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24-26 May 2013, Basel, Switzerland

Recipes for Sustainable Healthcare Conference

28 May 2013, Brussels, Belgium

Integrated Analysis of Tumour Genomics Data with R2

28 May 2013, Amsterdam, The Netherlands

Child Health Research, the Key to a Healthier European Society

30-31 May 2013, Dublin, Ireland

Paediatric Cancer Research at the INTERFACE

06-09 June 2013, Vienna, Austria

6th International Conference on Children's Bone Health

22-25 June 2013, Rotterdam Netherlands

FLIMS 15: ECCO-AACR-EORTC-ESMO Workshop on Methods in Clinical Cancer Research

22-28 June 2013, Waldhaus Flims Switzerland

17th ECCO - 38th ESMO - 32nd ESTRO European Cancer Congress

27 September-1 October 2013, Amsterdam, The Netherlands

SIOPE Congress 2013

25-28 September 2013, Hong Kong, China

Children without Cancer

Run/Walk, 2nd edition

September 29, 2013, Domaine National de Saint-Cloud, France

BDA congress "Improving oncology drugs development for children and adolescents"

18-19 November 2013, Paris France

Message from the President and the Office

Our President, Prof. Gilles Vassal, provides a short overview on the recent achievements of SIOPE, the 'hot topics' we are currently working on, and the new challenges our Society decided to embrace, in order to further progress in the improvement of research and cure of children and adolescents with cancer.



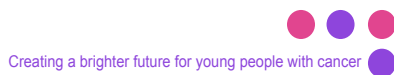
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SIOPE Europe's Community

Promoting better policies for children with cancer

The Clinical Trials Regulation: is it improving research for children in Europe?

International Childhood Cancer Awareness Day



Multinational clinical trials are vital to ensure optimal treatment for children with cancer, but their conduct was seriously impeded by the Clinical Trials Directive. SIOPE International Childhood Cancer Day event 2013 at the European Parliament focused on this, as today there is a potential for these limitations to be reversed by the Commission's proposal for a Clinical Trials Regulation (CTR).



[READ MORE](#)

The Clinical Trials Regulation: SIOPE's position

SIOPE calls for:

- 1. FAIR and proportionate risk categorisation of childhood cancer trials** where the use of medicinal products is often outside the terms of the marketing authorisation (off-label use), but based on high-level expertise, standard practice and decades of success
- 2. FAIR insurance** for academic trials treating children with rare diseases **secured through 'national indemnity schemes'**
- 3. FAIR and proportionate transparency measures**, with provisions for reasonable and secure reporting that protects young cancer patients and their personal data



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EU Project Updates

Our community is looking forward to a new EU project

At the beginning of this year SIOPE joined forces once again with other partners from the paediatric oncology community by submitting a new project proposal to the European Commission. This ambitious project will establish a network of paediatric oncology reference centres, thereby improving access to high-level diagnostic and expertise across borders for young people with cancer



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■ Latest News from EPAAC

The European Standards of Care for Children with Cancer : health inequalities can be fought

SIOPE will contact experts from every European Member State in order to carry out a comprehensive analysis of treatment and care received by young cancer patients. This survey will evaluate the implementation of the 'European Standards of Care for Children with Cancer' and will be essential to advocate for stronger efforts to be made to address health inequalities in Europe.



■ Latest News from ENCCA



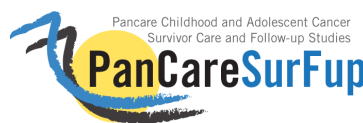
The Lancet Oncology series on paediatric oncology: an essential contribution to the global discourse on childhood cancer

Last February *The Lancet Oncology* journal launched a series dedicated to 'improving cancer care for children and young people'. The publication of these outstanding articles, suggesting solutions for the specific challenges of cancer in children and adolescents, is an important achievement, made possible thanks to the commitment of several SIOPE partners.



The Survivorship Passport: an innovative solution for follow-up

The partnership between professionals, survivors and IT experts to create a "Survivorship Passport" is an outstanding achievement of the ENCCA project. 80% of young people with cancer are now surviving, but it is essential to empower health systems in order to deal with this reality by informing everyone involved on possible late effects of cancer treatment.



■ Latest News from PanCareSurFup

Meeting of PanCareSurFup, Genoa, Italy

SIOPE, as a partner organisation in the EU-funded FP7 project PanCareSurFup joined experts in survivorship issues in the historical city of Genoa (Italy) in April. The aim of the meeting, which was held prior to the PanCare conference, was to discuss the advancements made to date. Steady progress is being made, despite the challenges in this ambitious project.



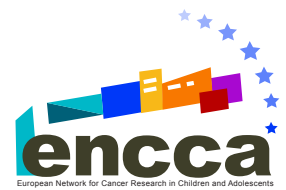
The Race of Brave Bikers: 2013 edition

After a successful launch last year, the second edition of the Race of Brave Bikers took place on Sunday, 28 April. This is a unique race hosted within the traditional Granfondo Fi'zi:k competition, with around 40 brave young people from all over Europe competing in a 10km itinerary along the roads and surrounding countryside of beautiful Marostica (Vicenza, Italy).



Our Community Profiled

Promoting better policies for children with cancer



This month's interview with our multidisciplinary community is with Ms. Sue Morgan, ENCCA partner and paediatric oncology nurse at Leeds General Infirmary. Her deep commitment to helping teenagers and young adults with cancer (TYA) has been appointed Member of the Most Excellent Order of the British Empire (MBE), the highest British honorary decoration.



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Special Features

Join SIOPE and give paediatric oncology a stronger voice in Europe!

SIOPE Europe, the European Society of Paediatric Oncology (SIOPE) is the only pan-European organisation aiming to ensure the best possible care and outcome for all children and young people with cancer in Europe. Today SIOPE needs to have direct access to European paediatric oncology professionals, who are the foundation and driving force of our society.



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Welcome to the new SIOPE Board Member Pamela Kearns

The SIOPE Board and office warmly welcomes on the Board Prof. Pamela Kearns from the Cancer Research UK Clinical Trials Unit of the University of Birmingham. She is Vice-Chair of the ECRC Steering Committee, and widely contributed in shaping SIOPE's position on the EU Clinical Trials Regulation



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May, the 'Month of the Brain'

May is the 'Month of the Brain' in the European Union and, this year, the EU invested up to €150 million for research in neuroscience and human cognition. Among brain diseases, brain tumours are enormously affecting children: we take therefore this opportunity to highlight the efforts made in raising awareness and empowering paediatric brain tumour patients.



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SIOPE Education and Training



Upcoming courses and training

The 15th joint ECCO-AACR-EORTC-ESMO 'Flims' workshop will be held in Flims, Switzerland, from 22 to 28 June, 2013. Also this year SIOPE will support the participation of 2 young and enthusiast paediatric oncologists with a grant, allowing them to learn the essentials of clinical trial design through this unique course. In our next edition, you can read about her experience of this unique and intensive workshop.



[READ MORE](#)

ENTYAC European Course on teenagers and young adults with cancer

The brand new international course “Teenagers and Young Adults with Cancer” organised by Institut Curie, in partnership with ENCCA, took place last 17-19 April in Paris. Among the highlights of the course there were the multidisciplinary perspectives and the exchange of information between clinical and biological approaches. Dr. Alvaro Lassaletta informs SIOPE about the discussions at this unique meeting.



