

News from the office

Dear Readers,

The SIOPE Europe office is busy preparing for the ECCO 15- ESMO 34 Congress taking place from 20th – 24th September in Berlin. Along with a comprehensive paediatric track SIOPE Europe will additionally have its own stand in the 'society' area of the Congress so please do drop by.

This edition of the newsletter flags up an important Symposium entitled 'Standards in Paediatric Oncology' organized by SIOPE Board Member Professor Kowalczyk. Taking place in Warsaw, Poland on October 14th, the aim is to discuss the variations in standards of care in Europe and is expected to be well-attended by both political dignitaries, patient organizations and of course the dedicated professionals in childhood cancer. Kindly supported by Communication without Barriers, this edition features an open letter promoting the event.

Another key feature of our summer newsletter is an article by SIOPE Board Member, Professor Gilles Vassal. He provides an informative overview of the EU Paediatric Regulation and the progress made by EMEA, the European Medicines Agency, underlining the impact this legislation has on the paediatric oncology community.

Finally, the SIOPE office would like to welcome Professor Dragana Janic who recently joined as a Committee Member of our Education and Training Committee. As the Head of the Department of Paediatrics and Haematology in the University Children's Hospital in Belgrade, she will be an important representative of paediatric oncology in Eastern Europe.

Should you have any comments on the newsletter, please do let us know by contacting us at office@siope.eu.

Message from the President

Dear Colleagues,

This is my last report for the SIOPE newsletter. In September, I shall be handing on the President's role to Professor Ruth Ladenstein (Austria). I wish her the very best in this endeavour and hope that all of you based in Europe will support the important activities we have planned for the coming years. In particular, I encourage you to visit our website and sign up as a SIOPE subscriber. This not only ensures that you continue to receive personal communications from the SIOPE office, but also shows your support for the European network of childhood cancer specialists, that is so crucial to future success in improving outcomes for children with cancer.

This is an exciting and productive time for SIOPE Europe. While we have many challenges ahead, particularly in relation to investigator-led clinical trials, we are identifying solutions and moving forward. The expected opportunity to bid for an EU-funded network of excellence in paediatric and adolescent oncology is a stimulus to grow our informal relationships with the clinical trial groups into a force for change. The aim is to improve infrastructure and add value to our diverse competencies in clinical trials and biological research through greater collaboration and sharing of methodologies and data platforms. This will improve our abilities as a network to deliver translational research to 21st century standards and timelines, for the benefit of our patients. Ruth Ladenstein's report on progress with the clinical trials support desk is the first step to standardising procedures and easing the bureaucratic burden of launching investigator-led multinational trials. We also aim to work closely with the new PanCare initiative to ensure uniform approaches to capturing long term outcome data and ensuring adequate health surveillance of European children who are cured of their cancer.

SIOPE's close alliance with the expanding public affairs activities of ECCO, the European CanCer Organisation, has helped us to ensure that childhood cancer has a high visibility in Europe with regulators, health service providers and funders of clinical research. Senior politicians are supporting a conference on 'Standards in Paediatric Oncology' organised by SIOPE Board member, Professor Jerzy Kowalczyk, to discuss the current status of paediatric cancer units in Europe and how to make improvements. This is planned for 14th October 2009 in Warsaw, Poland. All are welcome to attend and should use this opportunity to highlight their own national needs with their health service commissioners.

One of the most enjoyable aspects of the role of SIOPE Europe president is the invitations received to join colleagues around Europe during the annual meetings of their national childhood cancer organisations. Recently, I had the pleasure of participating in the summer meeting of



Prof. Kathy Pritchard-Jones
SIOPE President

the Hungarian Paediatric Oncology Group and hearing about the achievements of their network of treatment centres and their increasing participation in clinical trials. We also discussed the need for an annual educational meeting that would be easily accessible to the young doctors of Eastern Europe and neighbouring countries who are training in our speciality. The SIOPE Education and Training committee will engage with the organisers of the existing excellent training courses already provided in Europe to see how we can best meet this need to expand the capacity to offer relevant training across the whole of Europe.

It is still a challenge to ensure that all those training or working in the field of childhood cancer in Europe receive communications about relevant courses and congresses and other activities. Although we now communicate regularly with a key contact person in each country and clinical trial group, not all of them have the infrastructure to cascade onwards information in a comprehensive and timely fashion to all interested professionals in their country or group. These difficulties no doubt contributed to the slightly disappointing number of applicants for a SIOPE scholarship to attend this year's ECCO congress from 21st -24th September in Berlin (see inside for details of the excellent paediatric programme). These generous scholarships cover the costs of attending the entire meeting. Hence, I would urge you to sign up at the SIOPE Europe website (www.siope.eu) to receive personal communications from the SIOPE office and ensure you don't miss out on future opportunities.

