio!

"Bátor Tábör is a machine, in which children are thrown into, and a healthier, happier and more courage child comes out".

The camper experience as described by Paeti, aged 15.

Based upon the methodology of 'therapeutic recreation', campers are continuously encouraged to defy imagined limitations to pursue challenges that ensure positive experiences. Children can discover either their hidden potential or re-discover skills they believed they had lost due to their illness. Therapeutic recreation has a long-term impact that reaches far beyond the camp sessions: completion of these challenges is accompanied by success and recognition, allowing the campers to face and deal with their everyday challenges, experience positive changes and in so doing, Bátor Tábör boosts their confidence and self-image.

In order to reap the benefits of therapeutic recreation, close and personal relationships need to be created; maximum attention is provided through the recruitment of volunteers. Thus, 400 carefully selected and trained volunteers join the Bátor Tábör camp every year spending an average of 10 days at the camp. Half of the volunteers return on an annual basis. Approx. 50 volunteer medical professionals, paediatricians, paediatric oncologists, diabetologists, registered nurses, dieticians and physiotherapists based in hospitals across Hungary join the camp to run the medical service under the supervision of the Medical Director, Dr. Andrea Békési. This service is provided 24 hours a day in a child-friendly centre equipped specifically for treating children with chronic diseases. The development and maintenance of the campsite, including the activity programme, is supported by donations and is thus free-of-charge for families.

The Bátor Tábör Camp is part of the 'Hole in the Wall Camps Association, 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, Barretstown in Ireland, Over the Wall in the UK and of course Bátor Tábör.



Moreover, seven new camps are in various stages of development, and five Global Partnership Initiatives are being run in Africa and Asia.

Here is some feedback from Dr. Adrienne Horváth, a paediatric oncologist from Tirgu Mures, Romania on her patients after their adventures in Bátor Tátor:

“Two patients of mine, Eszter and Zalán have come recently for check-up to the hospital. I have noticed something very interesting. They were much braver at lumbar puncture, they did not cry, what is more, Eszter said, the treatment is easy for somebody who has been to Bátor Tátor. Another interesting thing is that since they returned from camp their appetite is much better and they became stronger making their parents happy. I do not know what happened at camp. Maybe the food was better, rich in vitamins... or their soul was lifted???”

Anyway, the late effect is perfect.”



Information on this article has been kindly provided by Bátor Tátor's Medical Director, Dr. Andrea Békési and Marketing Coordinator, Zsuzsanna Kun, in conjunction with SIOPE member, Dr. Miklos Garami.

If you are interested in finding out more, visit the Bátor Tátor website or email the team at batortabor@batortabor.hu.

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Join Us in Stockholm

After a hugely successful Paediatric Oncology Track at the ECCO 15-ESMO 34 Multidisciplinary Cancer Congress in Berlin – the largest of its kind in Europe – we are delighted to announce that SIOPE will be once again heavily involved in the scientific programme design and coordination of the European Multidisciplinary Cancer Congress, this highly popular ‘meeting of minds’ from across the oncology spectrum.

In 2009, a record number of almost 15,000 participants with more abstracts and late breaking data presented than ever before met in the International Congress Centre in Berlin. To view the Statistical Report from ECCO 15-ESMO 34, [CLICK HERE](#).

The paediatric oncology programme in Berlin included an update from each of the major paediatric trial groups in Europe, teaching lectures including new approaches to clinical trial design for rare tumours and childhood cancer, a special session on advances in fertility preservation for children and adolescents, as well as scientific symposia on how to select a new drug in paediatric oncology,



lessons from soft tissue sarcoma in young people, new imaging approaches and advances in leukaemia. Sharing knowledge, examining barriers and engaging with varied perspectives and expertise is central to SIOPE's work and ECCO 15-ESMO 34 represented the ideal forum to investigate all that is happening in paediatric oncology n your doorstep in Europe.

Next year's congress is likely to be just as exciting. Taking place in Stockholm, Sweden, our objective is to offer even more to the paediatric oncology community in Europe and to collaborate with related disciplines to truly provide an all-important multidisciplinary approach which is at the heart of this biennial congress. The Track Chairs, SIOPE President Associate Prof. Ruth Ladenstein and SIOPE Board member Prof. Gilles Vassal warmly welcome you to join us in Stockholm for the European Multidisciplinary Cancer Congress, 23-27 September 2011!