Institut Curie Paris
Training Unit – International Courses
Teenagers And Young Adults With Cancer
1st ENTYAC European Course
April 17 – 19, 2013

SPEAKERS
N. Bellver - Paris, France
L. Di Agostino - Villejuif, France
S. Cozzitelli - London, UK
U. Diekmann - Muenster, Germany
C. Dubois - Paris, France
J.C. Duron - Paris, France
A. Ferraro - Milan, Italy
T. Gnan - Leeds, UK
D. Hedder - Southampton, UK
A. Hoger - Madrid, Spain
L. Lantini - Liverpool, UK
R. Lawless - Glasgow - Mid-Ed, Scotland
S. Margolin - Leeds, UK

ORGANISERS
V. Lacombe - Paris, France
F. Duc - Paris, France
S. Mangan - Leeds, UK
P. Fioravanti - Rome, Italy
D. Sessa - Leeds, UK
L. Dragliras - Villejuif, France

SCIENTIFIC COMMITTEE
A. Bjerrth-Elvik, Sweden
P. Lassaletta, Asturias - Madrid, Spain
S. Munoz-Barragan, Valencia, Spain
P. Pignatelli - Paris, France

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EUROPEAN Cancer Congress 2013

The Paediatric Track, Regular Registration rate and Late breaking abstract submission

Be part of the multidisciplinary 17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress, the premier cancer congress in Europe, and don't miss the outstanding the Scientific Symposia of the Paediatric Track led by SIOPE. The SIOPE General Assembly and several not-to-be-missed SIOPE events will also take place in Amsterdam: see you there!



17th ECCO - 38th ESMO - 32nd ESTRO
European Cancer Congress
Reinforcing multidisciplinary
AMSTERDAM, 27 SEPTEMBER - 1 OCTOBER 2013

In partnership:
EACR
esso 33
SOP3

[READ MORE](#)

Paediatric Cancer Research at the INTERFACE

The ‘Paediatric Cancer Research at the INTERFACE’ symposium celebrating the 25th anniversary of the Children’s Cancer Research Institute, and co-organised with the ENCCA and ASSET projects, will take place on 7-8 June, 2013. The aim of this meeting is to update and discuss cutting edge biomedical research areas of relevance to future paediatric oncology.



Paediatric Cancer Research at the
INTERFACE
Symposium and 25th Anniversary

[READ MORE](#)

Parents & Patients' news

ICCCPO Europe meeting in Basel

The 4th ICCCPO Meeting of European member groups will be held from 24 to 26 May in Basel (Switzerland), hosted by the Basel Childhood Cancer Foundation and the Childhood Cancer Organization Switzerland. The meeting will focus on updates from the current EU-funded projects (ENCCA, PanCareSurFup, EPOC, IntReALL), an interactive session with SIOPE President G. Vassal and an educational workshop on clinical trials for parents and survivors representatives.



We care, we share
ICCCPO

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Treasurer's Corner

A new communication from the SIOPE Treasurer, Prof. Martin Schrappe from Kiel University Medical Center (Germany) with short updates on the status of the new SIOPE membership and on our Society in general.



[READ MORE](#)



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



Gilles Vassal, MD, PhD

Prof. of Oncology
Head of Clinical Research Division
SIOPE President and ENCCA Activity Coordinator
Institut Gustave Roussy, Villejuif, France



Samira Essiaf

SIOPE Secretary-General and ECCO Scientific Programme Manager, Belgium



Edel Fitzgerald

SIOPE Membership and Public Affairs Coordinator and ECCO Public Affairs Coordinator



Giulia Petrarulo

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Contact the SIOPE Office



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



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Message from the President and the Office

Our President, Prof. Gilles Vassal, provides a short overview on the recent achievements of SIOPE and the 'hot topics' we are currently working on in order to further progress in the improvement of research and cure of children and adolescents with cancer.

AMSTERDAM.

This is the wonderful city where the next ECCO meeting will take place from Friday the 27th of September until Tuesday October 1st.

As you know, this is also our biannual meeting of SIOPE Europe. A nice and exciting paediatric track has been prepared updating the hottest topics in paediatric oncology and will start on Saturday the 28th. Results from our ENCCA network will be shared, and we will discuss the project on Long Term Sustainability of Paediatric Oncology in Europe. In addition, excellent presentations in adult oncology and basic science will update the most recent knowledge and innovative treatments in the field of cancer.



Indeed, this meeting is a unique opportunity since one of our major goals in the next 10 years is to improve care and research in teenagers and young adult, through collaborative initiatives with our colleagues from adult oncology.

Take some free time to visit the extraordinary Rijks Museum which has just re-opened after a long restructuration: amazing!

Come to Amsterdam! Send your young colleagues in training! Join us!

This is where the future of paediatric oncology in Europe will continue to be built.

The Clinical Trials Regulation: is it improving research for children in Europe?

International Childhood Cancer Awareness Day, 20 February 2013

Multinational clinical trials are vital to ensure optimal treatment for children with cancer, but their conduct was seriously impeded by the [Clinical Trials Directive](#). Once again, SIOPE organised an event in February to mark International Childhood Cancer Day at the European Parliament dedicated to this topic. Parliamentary Rapporteur of the proposed EU Clinical Trials Regulation, Glenis Willmott, kindly hosted this timely event.



Multinational clinical trials are vital to ensure optimal treatment for children and adolescents diagnosed with cancer, but their conduct was seriously impeded by the [EU Clinical Trials Directive](#). Today, there is a potential for these limitations to be reversed by the European Commission's proposal for a [Clinical Trials Regulation](#) (CTR), currently debated by national ministries and Members of the European Parliament (MEPs). Therefore this year's meeting organised by SIOPE to mark the annual International Childhood Cancer (15 February each year) was well-timed.

Hosted by MEP Glenis Willmott, Rapporteur of the EU CTR for the European Parliament, the event, **"The EU Clinical Trials Regulation: Improving research for children and adolescents in Europe?"** resulted in a lively and forward-looking discussion on the Regulation with key decision-makers and experts from several paediatric disease areas.

MEP **Glenis Willmott** and [SIOPE](#) President **Gilles Vassal** introduced the theme. Clinical trials (CTs) for children and adolescents in Europe are mainly conducted by academic institutions and funded by public money, as the pharmaceutical industry have no economic benefits in investing in this type of research. The paediatric oncology community who helps patients in this field focuses on treatment optimisation, using well-established drugs aiming to make standard care safer and more effective and to improve the survivors' quality-of-life by integrating research into high-quality care. Therefore, SIOPE asks for a fair and proportionate new Regulation for childhood cancer trials that reflects the bureaucratic burden currently placed upon academics due to the CTD. Moreover, SIOPE supports the proposal by the European Commission to create an insurance scheme for academic CTs secured through 'national indemnity schemes' ([here](#) is the SIOPE list of amendments to the CTR and its position paper) as claims, particularly in paediatric oncology are very low yet rates set by insurance companies are very high.

Prof. Helms, who represented the European Network of Paediatric Research at the European Medicines Agency (former Chair of Enpr EMA), pointed out the lack of consideration of the paediatric population in the text of the CTR. In particular, he focused on the need to increase the availability of medicinal products authorised for use in the paediatric population, to further consider off-label therapy, to have more risk-adapted rules and to include the contribution of parents and children in clinical trials.



Explaining her personal experience of having a child who died due to lack of an available treatment, **Patricia Blanc**, parent and founder of the charity '[Imagine for Margo](#)', emphasised the importance of developing new and innovative treatments for children with cancer, by reducing red tape while ensuring safety for patients. She showed some key figures:



1 child in 440 has cancer before the age of 15
 The numbers are increasing by +1.5 % each year
 15,000 children and young adults are diagnosed each year in Europe
 3 700 will lose their battle
 10 kids a day are dying of cancer in Europe

Representing the European Commission, **Stefan Führung** introduced key elements of the proposal for a CTR, explaining the Commission's strategy to support investigator-driven trials in Europe through the new legislation, taking into account the limited budgets of academics already overburdened with administrative responsibilities.