Finally, I want to congratulate the successful applicants for the annual ECCO-AACR-ASCO 'Methods in Clinical Cancer Research' workshop. They will shortly be working round the clock to develop their clinical trial proposals under the mentorship of experts from around the world, in the conducive environment of the Swiss alpine resort of Flims. The standard of paediatric applicants was very high with seven out of thirteen applicants selected, compared to 80/204 overall. This is one of the premier training opportunities for those who aspire to be the future leaders of investigator-led clinical trials. It is never too early to start working on your trial proposal for next year's Flims workshop - the application deadline is in February 2010. A further training opportunity in all aspects of early phase clinical trials in children is the ITCC training course, to be held on 22nd-24th October in Rome. This year, the ITCC is opening its training course to non-ITCC centre staff. More information is given inside.

So, I feel the future looks bright for SIOPE and the work we have to do together in the coming months and years. I wish you all a relaxing summer break and hope to meet up with many of you during the autumn to hear your views about all our activities.

Kathy Pritchard-Jones
President, SIOPE Europe
office@siope.eu

SIOPE Europe's Community

SIOPE outreach and awareness building throughout Europe

Since February, SIOPE Europe has been engaged in a number of EU-related activities, including attendance at "The Pharmaceutical Forum - Delivering for the Patients" in Brussels, which was well-attended by key EU policymakers, representatives from a number of member states, pharmaceutical companies, health professional organizations and patient advocates. Other events included the Parliament Magazine's 'Action against Cancer' conference, as well as

collaborating with ECCO, the European CanCER Organisation, Eurordis, the European Organisation for Rare Diseases and EPHA, the European Public Health Alliance, amongst others. EPPOSI, the European Platform for Patients' Organisations, Science and Industry, also recently invited SIOPE Europe President, Professor Kathy-Pritchard Jones, to chair a break-out session at their event, 'Workshop on Clinical Trials'.



The EMEA has asked SIOPE to disseminate the need for feedback from the paediatric oncology community as it revises its 2008 priority list of off-patent medicines for children. This is an important opportunity to ensure the 'old', off-patent drugs of most interest to clinical researchers appear in this revised priority list, as this forms the basis for calls for funding proposals under FP7. SIOPE is currently coordinating responses from clinical trials' groups network to ensure the collective needs and priorities of the paediatric oncology community are taken into account.

Spotlight on the Council of the European Union's adoption of the proposed Recommendations on Rare Diseases, 9th June, 2009.

The European Commission's 'Communication on Rare Diseases: Europe's Challenges', aimed to support Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care and research for rare diseases in Europe, i.e.

- **Improve Recognition and Visibility of Rare Diseases**
- **Support Policies on Rare Diseases in the Member States**
- **Develop European cooperation, coordination, and regulation for rare diseases**

The Council, taking into account this Communication and its suggested initiatives, along with a number of other EU developments on rare diseases, agreed on a number of strategies to combat rare diseases. Initiatives include the following:

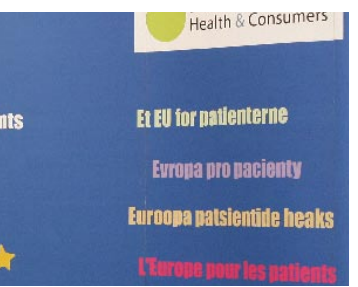
- A common definition of a rare disease is to be used, i.e. a disease affecting no more than 5 per 10,000 persons (this applies to virtually all childhood cancers individually, with ALL being on the borderline).
- Establish a coding and classification system of rare diseases at European level.
- Identify appropriate centres of expertise by the end of 2013 and encourage these centres to participate in 'European reference networks' (ERNs).
- Encourage Member States to combat rare diseases using common strategies.
- Generate greater collaboration with third countries more active in research on rare diseases to promote the sharing of information and expertise.

- Support the use of information and communication technologies such as telecommunication.
- Gather national expertise on rare diseases and support information exchange at the European level.
- Promote activities performed by rare diseases' patient organisations.
- Aim to guarantee the long-term sustainability of infrastructures developed on the information, research and healthcare for rare diseases through appropriate funding.
- Produce an implementation report by the end of 2013 to assess whether the proposed measures are working efficiently.

What is SIOPE doing for rare diseases?