A Heart for Children with Cancer 'Über-Lebens-Kunst' Exhibition in the European Parliament

Hosted by MEP Astrid Lulling

The patient organisation, 'Een Häerz fir kriibskrank Kanner' based in Luxembourg, recently organised an interesting exhibition in the European Parliament to highlight the emotional journey children with cancer and other rare diseases face every day. Hosted by MEP Astrid Lulling from Luxembourg, here 'Een Häerz fir kriibskrank Kanner' provide a summary of the event.

The Luxembourgish association "Een Häerz fir kriibskrank Kanner" or 'A heart for cancer sick children' presented the exhibition "Über-Lebens-Kunst" -or 'Surviving-Skills' in the European Parliament from 5th July - 23rd July 2010 in Brussels. The exhibition, which was officially launched on 13th July, was under the patronage of Madame Astrid Lulling, the Luxembourgish Member of the European Parliament (MEP). The exhibition consists of 24 portraits of children laughing and openly sharing their experience. Their vitality and love for life is captured perfectly in each of the images and through their personal stories their bravery shines through despite the many challenges they face on a daily basis: these children and young people all have serious chronic illnesses like cancer, rheumatism and diabetes.

The objective of the exhibition – the images and the accompanying personal story – is to highlight the challenges and restrictions these children and their families during the ordeal of such a serious illness. Apart from the many physical setbacks they must deal with, there are often multiple psychological problems. Nevertheless the exhibition indicates their phenomenal courage and their ambition to live a normal life with their families and friends. A team of paediatric oncologists, nurses, physicians and psychologists – the 'Care Team' support the whole family to cope with the problems linked with the illness.

It was the Iranian born artist Yousef A. P. Hakimi, known as Yaph, who created together with the therapists of the "Villa Kunterbunt" this exhibition. During the pregnancy of his wife, they had a recurring question of whether their child would be in good health or not and what would life be like should their child have a rare disease. This paternal concern inspired Yaph to create an artistic impression demonstrating the bravery of young people coping with rare diseases.

The exhibition aims to raise public awareness and in particular inform policymakers and decisionmakers about the numerous challenges facing our young people in Europe with chronic illness in order to gain more financial and political support to support scientific research and development for children with rare diseases in Europe. More research and post-care centres can only improve the fate of sick children, and thereby strengthen their joy for life and give them hope for a better future.

"Een Häerz fir kriibskrank Kanner" is a member of ICCCP- the International Confederation of Childhood Cancer Parent Organisations. For more information on the many activities organized by Een Häerz fir kriibskrank Kanner, please contact them directly:

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Treasurers Corner

At SIOPE we have a number of successes and achievements that I feel it is worth highlighting to you. As ever we are looking for new ways to get across the message that SIOPE already makes a significant contribution to the childhood cancer agenda in Europe. Our funding is heavily dependent on the income received from the ECCO meeting, but we still need additional funds to support our work and more importantly develop it further...

- The ENCCA project funded through the EU's Seventh Framework Programme (FP7) has its origins embedded in SIOPE. The various work packages have been defined and the budgets are being negotiated as this article is being written. Suffice to say that it is a major achievement for us to be involved in a project which really goes to the heart of the aims of SIOPE. The whole thrust of the ENCCA project is to provide a network of excellence providing key links and bridges and facilitating the coordination of the complex structures in existence already in Europe. We all have examples of such collaborative efforts and in general paediatric oncology has always been effective in this area. However there are always opportunities to improve. The ENCCA project will be the start of what we hope will be further successful funding opportunities to build on the infrastructure we put in place.
- Every year SIOPE provides an educational grant to support 2 students attending the 12th joint ECCO-AACR-EORTC-ESMO Workshop. For those of you who have never experienced Flims it is a very intensive week where the students are helped in designing and developing a clinical trial they have started to formulate ahead of the workshop. The quality and calibre of teaching on the course is exceptional and all candidates rate this meeting as one of the most valuable in their training. This year we supported Dr. Ladislav Krol from the Czech Republic and Dr. Dr. Natalie Gaspar from France. Look out for notification for requests for support to next years' meeting!
- Due to our relatively fragile financial position the SIOPE Board decided we should have a fundraising group to look at new opportunities to support our work. To that end, myself, David Walker and Edel Fitzgerald from the SIOPE Office have started to formulate some ideas. We have from time-to-time attracted interest from philanthropic individuals/groups. Explaining the work of SIOPE has always proved to be challenging especially when the organisation does not have direct responsibility for patient care and running trials or research (areas which commonly attract donations).