Dr. **Ingrid Klingmann** from the European Forum for Good Clinical Practice (EFGCP) and **Kathy Oliver**, patient advocate and Co-Director of the International Brain Tumour Alliance, chaired the two sessions of the event.

The first session focused on the **low-intervention categorisation of clinical trials**. Prof. **Pamela Kearns** clearly defined what a “low-intervention clinical trial” is: a trial where all drugs are licensed and used according to standard practice, and where no more than the minimal risk is posed to the safety of the subjects. The majority of paediatric CTs comply with this definition, and should be categorised as such, and the CTR applies a shorter timeline for low-intervention CTs authorisation, with reduced labelling requirement for investigational medicinal products, proportionate safety reporting and no insurance requirement. More clarity is nevertheless required, as there is still space for an ambiguous interpretation of what a low-intervention trial is.

Prof. **Kris de Boeck** presented the case of cystic fibrosis (CF), a rare paediatric disease which implies a high treatment burden on patients. In the case of this disease low-intervention ‘comparative effectiveness trials’ (to identify the best drug combination) are needed. However the complex labelling and safety reporting of the CTR impedes these trials to start smoothly.



Among the other issues related to enhancing paediatric research in Europe, the topic of **national indemnity schemes** is also very important. Prof. **Ruth Ladenstein**, ENCCA Project Coordinator, clearly illustrated the current situation, after the [2001 Directive](#) (CTD) introduced an obligatory insurance which substantially increased the costs and the administrative burden of conducting a CT:

Consequences of the [EU Clinical Trials Directive \(2001/20/EC\)](#):

25% decrease of CT applications

90% increase in the delay for launching a CT

However CTs do not always pose an additional risk to subjects compared to treatment in normal clinical practice, and damage compensation for low-interventional CTs should not be needed. The CTR proposal obliges EU Member States to set up a national indemnification mechanism (NIM) for compensating damage: Prof. Ladenstein welcomed the NIM, which has a potential of harmonisation across Europe, encourages fairer costs and secures future academic clinical research.

Dr. **Nicola Ruperto** from [PRINTO](#) illustrated the situation of paediatric rheumatic diseases research: CTs are also not-for-profit in this disease area and some drugs are not approved because they are used off-patent in mainstream treatment. Therefore, Dr. Ruperto called for a stronger recognition of the role of academia research and an insurance waiver on standard treatment studies.

At the end of the meeting, all participants were greatly impressed by the words of **Anneke Gommers**, who has suffered from a very young age with cystic fibrosis. Now 26 years old, she presented her personal story. Her enthusiasm in participating in clinical trials in order to improve the treatment regime, health conditions and quality-of-life of other patients reminded everyone why all efforts need to be made to enhance optimum paediatric research.

Building on this very engaging and insightful meeting, [SIOPE](#) will continue in its concerted efforts to ensure the needs of the European paediatric oncology community are heard.

More information:

All presentations and pictures from this event, as well as SIOPE's [position paper](#) and proposed [amendments](#) to the CTR are now online and downloadable [here](#).

Our community is looking forward to a new EU project

At the beginning of this year SIOPE joined forces - with other partners from the paediatric oncology community to submit a new project proposal to the European Commission. This ambitious project will establish a network of paediatric oncology reference centres, thereby improving access to high-level diagnostic and expertise across borders for young people with cancer.



At the beginning of 2013, SIOPE was informed about a call issued by the European Commission's DG Sanco (Health and Consumers' policies) for a project to establish a network of paediatric oncology reference centres. The call was inspired by the successful '**European Standards of Care for Children with Cancer**' initiative, initiated by SIOPE and part of the [EPAAC](#) project

The background to this call stems from the European Commission's aim to efficiently implement the [Cross Border Healthcare Directive](#)), piloting networks of cooperation between paediatric oncology centres.

The Commission has received our proposal, known as '**ExPO-r-Net**' or European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment and is currently reviewing it.

What is **ExPO-r-Net**?

The new project proposal of the SIOPE community is called '**ExPO-r-Net**' or European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment SIOPE is the Work Package leader for Dissemination and the whole project will be coordinated by the Austrian research institute [CCRI](#). Many institutions from the paediatric oncology community decided to take advantage of this opportunity and apply together as partners (18 associate partners and 42 collaborating partners). There will be a particular focus on very rare tumour types and the project will be closely connected with [ENCCA](#), [PanCareSurFup](#), [IntReALL](#) and [EPAAC](#).

Taking into account the current inequalities in childhood cancer survival and healthcare capabilities in different European Member States, as well as the burden of families seeking cross-border healthcare (i.e. leaving their cultural and language environment and entering



social isolation for treatments that may extend over many months), EXPO-r-NeT aims to improve the access to high-level diagnostic and expertise for young people with cancer. The project will create European Reference Networks (ERNs) in paediatric oncology by linking pre-existing paediatric oncology centres of excellence. Project partners will identify the target groups who have conditions that require a particular concentration of resources or expertise (e.g. in certain cancer conditions where the expertise is rare and case volume low) and then set the conditions to allow healthcare being provided to young people with cancer in a Member State other than the Member State of affiliation. Finally, they will provide - whenever possible - ICT tools and e-Health networks to facilitate the movement of information and knowledge rather than patients.

High-quality, accessible and cost-effective healthcare for childhood cancer will be achieved by strengthening the integration of pre-existing knowledge and expertise, and fostering stronger cooperation between patients, professionals and healthcare authorities. Although the selection process is still going on, the ambition and scope of this project could change the reality of many families of children with cancer in Europe.

More information:

[Executive Agency for Health and Consumers](#)

The European Standards of Care for Children with Cancer: addressing health inequalities

SIOPE will contact experts from every European Member State in order to carry out a comprehensive analysis of treatment and care received by young cancer patients. This survey will evaluate the implementation of the 'European Standards of Care for Children with Cancer' and will be essential to advocate for stronger efforts to be made to address health inequalities in Europe.

While the demographics are changing in Europe and people are living longer, health inequalities are at the same time increasing between different countries in health research, treatment and care. If cancer is today the leading cause of premature death in Europe, the divide between Western and Eastern countries in the quality of its treatment has been re-affirmed in 2012 (see [report](#)), and it is also valid in the paediatric oncology area. After having published the [Cross-border Directive](#) and several [communications](#) on this topic, the Commission is today preparing new actions to help national authorities addressing health inequalities and improving the current situation.

In this framework, it is essential to facilitate the exchange of information and compare healthcare standards in Europe for the treatment and care of children and adolescents with cancer. SIOPE believes that every child diagnosed with cancer should have the same access to the best quality treatments, independently of where they live. There is a need to improve and harmonise the current European standards of care in paediatric oncology, and this is why SIOPE, right from the beginning, has been keen to address this topic through the **'European Standards of Care for Children with Cancer'** project.



European Standards
of Care for Children with Cancer

Warsaw, 14 October 2009

1

The **'European Standards of Care for Children with Cancer'** outlines the most important basic requirements that centres specialised in the treatment of children with cancer in the EU should have. Initiated by ICCCPO and led by Professor J. Kowalczyk together with SIOPE, the document was agreed by several stakeholders (patient/parent groups, paediatric oncologists, psycho-social care workers, physiotherapists and legal experts), including the Polish Ministry of Health and the Polish "Communication without Barriers Foundation".

The Standards stem from a survey carried out by SIOPE in 2008 to assess the level of care, and the data collected on the existing national regulations and specific standards for the paediatric oncology/haematology wards provided the necessary information to draft the Standards of Care

Today this project has been incorporated in the [European Partnership for Action Against Cancer](#) (EPAAC), an initiative which brings together stakeholders from the entire cancer continuum (from

national health ministries to patient groups and industry) to address inequalities in cancer, research, treatment and care in Europe.