- Marking International Rare Disease Day on 29th February, SIOPE attended an event at the European Commission to celebrate 'Rare Disease Day' and met the Commissioner for Health, Ms. Androula Vassiliou, as well as a debate on rare diseases hosted by MEP and Parliament Rapporteur, Professor Antonios Trakatellis of the European Commission's Communication on Rare Diseases.
- SIOPE was kindly represented by paediatric oncologist, Dr. Gianni Bisogno, of the Hospital of Padova, Italy at the RARECARE meeting, an EU-funded project on rare tumours; one of the key outcomes is to determine an operational definition of "rare cancers" and a list of cancers that meet this definition.
- Other initiatives include inviting our national childhood cancer organisations to contribute to the EU-funded Polka Project, 'Patients' Consensus on Preferred Policy Scenarii for Rare Diseases'.
- SIOPE participated in the Public Consultation by the European Commission on Rare Diseases in 2008; to view our contributions, please [click here](#).

For further information on SIOPE Europe's work on rare diseases, please [click here](#). To access the Council Recommendation in full, please [click here](#).



ECCO
15



See you at the joint
ECCO 15 and 34TH ESMO
Multidisciplinary Congress
BERLIN, 20-24 SEPTEMBER 2009

★★★ CONGRESS
ESMO
34

SIOPE at ECCO 15 - ESMO 34

SIOPE Europe, the European Society for Paediatric Oncology, has been heavily involved in the scientific programme design and coordination of ECCO 15-ESMO 34, specifically in this year's comprehensive Paediatric Oncology Track. The programme includes 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 or 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. This is the ideal forum to obtain a 'state of the art' update on novel anti-cancer therapies and all that is happening in paediatric oncology, on your doorstep in Europe!

Highlights include the Society Session as per below, as well as debates (such as 'This house believes that teenage and young adult units improve outcomes' and 'This house believes that traditional Phase II trials are a waste of time and money') and a scientific session

on selecting a new drug including early phase trials in solid tumours. SIOPE's General Assembly will also take place on Monday evening, 21st September, 2009 at 18.30, immediately after the last paediatric session of the day. For the complete paediatric track, please click here. To view the entire scientific programme and to register, just click here.

SIOPE Europe Society Session

Date: Monday, 21st September, 2009

Time: 11.00 – 13.00

Chaired by eminent paediatric oncologists and SIOPE board members, Professor Kathy Pritchard-Jones and Dr. Ruth Ladenstein, this session will feature the pick of the submitted abstracts with a paediatric oncology theme and will commence with the biennial SIOPE award. For 2009, the award will be presented to Professor Helmut Gadner, Head of the Children's Cancer Research Institute and St. Anna Children's Hospital, for his internationally recognized work on Histiocytosis.

SIOPE Clinical Trials Groups

SIOPE Clinical Trials Information Desk

Improving the infrastructure to ensure clinical trials work efficiently was the central focus point at SIOPE Europe's first Clinical Trials Standardisation Committee meeting in Mechelen, Belgium.

Attended by representatives from I-BFM and SIOPEN as well as SIOPE Europe, we assessed how to proceed in our work to harmonise the contracts as well as to define the short, middle and long-term plans in our overall objective to create a standard SIOPE Phase III and contract template for the European Clinical trial groups.

The meeting was very productive and we are nearing our goal to create a 'one-stop shop' for the latest in clinical trial information and best practice information, adapted of course to the needs of paediatric clinical trials specifically. At the ECCO 15-34th ESMO Congress in September, the Clinical Trials Standardisation Committee will provide further information on the progress made.

For further information about the SIOPE Clinical Trials Support Desk and its Working Groups or to express an interest in joining these activities, please contact Ms. Samira Essiaf at: samira.essiaf@ecco-org.eu.



Pictured l-r Prof. Pritchard-Jones, SIOPE, Dr. Ladenstein, SIOPE and SIOPEN, Dr. Canete, SIOPEN AND Dr. Stanulla, I-BFM.

Committee Reports and Roundups

SIOPE Education and Training



Participants from the ESO-SIOPE Masterclass in Paediatric Oncology, 24th-30th October, 2008, Orta San Giulio, Italy.

Launch of the 2nd ITCC Training Day, October 22nd- 24th October, 2009

Professor Riccardo Riccardi, Rome, Italy

Chairman of the SIOPE Education and Training Committee

After the success of the first workshop last year, ITCC, the European non-profit Consortium, is pleased to announce the 2nd "ITCC Training Days: New Drug Development in Paediatric Oncology" that will be held on October 22-24, 2009 at Università Cattolica del Sacro Cuore in Rome. Taking place over 2 and half days, the course is devoted to early drug development in paediatric patients with cancer. A clinically-oriented educational programme, it is designed for paediatric oncologists who wish to improve their skills in the conduct of early clinical trials.