Kathy Pritchard-Jones produced some excellent presentation material when she was President of SIOPE which we hope to capitalise on and develop further. We feel the greatest contribution SIOPE makes is its ability to act as a powerful professional voice and lobby for increased attention for issues around childhood cancer at the EU. In addition our continuing contribution to the education agenda for trainee doctors and other professionals involved in cancer care is very valuable. These areas are potentially not that "sexy" for donors but we would really like you to help us with any contacts you may have or for ideas on how to sell our message.

- There will be an announcement in Boston about changes to the way in which SIOPE membership fees can be used by Continental Branches. In the past your SIOPE membership has all been directed to SIOPE International and SIOPE, like all Continental Branches has received no direct financial support. The proposal will be made in Boston that Continental Branches be allowed to add a subscription to the main fees to support their activities. This will need approval at the AGM and any proposal to charge European members an additional fee will need approval at a SIOPE AGM. However it will provide us with an important opportunity to make our somewhat unstable financial position more secure. More detail will follow but we hope this will meet with general approval.
- Finally another successful outcome of our joint collaborations driven through ECCO has been the SIOPE- EONS-ECCO "Special Project". Regular updates to this large piece of funded work have been given at both SIOPE and ECCO meetings led by Faith Gibson and her team. The project is nearing its completion and more will be heard about the successes of the project in Boston. This has been an excellent example of facilitating true multidisciplinary working and has been recognised as an "exemplar" by senior figures within ECCO. Well done to everyone involved and let's hope it provides a stimulus for further funding to support future Special Projects. 🍁

Upcoming Events

THE INNOVATIVE THERAPIES FOR CHILDREN WITH CANCER (ITCC) ANNUAL MEETING

30 September – 01 October, 2010

Paris, France

www.itcc-consortium.org

13TH EUROPEAN HEALTH FORUM GASTEIN

06-09 October 2010

Bad Hofgastein, Austria

To find out more on this event, please [CLICK HERE](#).

VIII CONGRESS OF THE MEDITERRANEAN ASSOCIATION OF PAEDIATRIC SURGEONS

08-10 October, 2010

Grand Resort Limassol, Cyprus

www.topkinisis.com/Pediatricsurgery/10-10-10/

THE 33RD WORLD CONGRESS OF THE INTERNATIONAL SOCIETY OF HEMATOLOGY (ISH 2010)

10-14 October, 2010

Jerusalem, Israel More information is available by [CLICK HERE](#).

SIOP 2010- THE 42ND CONGRESS OF THE INTERNATIONAL SOCIETY FOR PAEDIATRIC ONCOLOGY

21-24 October, 2010

Boston, USA

www.siopboston2010.com/

52ND ASH ANNUAL MEETING AND EXPOSITION

04-07 December, 2010

Orlando, Florida, USA

www.hematology.org/

AACR 102ND ANNUAL MEETING 2011

02-06 April, 2011

Orlando, Florida, USA

[CLICK HERE](#) for more details

37TH EBMT ANNUAL CONGRESS

03-06 April, 2011

Paris, France

<http://www.congrex.ch/ebmt2010/>

THE FIRST INTERNATIONAL SYMPOSIUM ON CHILDHOOD, ADOLESCENT AND YOUNG ADULT HODGKIN LYMPHOMA (1-ISCAVAHL)