As part of SIOPE's deliverables for EPAAC, this year we need to launch a **new Europe-wide survey**. SIOPE will shortly be contacting the Chairs of Europe's National Paediatric Haematology and Oncology Societies (NaPHOS) to acquire their input and gather the required information on facilities available in their country, in order to carry out a country-by-country analysis of treatment and care received by young cancer patients. This detailed survey is essential in order to evaluate the implementation of the Standards across Europe and assess the current national situation. Thanks to the survey, we will be able to We hope by doing so that we can improve the quality-of-care of children and adolescents with cancer. All European countries will contribute and provide accurate expert answers to the survey, giving a clear picture of the situation and assessing the relevant organisational aspects, issues and hurdles of the national paediatric oncology centres and wards. The results of this European-wide assessment can greatly support SIOPE in its advocacy work to policymakers to address inequalities and help patients: only by having information on the relevant organisational aspects, issues and hurdles of the national paediatric oncology centres and wards in each European country can we successfully provide a true analysis to EU and national decision-makers.



More information

[SIOPE website](#)

The Lancet Oncology Series on paediatric oncology: an essential contribution to the global discourse on childhood cancer

Last February The Lancet Oncology journal launched a Series dedicated to 'improving cancer care for children and young people'. The publication of these outstanding articles, suggesting solutions for the specific challenges of cancer in children and adolescents, is an important achievement, made possible thanks to the commitment of several SIOPE partners.

Thanks to a global faculty of 34 experts from 19 countries, whose combined experience covers everything related to care, research, and education, these articles successfully conveyed the concerns of the paediatric oncology community to a broad audience of professionals and policy-makers.



Published in the Lancet Oncology on 20 February 2013, the same day of **International Childhood Cancer Awareness Day** organised by SIOPE at the European Parliament, many of the issued addressed in the journal prepared the discussion that took place on that occasion on the scope and issues at stake inherent to the CTR. In particular, the Series' **first article** '[Sustaining innovation and improvement in the treatment of childhood cancer: lessons from high-income countries](#)' emphasised SIOPE's position on the CTR by extensively explaining the current hurdles childhood cancer experts face, with a special focus on those related to the unaffordable and complex regulatory bureaucracy for investigator-led clinical trials. Moreover, this comprehensive publication promoted the [ENCCA project](#) and the [European Standards of Care for Children with Cancer](#) as tools for improving paediatric oncology research and care in Europe.

In the same issue of *The Lancet Oncology*, there is also an [introduction](#) on the global discourse on paediatric oncology, along with a [paper](#) focused on the need for novel development pathways for new paediatric oncology drugs (led by SIOPE President Gilles Vassal). There is also an [article](#) on the needs of low and middle income countries (led by Ian Magrath) and a [final paper](#) on policy issues (led by Richard Sullivan and Kathy Pritchard-Jones).

The realisation of this influential publication project was the result of successful engagement with SIOPE and the impressive work of many ENCCA and SIOPE partners (including Gilles Vassal, Edel Fitzgerald, Kathy Pritchard-Jones and the ENCCA Project Management Team).



More information:

[The Lancet Oncology Series' press release](#)

[The Lancet Oncology website](#)

The Survivorship Passport: an innovative solution for follow-up

The partnership between professionals, survivors and IT experts to create a “Survivorship Passport” is an outstanding achievement of the ENCCA project. 80% of young people with cancer are now surviving, but it is essential that health systems are able to deal with this reality by informing everyone involved on possible late effects of cancer treatment.

Treatments for children and adolescents with cancer are very complex: they may involve different types of treatment (e.g. surgery, chemotherapy, radiotherapy) and may lead to late effects and risks that will strongly impact the quality-of-life of the young patients once they reach adulthood. The current lack of information on many patients’ medical history becomes particularly critical as children become adults or as they move to another country.



The Survivorship Passport can provide a solution to this problematic situation. This innovative tool provides relevant information on the medical history of patients who ended a cancer therapy, making survivors, GPs and healthcare professionals aware of the potential risks or late effects stemming from the previous disease and treatment received. Developed by the Italian Interuniversity Consortium Cineca, in collaboration with survivors representatives (ICCCPO), and clinicians coordinated by the Gaslini Institute the passport is one of the main deliverables of the EU-funded project [ENCCA](#), and it has been designed in close collaboration with the [PanCareSurFup](#) project.

The information on the document is written in a simple and understandable way, and – on the basis of the personal data collected – the passport includes recommendations for a tailored follow-up based on up-to-date clinical guidelines (developed with [PanCareSurFup](#)) to facilitate the prevention, early detection and treatment of potential late effects or relapses. The passport is generated through a secured web-based platform which is patient oriented, accessible in multiple languages by all type of users (patients, clinicians, etc.) and can be integrated with national/hospital databases and clinical trials databases.

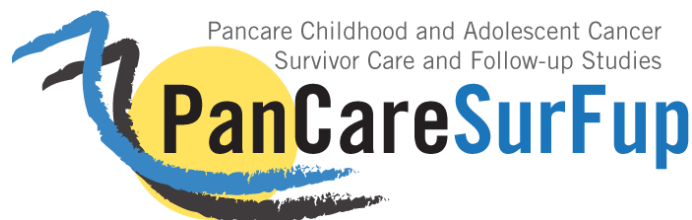
The Survivorship Passport aims to harmonise the follow up on former cancer patients across Europe, by promoting homogeneous criteria and evidence-based guidelines from clinical practice for prevention, early detection and treatment of physical and psychosocial late adverse effects. In the age of personalised medicine, this simple and accessible tool can enhance an age-appropriate healthcare and address individual patient issues specific of paediatric cancer survivors, possibly leading to important breakthroughs in the monitoring and cure of childhood cancer survivors on the long-term.

More information:

[SIOPE website](#)

Meeting of PanCareSurFup, Genoa, Italy

SIOPE, as a partner organisation in the EU-funded FP7 project [PanCareSurFup](#) joined experts in survivorship issues in the historical city of Genoa, Italy, in April. The aim of the meeting, which was held prior to the [PanCare](#) meeting, was to discuss the advancements made to date. Steady progress is being made, despite the challenges in this ambitious project.



SIOPE, as a partner organisation in the EU-funded 7th Framework Programme (FP7) project [PanCareSurFup](#) – *PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies* – joined experts in survivorship issues in the historical city of Genoa, Italy, last April. The aim of the meeting, which was held prior to the [PanCare](#) meeting, was to discuss the advancements made to date. Steady progress is being made, despite the challenges in this ambitious project.

The largest ever study of its kind to date, PanCareSurFup will follow around 80,000 survivors of childhood and adolescent cancer assessing the cohort-based risk of all second malignancies, cardiac disease and late mortality (more than 5 years from diagnosis). Nested case-control based risk assessments for cardiac disease, subsequent primary sarcomas and subsequent primary carcinomas will also be done. Evidence will be established on the doses of radiotherapy to each organ in order to identify tighter estimates of risk for cardiac disease, second cancers and late mortality. These data, collated with results from other studies provide the basis for guidelines on follow-up for Europe which have already started, in the project.



SIOPE works with Drs. Momcilo Jankovic and Julianne Byrne on dissemination of PanCareSurFup. Discussion focused on strategies to improve the dissemination of the achievements made to date and in particular how we can communicate to our target audiences, such as GPs, paediatric oncology clinical trial leads and survivors and their families. A communication/ dissemination strategy was presented and SIOPE will

increasingly integrate even more activities related to dissemination of this important EU project.