This course aims to embody the Innovative Therapies for Children with Cancer (ITCC) Consortium objectives and philosophy. The training course was conceived with the objective of translating the knowledge reached in this field, making it accessible to young researchers and physicians. In fact the modules foreseen in the scheduled programme would like to mimic the predicaments that take place on a daily basis when running early phase programmes by articulating them in a pragmatic environment. By participating in last year's ITCC Training Days, we have tested and experienced its potential as a standard training format to be addressed to the personnel working in the field of paediatric oncology and, in particular in centres where new drug development is carried out. The ITCC Educational Task Force Members are namely Huib Caron, Francois Doz, Darren Hargrave, Gilles Vassal and Riccardo Riccardi as Chairman.

The programme offers plenary lectures, small group workshops and case studies focused on new European regulation, conduct and biological endpoints of early clinical trials, imaging and statistics, as well as the role of pharmaceutical companies and ethical issues related to new drug development. The goal of the workshop group sessions is to have an interactive course in which participants play a central role, they present examples of trial designs, debate the content of the speakers' presentations, and of course experience the interaction between clinical staff and parents when planning a new trial.

The course features training and guidance from numerous well-established international experts working in the field of Phase I-II studies in paediatric oncology and it is aimed at doctors and research nurses working in ITCC centres who can avail of a reduced registration fee. However, motivated paediatric oncologists from other institutions, including personnel from pharmaceutical companies, are also invited to apply.

Forty candidates will be selected on the basis of their CV. To avail of this opportunity, please contact the Organising Secretariat (PTS Congress – Maura Stella, maura.stella@ptsroma.it) and request a CV form. Deadline for receipt of applications is October 1st, 2009. You may also contact Ms. Sonia Terella for further information (oncped2@rm.unicatt.it).

Report on the SIOP Europe/ EONS/ECCO Special Project



Collaboration Between Nurses and Doctors in Paediatric Oncology – phase 2

Professor Faith Gibson, London, UK

Project lead

Alison Arnfield, London, UK

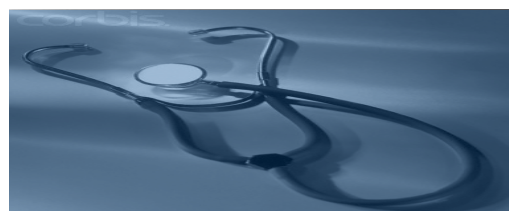
Project co-ordinator

Phase one of the project which lasted for two years ended at the end of 2008 with 11 of the original 15 countries that participated completing their individual projects to improve nurse doctor collaboration in their places of work. A range of projects were undertaken, all using Appreciative Inquiry (AI) as the research methodology to develop their work. Each nurse/doctor team looked at an area of collaborative working that was already successful in their workplace and using AI, asked how it could be enhanced to work better. Their results were impressive with considerable strides in interprofessional understanding and empathy being made as well as further improvements to patient care. Topics included: multi-professional education, several aspects of communication between the professions and with families and a pain-management pathway.

Several participants presented their findings in a free papers session at the SIOP conference in Berlin in September 2008 and were well received. On the basis of the interest shown, the project co-ordinators led by Dr Faith Gibson in the UK, and supported by four other coordinators, two from the UK and two from Italy (who had run a similar project on their homeground in advance of this work), applied for new funding to rollout the project to other countries. We were successful in gaining funding for a further year to continue to work with our present cohort in terms of sustaining the work they had commenced, as well funding for a new cohort who would volunteer to lead a similar project in their own countries: applications were sought. These are currently being evaluated and a meeting in Berlin in September 2009 is planned.

This meeting serves two purposes: it will be the final seminar working with participants from phase 1, and working with participants/materials for phase 2. It seems likely that the format will be different for phase 2 with an emphasis on providing materials for centres to develop their own work locally using the tried and tested methodology we have developed over the last two years.