12-14 May, 2011

Washington DC, USA

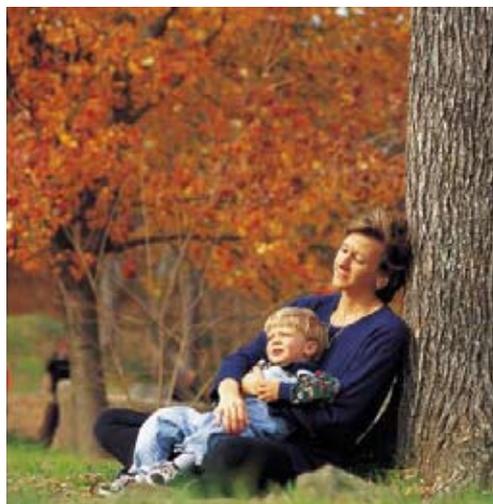
To find out more, [CLICK HERE](#).

THE EUROPEAN MULTIDISCIPLINARY CANCER CONGRESS

23 - 27 September 2011

Stockholm, Sweden.

<http://www.ecco-org.eu>





SIOPE 's **Seven Point Plan**

Seven Point Plan investing in the Health of Europe's Children

Last October, some SIOPE Board members came together in Warsaw to discuss the current situation of standards of care for children with cancer in Europe. It was decided that to ensure SIOPE's message are clear for EU decision-makers we needed a plan: the SIOPE Seven Point Plan. With the support of numerous parent and patient organisations from across Europe, a plan was created to demonstrate how to investment in the health of Europe's young people.

Cancer in children and adolescents is a significant European health burden. There is inequality in survival rates across Europe and significant long-term side effects in many survivors. In many instances this is due to different treatment approaches and resources across Europe. This situation must and should be improved to prevent our young citizens dying or suffering unnecessarily.

Almost 20,000 young people (aged 0-19 yrs) will be diagnosed with cancer this year in the EU. This is the leading cause of death from disease among our young citizens.

Early diagnosis leads to good treatment. In turn, quality treatment with modern multiprofessional care increases the success rate. The good news is that currently 80% of children will survive. Integration of care and research is a hallmark of pediatric oncology and access to clinical research has led to the significant increase in survival of children with cancer during the last 50 years.

Approximately one in every 1,000 adults in Europe is now a childhood cancer survivor. This proportion is going to increase. Treatments are complex, require specialist input and have the potential to cause long-term health problems. Substantial numbers of today's young cancer patients therefore require appropriate life-long follow up to maximise their quality of life. With the rapidly changing landscape for cancer treatment, there are new opportunities to design less toxic, more effective therapeutic approaches and implement these into 'best practice' standards across the

European Union. Unfortunately in many parts of Europe, children and young people and their carers are currently not able to benefit from these advances in treatment.

How to address the current challenges faced by children and young people with cancer in the European Union:

- 1** All EU Member States to have National Cancer Plans that contain specific standards for age-appropriate treatment and care for children and adolescents with cancer
- 2** Every country to support prospective registration and outcomes of all cases using the International Childhood Cancer Classification scheme, extended to include adolescent cases
- 3** Defined referral pathways so that every patient is managed by an age-appropriate specialist treatment centre that works within a supported national or cross-border network structure and can have a facilitated access to innovative therapies in development when needed
- 4** Every child and adolescent with cancer to be treated by a multi-professional team with sufficient volume of activity to maintain expertise and which participates in audit and accreditation schemes
- 5** Recognition of specialist training in paediatric haematology in every European country
- 6** Recognition that parental/family support is critical to treatment outcome and survival of the young cancer patient
- 7** Greater EU and national support for investigator-led clinical and translational research, to reverse the recent decline in participation in clinical trials which, to date, has greatly benefited the development and delivery of 'best practice' of care of for young people with cancer

For more information, contact SIOPE

About US



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

www.siope.eu

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

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

Support and facilitate professional, medical, scientific and educational co-operation and training across Europe

Integrate patients and parents and bridge the gap between family groups, professionals and policymakers in Europe

Optimise access to information and promote multi-centre and multinational clinical trials, forming a common platform for best practice guidelines in clinical research

Promote better policies for children with cancer and raise awareness of the numerous challenges faced by paediatric oncology professionals to EU policymakers

Elevate standards for training and care in paediatric oncology and develop European guidelines

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

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