All partners will once again assemble in Amsterdam in September for the General Assembly of PanCareSurFup. In the paediatric oncology track of the European Cancer Congress, there will be a specific session dedicated to this topic: 'Empowering survivors of Childhood and adolescent cancers'. Project Coordinator Dr. Lars Hjorth is co-chairing the session, along with Prof. Kathy Pritchard-Jones.



SIOPE is delighted to announce that initiatives being developed by PanCareSurFup and ENCCA will be discussed in the Paediatric Oncology Track of the European Cancer Congress, on Monday, 30 September 2013 in Amsterdam.

The Race of Brave Bikers: 2013 edition

After a successful launch last year, the second edition of the Race of Brave Bikers took place on Sunday, 28 April. This is a unique race hosted within the traditional Granfondo Fi'zi:k competition, with around 40 brave young people from all over Europe competing in a 10km itinerary along the roads and surrounding countryside of beautiful Marostica (Vicenza, Italy).



Today, 80% of children and teenagers who suffered from cancer survive: however, it is essential to ensure that long-term survivors of childhood cancer can live a healthy life, integrating back into society, with little side-effects or relapses due to the intensive treatment received.

The **Race of Brave Bikers** took place on 28 April and around 40 people from all over Europe volunteered to take part in this initiative in order to give a strong message of hope by riding their bike and competing over a 10km itinerary along the roads and surroundings of beautiful Marostica. All participants to the race had in fact an important element in common: they all suffered from cancer, and could overcome this challenge thanks to top-level medical research and, most importantly, to their courage. Organised by the dissemination work package of the EU-funded Seventh Framework Programme (FP7) project [PanCareSurFup](#) (of which SIOPE supports), [PanCare](#) and the town of Marostica, and kindly sponsored by the Italian companies [Fi'zi:k](#) and [Near](#), this special event attracted a lot of attention – not only from sports fans – and informed the general public about a very important topic: the needs of long-term survivors of childhood cancer.



The race was preceded by a **Round Table** discussion, whose aim was to bring together survivors, parents, doctors and researchers, and to brainstorm on how to increase public awareness in Europe. Dr Lars Hjorth, the coordinator of [PanCareSurFup](#), introduced the scope and results of this project which carries out research studies on late effects of cancer treatment, with the final objective being to provide every survivor with better access to care and better long-term health.

Sabine Karner illustrated the work carried out by the International Confederation of Childhood Cancer Parent Organisations ([ICCCPO](#)), an international network of parents' support groups which encourages and provides guidance for the creation of new groups at the local level, including survivors' groups, facilitates information-sharing and represents parents and patients' positions at the European and international level. During the discussion, some survivors addressed the specific role of their groups (often composed of young adults) within parents/patients' organisations, as they can have specific perspectives, different from the outlooks of parents and families

Profs. Andrea Biondi and Momcilo Jankovic from Italy introduced the research and work performed by S. Gerardo Hospital, the *Fondazione Monza e Brianza il Bambino e la sua Mamma* and the Italian Paediatric Haemato-Oncology society (AIEOP). Bill Niada from [Near](#) and the *Magica Cleme* foundation introduced the initiative [B.Live](#), a fashion project involving some patients of the Milan Institute of Tumours through workshops with photographers, stylists and journalists, to create a fashion collection that would disseminate their message. Dr. Julianne Byrne from Ireland joined Prof. Jankovic to explain the important role of dissemination in [PanCareSurFup](#) Dissemination not only raises awareness of the results of the research but also can empower survivors to take control of their health, and they are the real beneficiaries of the project.

Young survivors attending the Round Table discussed how best to contribute to the project and the general situation of European survivors' groups. Thomas Cremona, a survivor Malta presented his incredible achievements in raising awareness through sport; through the initiative 'Row4Cancer' he rowed from the Moroccan coast to Barbados islands, breaking the world record (see news [here](#)) and receiving the highest Maltese honorary decoration. Now 25-years old and accountant by profession, Thomas is an outstanding example of the amazing bravery of survivors. Thomas was treated for acute lymphoblastic leukaemia at four years of age. He continues to raise international awareness that there is life after cancer. Thomas strongly encouraged other survivors in the audience not to give up and to initiate similar (although maybe less risky!) initiatives.

Survivors attending were generally very proactive and pointed out to the current lack of international cross-border initiatives to inform the general public on their needs as well as the requirements for European survivors' groups to make coordinated efforts and share information with other survivors who don't belong to a group. They also addressed the insufficient communication with adult oncologists, the short duration of average follow-up after cancer treatment in some countries and the lack of EU-wide harmonised guidelines for follow-up. Although





there are few funds specifically dedicated to long-term survivors' follow-up, the biggest problem is probably the lack of correct and widely disseminated information on the topic: participants therefore suggested to address this problem through online (and low-cost) new online tools to communicate such as social media, and also agreed to contribute to other small initiatives launched during the meeting, like survivors producing YouTube videos on their previous disease as well as short articles on their experience in Marostica. All participants were keen to support and improve the work currently performed on the long-term follow up of paediatric cancer survivors.

Again, for the second year, this special event successfully spread a message of hope through the example of these incredible former patients, confident and positive despite their traumatic experience. Prof. Jankovic and Bill Niada and his team were commended for their great efforts in raising awareness and organising the meeting. Next year the same event will take place again: let's support long-term survivors of childhood cancer, let's prepare for a new exciting adventure!

More information:

[SIOPE website](#)

[PanCareSurFup website](#)

[PanCare website](#)

[Granfondo competition](#)

Our Community Profiled



Sue Morgan

This month's interview with our multidisciplinary community is with Ms. Sue Morgan, a paediatric oncology nurse at Leeds General Infirmary whose deep commitment to helping teenagers and young adults with cancer (TYA) has been appointed Member of the Most Excellent Order of the British Empire (MBE), the highest British honorary decoration.

- Can you tell us how did you receive such a high-level honour decoration?

SM: I am not too sure really!! I came home from work one day and there was a letter that I thought was a speeding fine asking me if I would accept the honour. Of course, I did. It was for 'Services to nursing and the NHS'. I am not at all sure who nominated me – that is kept secret – but, it was about the work I had been doing with teenagers with cancer. It came completely out of the blue and I regard it as a massive honour. I was invited to Buckingham Palace and could take guests, so I went with my mum and my daughter Beth. My dad was unwell and at home, which was a shame, and my brother Keith came and waited at the gate. It was given to me by the Queen – which was a very surreal experience. When we left the Palace we walked toward the famous gates and there were people from my team and teenagers who had come down on the train waving home-made flags! A lovely, lovely day.

- What are the specificities of cancer in teenagers and young adults (TYA)? Why do you think this age group is becoming increasingly important in the oncology world?

SM: In the past teenagers and young adults with cancer have been marginalised and they were looked after in either children or adult wards. It has become increasingly clear that they have distinct psychological needs because of their stage of development, and that age-appropriate care, alongside their peers, is pivotal. It is also becoming apparent that some of the diseases that we are treating have a different biology and therefore may need targeted treatments that are different from those given to either children or adults. We also know that young people are less likely to comply with treatment; we know that they often experience delays in treatment as well as not being able to access clinical trials.

Therefore, a new speciality is being developed, requiring separate services and research in order to ensure that patients have top treatment delivered by experts in their care and disease. The ultimate aim is to increase survival and offer them more holistic care appropriate to their age.

- Did anyone inspire you when you chose your job? What do you love most about it?

SM: I am trained as both an adult and paediatric nurse and my first job as a qualified paediatric nurse was in paediatric oncology. I worked in 3 major centres in the UK, eventually settling in Leeds where I was a sister on a Paediatric Oncology ward when the position as a TYA Clinical Nurse Specialist became available. I applied and got it: that was 15 years ago! I didn't deliberately choose to go into paediatric oncology, but it was the job that was available at the time, and I have never left.