For further information about this project please contact Edel Fitzgerald at the ECCO office:
Edel.Fitzgerald@ecco-org.eu



Special Features

Children with cancer and the New European Paediatric Medicines Regulation

Gilles Vassal

Chair of the ITCC consortium

Institut Gustave Roussy, Villejuif, France

In December 2000, the European Parliament voted on a resolution addressing the need for better medicines for children in Europe and asked the Commission to prepare a new regulation. Indeed, 50%-75% of medicines used in children have not been studied adequately in the paediatric population to provide appropriate labelling information. In paediatric oncology, within the last 30 years, available anticancer drugs have been prospectively studied in clinical trials run by the academic networks, such as SIOP Europe and IBFM, without the help of the pharmaceutical industry and significant progress has been achieved in the outcome of many paediatric malignancies. However, **children in Europe have been denied access to innovative anticancer therapies while in the meantime many truly innovative medicines have been developed for the treatment of adult cancers.**

Six years later, the European Paediatric Medicines Regulation was published and entered into force on January, 26th, 2007. The goal is to improve the health of children in Europe by i) increasing high-quality research into medicines for children, ii) promoting the development and authorisation of such medicines, iii) improving information on medicines designed for children while avoiding unnecessary studies in children and not delaying the authorisation of medicines for adults. When there is a need for a drug in the paediatric population, the pharmaceutical company must prepare and submit a Paediatric Investigation Plan (PIP). Once approved by the European Medicines Agency (EMA), the PIP should be undertaken to generate paediatric data that will eventually be submitted in the application. If there is no paediatric need for a drug, a waiver to study the compound in children can be issued. The pharmaceutical company obtains a reward - a 6-month extension of the duration of the patent or the supplementary protection certificate. A compound is usually protected for 7 years during which no generic compound can be marketed and the pharmaceutical company can thus enjoy returns on its investments.

The 6-month extension is a substantial reward for most of the drugs since the extended market exclusivity represents significant benefits when the drug is sold throughout Europe.

This European law is going to significantly impact on access to new drugs for children with cancer. By considerably changing the landscape of drug development for children and by obliging pharmaceutical companies to study their drugs in children, the law will provide an opportunity to make further progress in the cure and quality of cure of children with cancer. Indeed, more than 500 new anticancer compounds are in development yearly and several drugs with a new mechanism of action, the so-called targeted therapies, have been already approved for the treatment of highly refractory malignancies in adults such as kidney and liver cancers.

The EMA plays a central role. The EMA Paediatric Committee was set up in July 2007 and is composed of 27 members representing all fields of interest in paediatric medicine, in addition to representatives from all EU member states.

Parent representatives and healthcare professionals are also full members. The Paediatric Committee assesses paediatric investigation plans and provides advice. All information is made public on the EMA website (<http://www.ema.europa.eu/htmls/human/paediatrics/introduction.htm>). Since July 2007, the Paediatric Committee has evaluated nearly 400 Paediatric Investigation Plans and requests for waivers corresponding to more than 600 different indications. About 25% were in the field of paediatric oncology. As of May 2009, 115 PIPs have been approved including 12 in oncology and 68 waivers have been issued including 11 in oncology. This illustrates that oncology is a major area for the Pharmaceutical industry and many compounds are and will be available to develop innovative treatments for children with cancer.

This regulation will impact profoundly on paediatric oncology. Everything is in place to improve early

access to innovative therapies for children with cancer, to introduce them into standard care and to launch the long-term follow-up programmes which will anticipate long-term sequelae and adverse effects. The European Paediatric Medicine Regulation has created a unique situation where all stakeholders, namely the paediatric oncology community, parents, regulatory bodies and pharmaceutical companies, have common and specific interests in developing better pharmaceuticals for children, provided they build strong and win-win partnerships. This represents a unique opportunity to speed up therapeutic research for children with cancer at a time when so many new drugs are under development and translational research is creating hopeful prospects for better cure in children with cancer.

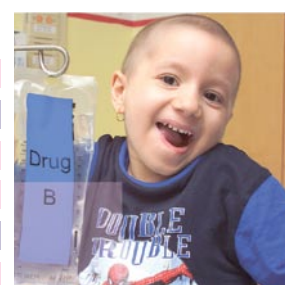
However, there are some risks that need to be anticipated and controlled in order to ensure that children will eventually benefit from the European initiative.

Prioritisation will be a major goal. There are around 2000 new compounds under evaluation each year, including more than 500 anticancer compounds. Current surveys indicate that only 5% of oncology drugs under clinical development will eventually be authorised and marketed (the so-called attrition rate). In addition, the oncology portfolio of pharmaceutical companies is expected to continue to grow significantly, while efforts are being made to improve the success rate of drug development through the early use of biomarkers in order to identify patients who are likely to benefit. In this situation, a key objective for all stakeholders (paediatric oncologists, parents and patients, pharmaceutical companies and regulatory bodies) is the selection of compounds that need to be studied in children. Prioritisation should be based on better knowledge of paediatric tumour biology, on the preclinical evaluation of compounds and on the definition of therapeutic needs in each disease by the paediatric community.

The waiver list (list of cancers occurring in adults but not in children) may be misused. Indeed, a waiver in oncology should not be issued on the histological type of disease, but rather on the mechanism of action. Breast cancer does not occur in children and it is therefore appropriately included among the EMEA list of waivers. This means that the companies should not be asked to develop a drug in breast cancer in children. However, this should not mean that a drug developed in breast cancer will not be tested in paediatric cancers. Obviously the same drugs (e.g. anthracyclins, cyclophosphamide) help to cure both women with breast cancer and children with cancer.

Gold standards for drug development plans should take into account the specificities of the paediatric population. For example, a randomised clinical trial in relapsing patients comparing a new drug versus the best supportive care (i.e. no anticancer treatment) is unacceptable to parents. In addition, there is a need to innovate the design and methodology of a new drug trial in order to speed up development. A focus on better extrapolation from adults to children would certainly be of major interest.

Moreover, it is unlikely that paediatric needs will be covered exclusively by pharma-sponsored trials. The development of anticancer compounds is more complex than in the past. Drugs need to be developed with their biomarkers. Often, only subsets of patients suffering from a frequent cancer benefit from those targeted therapies, based on their tumour biology. In such a complex situation, it is unlikely that pharmaceutical companies will devote substantial resources to paediatric cancers, especially at a time when major changes are taking place in the pharmaceutical industry as a result of the global economic crisis. For most new drugs, pharmaceutical companies will limit their investments to the approved PIPs that are unlikely to cover all the needs in a dynamic way.



Introducing innovative therapies to treat children with cancer should partly remain or be a non-commercial issue that requires funding from public bodies (EU and member states), charities, as well as pharmaceutical companies. Increasing the capacity to run high-quality investigator-driven clinical trials that include translational ancillary studies is of crucial importance.

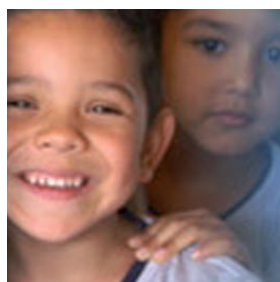
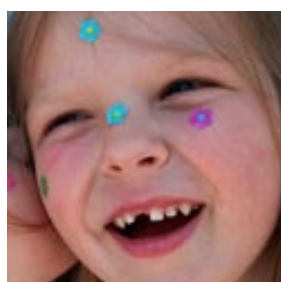
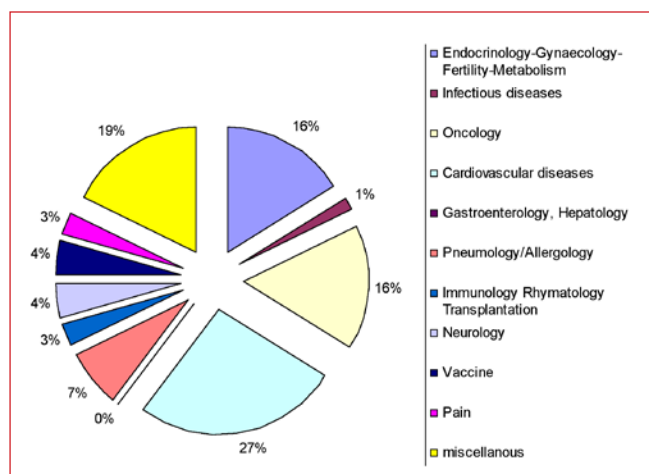
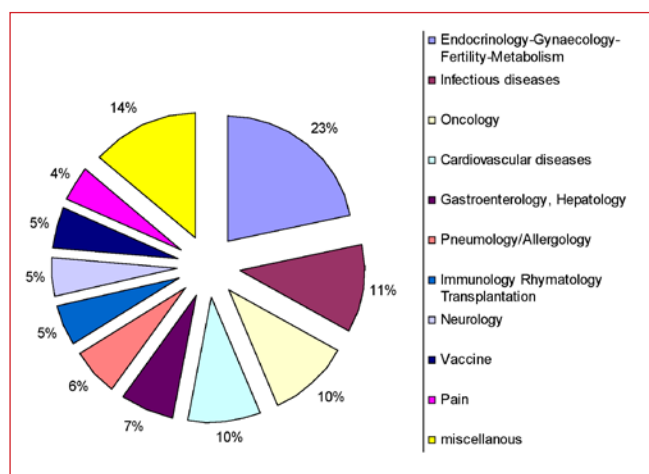
Introduction of safe and effective innovative therapies in the care of children with cancer in Europe will thus require **strengthening the European structure for clinical research in paediatric oncology**. This could be done by creating and funding a network of existing clinical research groups such as the ITCC, the SIOE Europe tumour groups and the IBFM, to facilitate the implementation of such an agenda in all European member states. This will require commitment on the part of pharmaceutical companies to establish public/private partnerships and to devote resources to paediatric oncology. **Funding of basic biology research and preclinical evaluation by both pharmaceutical companies and Europe would be crucial and best invested in a network of the major labs in Europe in the field.** The need for Europe and member states to fund paediatric research is highlighted by the public health issue that cancer represents in children. Charity organisations may be keen to support such a comprehensive programme from basic research to paediatric cancer care that is conducted through a well integrated and coordinated European network.