However, when I was 11 years old my younger brother Neil, aged 3 years, was diagnosed with lymphoblastic leukaemia. He got better (not bad for the 1960's!) but then developed a different form of leukaemia (myeloid) when he was 13 years old, and I was about to do my nursing finals. He sadly died a few months later but, just before, he told me that I was 'better than a nurse!'. He has always been my inspiration and, since then, I have endeavoured to live up to the biggest compliment of my life.

I love my job for many reasons: I love being on the ward with young people, getting along with them, communicating well despite my age (55 years), working with them, helping them and being inspired by them. They, and their families, are incredible: they have taught me so much. I love working with the teams around me; in particular my close-working team who are all so motivated to help the young people and their families and in developing the service. I also enjoy the more recent work involving Europe, with ENCCA, and the occasional invitations I get to go and talk at conferences – the latest exciting ones being Texas and, more recently, Paris. I love to be around motivated people – so, that all helps!

- How can research improve the condition of TYA patients? On which topics should it focus more?

SM: I have explained this above, but I think it should focus more on delays in diagnosis as well as the aspects of the different biologies and treatment.

There is a recent study in the UK, called 'Brightlight', which is assessing the essence of care and the young person's experience in England. This is a fantastic piece of work, and every centre in England who looks after TYAs (whether in a specific unit or general hospital) has been approached to take part. This research is timely and will add to our knowledge base.

- How did you get involved with ENCCA?

SM: I have the privilege of working in Leeds with Prof. Ian Lewis, one of the first pioneers of TYA care in the UK, and Dr. Dan Stark, s a prominent figure in the TYA world in the UK. Both of them are leading [Work Package 17](#) 'Creating a European network for teenagers and young adults with cancer (ENTYAC)' in ENCCA, and I was asked if I would lead on Task WP

17.6, which aims to involve patient advocates from across Europe in the project. Getting young people to have a 'voice' in a multitude of languages is a big task, and it is not easy. If anyone reading this would like to be a part of this work, please let me know.

- Do you think by being a paediatric oncology nurse you may have a different perspective from the other professions represented within the ENCCA project?

SM: I will certainly have a nursing perspective! I recently attended the ENCCA meeting in Brussels and I was the only nurse there in a room full of about 100 doctors. That was not good, and I informed the group. I would absolutely encourage nurses to be a part of ENCCA and to please contact me should they wish to know more, so that I can point them in the right direction.

In the UK nurses, who have often been the voice of TYA care, work alongside doctors to develop TYA services. I don't think that the UK would be in such a good position with regard to TYA care had such partnerships not existed. Nursing involvement should be encouraged across Europe.

- What are the main challenges encountered by Work Package 17 and by ENCCA in general?

SM: I think that the main challenge is about communication, on many levels. There is clearly a language barrier, not so much among doctors but most certainly with nurses and other allied health professionals. Translation services are fairly expensive to utilise so we need to think of alternative ways to do this. As concerns teenagers and young people, we would work through the support and patient/parent groups to help – nursing is a little different and we need to work with the leaders in nursing and then cascade the information in that way – it's a big task.

In my opinion, a website area with access for the young people would be beneficial, and we are working on that.

Also, the project is for a finite time, the work must continue when it has ended and we need to find ways of ensuring that it does. There are so many motivated people working in this area that I am sure that it will, in one form or another.

- What would you like to include in new ENCCA website section on TYA?

SM: The website clearly needs to have information about TYA care across Europe and access to all types of information, as well as being a portal to the other units at all stages of development. From my point of view we need to have a page where young people can access, we can ask their opinions about all aspects of work that we are doing as well as being a place that will join up all TYAs with cancer in Europe. This would need very careful planning and moderating – but, we could make it work.

- Do you think adolescent patients should know more about their rights and be more involved in the choices about their treatment?

SM: Absolutely! No question. We are in the process of developing an online survey for young people with cancer that we would like to get out across Europe via ENCCA, asking them questions that will allow us to 'map' practice. We are asking if they have heard about the 'International Charter of Rights for Young People with cancer?' (have you? www.cancercharter.org) and what they think about it. It will be interesting to see what they say.

Again, we need to share the expertise that is in Europe and other countries (i.e. USA, Canada, and Australia), to show what we have learned in looking after this patient group and to share our expertise.

- What kind of advice would you give to the families of children with cancer?

SM: I would advise them to keep the nucleus of the family together; to make joint decisions, where possible, and not to regret anything, keeping the child/young person at the centre of everything that they do.

The care of children and young people with cancer, as well as the research and treatment undertaken, is in safe hands in centres of excellence; there have been many advances and there are very motivated professionals who have dedicated their working lives to making the care and outcomes better. So, entrust the care of you/your child to these people.



Join SIOPE and give paediatric oncology a stronger voice in Europe!

SIOPE Europe, the European Society of Paediatric Oncology (SIOPE) is the only pan-European organisation aiming to ensure the best possible care and outcome for all children and young people with cancer in Europe. Today SIOPE needs to have direct access to European paediatric oncology professionals, who are the foundation and driving force of our society.



The European Society of Paediatric Oncology (SIOPE) is a pan-European organisation dedicated to improve cancer awareness, research and treatment as well as optimal standards of care for children and young people with cancer (www.siope.eu).

As the only comprehensive of health professionals working in this field, our Society connects paediatric haemato-oncology national societies, clinical trial groups, patients and professionals all over Europe. Moreover, SIOPE promotes multinational clinical trials, facilitates information exchange on the common regulatory and bureaucratic issues, furthers European scientific and professional co-operation and training and raises awareness on childhood cancers across borders.

Since its foundation, SIOPE's remit within the EU policy arena has grown considerably, being recognised today by policymakers as the main representative for promoting better policies for children with cancer. In less than 5 years SIOPE developed into a professional and widely recognised non-profit organisation, partner in the [ENCCA](#) research network of excellence – which comprises 34 influential research institutes from 11 European countries – as well as in the [EPAAC](#) and [PanCareSurFup](#) projects. Based in Brussels, our society is steered by a Board of 8 members and Professor Gilles Vassal, from Institut Gustave Roussy (Villejuif, France), is the current SIOPE President.

In order to become even more representative of the European paediatric oncology community and, thereby, better fulfil its mission, SIOPE recently decided to re-define its membership model. Therefore last year SIOPE started a process aiming to have a more

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direct access to European paediatric oncology professionals, who are both the foundation and the driving force of our society, asking all members of the European National Paediatric Haemato-Oncology Societies or groups ('NaPHOS') to become part of the SIOPE network. In order to ensure an open and ever-expanding community, professionals who are not members of a NaPHOS can also join SIOPE, especially in countries where no such NaPHOS exists, with the only condition of being paediatric oncology professionals in medical institutions and treatment centres specialised in cancer care for children and young people.

With currently approx. 600 members, we encourage you today to be part of this unique adventure, and give a stronger voice to our community at the European level. Becoming member of SIOPE, with a small annual contribution of only 20€, you can also enjoy several advantages:

- **Be part of a Europe-wide network** – SIOPE is part of a powerful, multidisciplinary network. It is a member of:
 - ✓ ECCO – the European CanCer Organisation (Founding Member)
 - ✓ SIOP – International Society of Paediatric Oncology (Continental Branch)
 - ✓ EURORDIS – Rare Diseases Europe
 - ✓ EFGCP – European Forum for Good Clinical Practice
 - ✓ Rare Cancers Europe
 - ✓ Council of European Rare Disease Federations

Moreover, SIOPE has close ties with parent and patient advocates through ICCCP (the International Confederation of Childhood Cancer Parent Organisations) and the ECCO Patient Advisory Committee.