The European initiative on paediatric medicines will impact on paediatric oncology, even though there are still not enough new compounds under study in children. Strengthening our academic community and developing win – win partnerships with the Pharmaceutical industry will ensure that innovative therapies are introduced into standard care in a timely

fashion according to the needs. This will preserve the values of paediatric oncology on which the clinical research academic networks have been built. If this is achieved, children will continue to benefit, as they already have, from the commitment of the paediatric oncology community in the last 50 years.

For more detailed information, please consider the following article: Will children with cancer benefit from the new European Paediatric Medicines Regulation ? Eur J Cancer 45, 1535-1546, 2009.

Source : <http://www.emea.europa.eu/htms/human/paediatrics/decisions.htm> on June 3rd, 2009





JOLANTA KWASNIEWSKA'S FOUNDATION
Communication Without Barriers



Letter to the SIOP Europe Community Supporting the Symposium on 'Standards in Paediatric Oncology, 14th October, Warsaw, Poland

Since its foundation twelve years ago, Jolanta Kwasniewska's Foundation, 'Communication without Barriers' has prepared programmes that focus on changing and improving systems of care over children with cancer and their families in Poland. The Foundation has already funded many oncological and hematological wards and helped in opening new transplant wards, renovating and maintaining hospital rooms. Furthermore, the Foundation financed the building of the new children's clinic of oncology, especially designed for children's needs, decorated with joyful and colourful paintings on the walls.

We support children's rehabilitation and every year we organize camps for children with cancer so as to divert children's attention from illness and pain by opening a window to a normal world. We are in touch and cooperate with doctors and other organisations in Poland and from all over the world that are established by the parents of children with cancer. We gathered information on the difficulties that children with cancer from different sections of society face in their fight against the illness. This experience obliges us to make an effort to give children in the EU an equal opportunity to overcome cancer.

We are working on implementing a common system of care for children with cancer in the EU, which puts together all disciplines so as to conquer cancer. We realise that many European countries vary greatly in the standards of care of patients, but as we discovered from the survey conducted by Professor Jerzy Kowalczyk, National Consultant in Children's Haematology and Oncology in Poland and SIOPE Board Member, it is vital to improve the situation and regulate the diagnostic and treatment process in all European countries in order to give an equal opportunity to all young sufferers of cancer.

We are aware of the fact that the current economic crisis has harmed many countries and forced them to reassess their priorities and critical goals. Most of us will have to forego our dreams but children with cancer cannot give up and stop dreaming about recovering in the midst of the global economic downturn. Suffering is not shared equally and justly by everyone. Moreover, it is not a punishment but it is a part of being human. We should let children grow up healthy and happy. Let's make a concerted effort to work together towards the important goals. A joint approach to a common goal will undoubtedly prove to be more fruitful.

In order to ensure that a child can enjoy a healthy life, progress needs to accelerate across all medical disciplines. With this in mind, we are delighted to present the standards of care of children with cancer on the Symposium which will take place on 14th October in Warsaw. We hope that you will show your enthusiasm and understanding for those who work on behalf of children with cancer; those people whose hearts and souls are dedicated to the weakest and of whom your support greatly depends.

With best regards,

Jolanta Kwasniewska
Founder and President of the "Communication Without Barriers" Foundation
Former First Lady of Poland

Dates to bookmark

A Single CTA in Multinational Clinical Trials
- Dream or Option? Organized by the European
Forum for Good Clinical Practice (EFGCP)
7 July, 2009 in Brussels, Belgium
For more information, please [CLICK HERE](#)

The first SCOPE summer school, 'Obesity
management for medical professionals'
2-5 August, 2009 in Cambridge, UK
To find out more, please [CLICK HERE](#).