- **Hear about updates and initiatives in your field first** – A quarterly SIOPE e-newsletter and regular email communications inform members on the latest news, events, educational opportunities, EU health policies and funding opportunities.
- **Avail of reduced rates at conferences** – You can attend the biennial European Multidisciplinary Cancer Congress, the largest European cancer congress of-its-kind, at a reduced rate. SIOPE will lead the Paediatric Oncology Track of this Congress and ensure our members' expertise is presented. This high-level multi-stakeholder meeting will open many doors for the paediatric oncology community, as it is the right platform where synergies and cross-fertilisation of expertise with other sectors take place.
- **Be actively involved and showcase your initiatives** – You will participate in our advocacy initiatives at EU level. Any relevant initiatives, campaigns or news carried out by members at national level can be promoted through SIOPE's communication channels
- **Participate in education and training initiatives** – You will be regularly informed about educational opportunities.



- **Collaborate with your European colleagues** – You will avail of cross-talk on key issues, share knowledge on issues affecting the entire community and learn about EU projects and funding opportunities.
- **Network with the pharmaceutical industry** – SIOPE will encourage collaborations between academic and commercial research and can create opportunities for you to meet potential pharmaceutical partners.

THANK YOU for joining SIOPE!

**You gave paediatric oncology a stronger voice in Europe
to create a brighter future for children with cancer**

More information

[SIOPE website](#)

Welcome to the new SIOPE Board Member Pamela Kearns

The SIOPE Board and office warmly welcomes Prof. Pamela Kearns from the Cancer Research UK Clinical Trials Unit of the University of Birmingham, as our newest SIOPE Board member. She is Vice-Chair of the ECRC Steering Committee, and widely contributed in shaping SIOPE's position on the EU Clinical Trials Regulation.

The SIOPE Board and office warmly welcomes Prof. Pamela Kearns from the University of Birmingham (United Kingdom) on the Board. Prof. Kearns has been also recently elected Vice-Chair of the European Clinical Research Council for Paediatric Oncology (ECRC) Steering Committee.



Pamela Kearns is a Senior Lecturer in Paediatric Oncology in the School of Cancer Sciences and is an Honorary Consultant Paediatric Oncologist at the Birmingham Children's Hospital

Today Senior Lecturer and Honorary Consultant in paediatric oncology, Dr Kearns studied Medicine at the University of Aberdeen after obtaining a BSc Honours degree in Physiology. She trained as a paediatric oncologist in Newcastle upon Tyne, where she also started her research career as a Leukaemia and Lymphoma Research (LLR) Clinical Fellow investigating drug resistance in childhood leukaemias. After being awarded a PhD, she was appointed as a Consultant and Senior Lecturer in Paediatric Oncology at the University of Bristol and in 2007 relocated to Birmingham, where she further developed her research in new therapeutic approaches for refractory childhood acute leukaemias, focusing on pre-clinical models for evaluating novel treatments and the design and development of early phase clinical trials investigating novel therapies for childhood leukaemias.

In 2010, she established the Children's Cancer Trials Team within the University of Birmingham's Cancer Research UK Clinical Trials Unit (CRCTU), the designated national children's cancer trials unit in the United Kingdom. In July 2012 she was appointed Director of the CRCTU, one of the largest cancer trials units in the UK specialising in the design, conduct and analysis of phase I to IV cancer clinical trials for investigators for a wide range of cancers and leukaemias across all ages.

Today, Dr. Kearns is on the Executive Committee and is Treasurer of the [ITCC](#) (Innovative Therapeutics for Children with Cancer), Vice-Chair of the [ECRC](#) and, last but not least, member of the SIOPE Board.

SIOPE Board 2013



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Past President Professor Ruth Ladenstein
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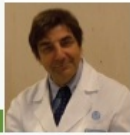
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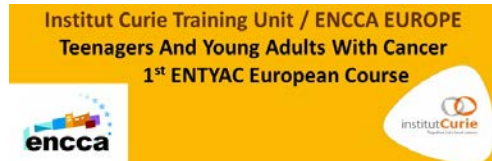
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Children's Brain Tumour Research
Centre, Nottingham, UK

More information

[Birmingham University staff](#)

[SIOPE Board](#)

ENTYAC European Course on teenagers and young adults with cancer



The brand new international course “Teenagers and Young Adults with Cancer” organised by Institut Curie, in partnership with ENCCA, took place last 17-19 April in Paris. Among the highlights of the course there were the multidisciplinary perspectives and the exchange of information between clinical and biological approaches. Dr. Alvaro Lassaletta informs SIOPE about the discussions at this unique meeting. Dr. Alvaro Lassaletta discusses the success of the first European course on “Teenagers and Young Adults with Cancer”, organised in association with ENCCA.



*M. Wilhelm, D. Wright, V. Laurence, U. Dirksen, R. Riccardi, D. Stark, P. Olsen, I. Lewis, A. Ferrari, D. Hobin, S. Morgan, A. Lassaletta, L. Rosali, A. Kogan Wais, A. Cook, T. Grew.
Credits: A. Lescure*

The first European course on “Teenagers and young adults with cancer” organised with the ENCCA initiative, the ‘European Network for Teenagers and Young Adults with Cancer (ENTYAC)’, was hosted by Institut Curie, Paris, between 17 and 19 April, 2013 to discuss the global approach in taking care of teenage and young adults (TYA) cancer patients. In particular:

- Cancer accounts for the greatest loss of life due to illness among 15-24 years old, second only to road traffic accidents;

- There are approximately 12,500 new cases of cancer every year among those aged between 15 and 24 in the European Union.

Many countries in Europe have now individualised the care for adolescents, with several national groups devoted to TYAs; in some countries, initiatives are led by paediatricians and in others by adult oncologists. Beyond the accessibility of appropriate facilities for age, these efforts should aim to offer patients the best care and medical expertise both from medical oncologists and paediatricians and access to clinical trials.

Discussions at the ENTYAC course integrated a multi-professional, pan-European approach: among the 80 participants, there were paediatric and adult oncologists in training, nurses and other healthcare providers, psychologists, psychiatrists as well as social workers with a paediatric or “adult” background. 14 European countries were represented and one MD from Venezuela also attended. This allowed multiple exchanges of information between clinical approaches and integrated the new challenges in biology.



Above all, we would like to highlight the interaction and participation of all the attendants. The quality of the sessions and the bilateral interaction made the meeting a success. The programme included the following subjects:

- The perspective from the doctor, the nurse and the cancer services dealing with TYA with cancer;
- Clinical and biological aspects of Ewing, osteosarcomas, and synovial sarcomas from the paediatric and adult perspective;
- Therapeutic options, epidemiology and biological features of leukaemia in TYAs;
- Access to new drugs for TYA;
- Psychological specificity in TYA with cancer;
- Consent, assents and ethical aspects in TYA with cancer;
- Fertility preservation;
- Sexuality, cancer and TYA;
- National groups and pathways of care in Europe.

There was also a very interesting multi-professional workshop with TYA cancer survivors where they could provide their views.

The objectives of the meeting were:

- To create a European multidisciplinary framework and network for TYA cancer;
- To promote and develop TYA multi-professional education;
- To improve the access to clinical trials for TYA;
- To develop a European TYA research initiative;
- To promote healthy lifestyles in TYA population and cancer survivors;
- To establish links to patient and support organisations.



*Multiprofessional workshop chaired by I. Lewis, R. Lorenzo, P. Olsen, T. Grew, A. Kogan, A. Cook.
Credits: A. Lescure*

We think that TYAs with cancer deserve the best of both worlds: medical expertise from paediatric and adult oncology, age-appropriate facilities and expertise, peer support, education and training.