Joint 15th Congress of the European CanCer
Organisation and 34th Congress of the European
Society for Medical Oncology
20-24 September 2009 in Berlin, Germany
For further information, please [CLICK HERE](#).

PTCOG 48 - the 48th Particle Therapy
Co-Operative Group Meeting
28th September 28th – 3rd October 3rd
Heidelberg, Germany
To access the programme, please [CLICK HERE](#).

41st Congress of the International Society of
Paediatric Oncology (SIOP)
5-9 October, 2009 in Sao Paulo, Brazil
For further information, please [CLICK HERE](#)

'Symposium on Standards in Paediatric
Oncology' organized by SIOPE Board Member
Prof. Jerzy Kowalczyk and the 'Communication
without Barriers' Foundation
14th October, 2009 in Warsaw, Poland
For more information, please contact Ms. Magdalena
Gwizdak or the SIOPE office (office<at>siope.eu (please replace <at> with @)).

Innovative Therapies for Children with Cancer
(ITCC) European Consortium Training Days 2009:
New Drug Development in Paediatric Oncology
22-24 October, 2009 in Rome, Italy
For more information, please contact Maura Stella
(maura.stella<at>ptsroma.it (please replace @ with @)).

EPPOSI 10th Workshop on Partnering for Rare
Diseases Therapy Development
26-27 October, 2009 in Brussels, Belgium
For further information, please [CLICK HERE](#).

The European Symposium on Late Complications
after Childhood Cancer 2009 (ESLCCC09)
29-30 October in Edinburgh, Scotland
For further information, please [CLICK HERE](#).

The Biennial Esphi Congress: New Trends in
Paediatric Haematology and Immunology
40th Anniversary of the European Society for
Paediatric Haematology and Immunology
November 5-8, 2009 in Lecce, Italy
For further information, please [CLICK HERE](#)

7TH International Congress on the Biology of
Renal Tumours of Childhood
1-3 March, 2010 in Banff, Canada
For further information, please contact kathy.pritchard-
jones<at>icr.uk (please replace <at>with @)

International Paediatric Oncology and
Haematology Update Meeting (IPHOUM)
April 29-30, 2010 in Edinburgh, Scotland
For further information, please contact the IPHOUM
office (iphoum<at>indexcommunications.com (please
replace <at> with @)).

Advances in Neuroblastoma Research (ANR 2010)
21-24 June, 2010 in Stockholm, Sweden
(please note slight change in date to that on website as
per 04/06/09)
For further information, please [CLICK HERE](#).

Why become a Subscriber of SIOPE ?

SIOPE, the European Society of Paediatric Oncology, is the only pan-European organisation actively engaged in promoting awareness of childhood cancers. Join an active network of oncologists, radiotherapists, surgeons, parents organisations and scientists dedicated to optimising the care of children and adolescents with cancer.

Use our connections

You will have exclusive access to our database including the European Clinical Trials Groups and National Childhood Cancer Organisations.

Be represented

You will be represented at EU conferences and seminars. SIOPE canvasses its subscribers to ensure a coordinated response in order to voice your opinion to key policymakers.

Access the European Journal of Cancer

With 18 issues annually, you can benefit from online access to the international oncology journal that publishes original research, editorial comments and review articles on experimental oncology, clinical oncology (medical, paediatric, radiation, surgical), and on cancer epidemiology and prevention.

Influence

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Be regularly informed by email

You will receive regularly updates by email on SIOPE activities, EU decision-making, job opportunities, training seminars and relevant conferences and events.

Receive our e- newsletter

You will receive three newsletters per year which gives a wealth of information on upcoming meetings, educational courses, proceedings at EU level, SIOPE activities and information on how to get involved.

Gain training

SIOPE is dedicated to promoting information-sharing and training. Educational projects include the organisation of workshops and seminars related specifically to paediatric oncology. SIOPE works on training projects with the European School of Oncology (ESO), Innovative Therapies for Children with Cancer Consortium (ITCC) and the European Oncology Nursing Society (EONS), for example.

Share best practice and experience

As a subscriber, you are part of a large, interdisciplinary network that allows you to share best practices and network across Europe.

Be actively involved

Contribute to SIOPE by pinpointing the issues and helping us achieve results at EU level.

You can receive reductions to conferences and seminars such as the ECCO-ESMO biennial conference as well as the opportunity to apply for travel grants.

Be part of a global network

SIOPE is part of the worldwide organisation, SIOP, the International Society of Paediatric Oncology, with over 800 members situated in Europe.

To join an active network dedicated to improving the care of children with cancer, please email office@siope.eu or visit our website, www.siope.eu.