We believe in a Europe-wide project on TYAs with cancer as a tool to overcome many of the barriers which different countries are facing locally. Partnerships and joint working serves TYA patients in many ways, including availability of trials, and perhaps recruitment.

Dr. Alvaro Lassaletta

Organisers: L. Brugières (Villejuif, France), F. Doz (Paris, France), V. Laurence (Paris, France), S. Morgan (Leeds, UK), R. Riccardi (Rome, Italy), D. Stark (Leeds, UK).

Speakers: N. Boissel (Paris, France), L. Brugières (Villejuif, France), S. Davies (TCT, UK), U. Dirksen (Muenster, Germany), J-C. Dupont (Paris, France), A. Ferrari (Milan, Italy), D. Hobin (Birmingham, UK), I. Lewis (Liverpool, UK), R. Lorenzo (Madrid, Spain), S. Morgan (Leeds, UK), P. Olsen (Aarhus, Denmark), A. Pacey (Sheffield, UK), S. Piperno-Neumann (Paris, France), R. Riccardi (Rome, Italy), E. Seigneur (Paris, France), S. Smith (TCT, UK), D. Stark (Leeds, UK), F. Tirode (Paris, France), M. Wilhelm (Stuttgart, Germany).

More information:

[ENTYAC course website](#)

EUROPEAN Cancer Congress 2013

The Paediatric Track, Regular Registration Rate and Late-breaking Abstract Submission



*Be part of the unique multidisciplinary 17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress, the premier cancer congress in Europe, and don't miss the outstanding the Scientific Symposia of the **Paediatric Track** led by SIOPE. The SIOPE General Assembly and several not-to-be-missed SIOPE events will also take place in Amsterdam. **SIOPE members save money on registration** and present your data! See you there!*

Take advantage of your SIOPE membership !

SIOPE members can attend the **European Cancer Congress** at a reduced rate

Be part of the world-renowned multidisciplinary **17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress**, the premier cancer congress in Europe presenting the latest, ground-breaking and practice-changing data. The European Cancer Congress will take place from 27 September to 1st October 2013 in Amsterdam (The Netherlands) and is held **in partnership with SIOPE** and the other ECCO founding members.

The **Paediatric Track** led by SIOPE includes some outstanding Scientific Symposia about cancer in Teenage and Young Adults (TYA), the empowerment of survivors of childhood and adolescent cancer, targeted drugs and personalised medicine in paediatric oncology and, last but not least, the future of paediatric oncology in Europe. The first day of the congress' Paediatric Track will be the 28th September 2013, and already some not-to-be-missed symposia are scheduled, like the following:

- Cancer in Teenage and Young Adult, Chair: S. Bielack (Germany) on Saturday, 28 September
- Empowering Survivors of Childhood and Adolescent Cancer, Chairs: L.J. Hjorth (Sweden), K. Pritchard-Jones (United Kingdom), Monday, 30 September
- Targeted Drugs and Personalised Medicine in Paediatric Oncology, Chairs: G. Vassal (France), M. Schrappe (Germany), Monday, 30 September
- The Future of Paediatric Oncology in Europe, Chairs: A. Biondi (Italy), R. Ladenstein (Austria), Tuesday, 01 October

SAVE THE DATE: SIOPE General Assembly, Sunday, 29 September, 18.15-19.15

SIOPE members are also invited to attend the annual **SIOPE General Assembly** during the congress on **Sunday 29 September, 18.15-19.15**. The General Assembly is the ideal opportunity to meet colleagues from different countries in person, AND exchange and debate ideas to help SIOPE build upon its successes for the term ahead. At the General Assembly, SIOPE's activities of the last 12 months are discussed, the objectives and strategies for the near future are outlined and especially this year, after the change in the SIOPE membership model, several updates will be communicated to the new SIOPE members. A Reception for SIOPE members will be arranged after the General Assembly.

Other key SIOPE-related meetings will also take place:

- **SIOPE Society session**, Saturday 28 September 2013, 16.00–18.00
On this occasion, the **SIOPE Lifetime Achievement Award** will be granted to a distinguished paediatric oncologist, whose eminent work, dedication and scientific excellence in enhancing the research, treatment and cure of children with cancer in Europe has been widely recognised by our community.
- **SIOPE Board Meeting**: Sunday 29 September, 12.00-13.30.
- **Meeting of the European Clinical Research Council for Paediatric Oncology (ECRC)**, Monday 30 September, 17-20.

Don't forget the **congress key dates**:

- 6 Aug 2013: [Regular rate registration closes](#)
- 7 Aug 2013: [Late breaking abstract submission deadline](#)
- 15 Aug 2013: [Housing reservation closes](#)
- 20 Sep 2013: [Late rate registration closes](#)
- 27 Sep - 1 Oct 2013: [Congress](#)

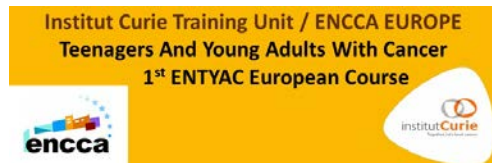


More information:

[SIOPE website](#)

[ECC 17 website](#)

ENTYAC European Course on teenagers and young adults with cancer



The brand new international course “Teenagers and Young Adults with Cancer” organised by Institut Curie, in partnership with ENCCA, took place last 17-19 April in Paris. Among the highlights of the course there were the multidisciplinary perspectives and the exchange of information between clinical and biological approaches. Dr. Alvaro Lassaletta informs SIOPE about the discussions at this unique meeting. Dr. Alvaro Lassaletta discusses the success of the first European course on “Teenagers and Young Adults with Cancer”, organised in association with ENCCA.



*M. Wilhelm, D. Wright, V. Laurence, U. Dirksen, R. Riccardi, D. Stark, P. Olsen, I. Lewis, A. Ferrari, D. Hobin, S. Morgan, A. Lassaletta, L. Rosali, A. Kogan Wais, A. Cook, T. Grew.
Credits: A. Lescure*

The first European course on “Teenagers and young adults with cancer” organised with the ENCCA initiative, the ‘European Network for Teenagers and Young Adults with Cancer (ENTYAC)’, was hosted by Institut Curie, Paris, between 17 and 19 April, 2013 to discuss the global approach in taking care of teenage and young adults (TYA) cancer patients. In particular:

- Cancer accounts for the greatest loss of life due to illness among 15-24 years old, second only to road traffic accidents;

- There are approximately 12,500 new cases of cancer every year among those aged between 15 and 24 in the European Union.

Many countries in Europe have now individualised the care for adolescents, with several national groups devoted to TYAs; in some countries, initiatives are led by paediatricians and in others by adult oncologists. Beyond the accessibility of appropriate facilities for age, these efforts should aim to offer patients the best care and medical expertise both from medical oncologists and paediatricians and access to clinical trials.

Discussions at the ENTYAC course integrated a multi-professional, pan-European approach: among the 80 participants, there were paediatric and adult oncologists in training, nurses and other healthcare providers, psychologists, psychiatrists as well as social workers with a paediatric or “adult” background. 14 European countries were represented and one MD from Venezuela also attended. This allowed multiple exchanges of information between clinical approaches and integrated the new challenges in biology.



Above all, we would like to highlight the interaction and participation of all the attendants. The quality of the sessions and the bilateral interaction made the meeting a success. The programme included the following subjects:

- The perspective from the doctor, the nurse and the cancer services dealing with TYA with cancer;
- Clinical and biological aspects of Ewing, osteosarcomas, and synovial sarcomas from the paediatric and adult perspective;
- Therapeutic options, epidemiology and biological features of leukaemia in TYAs;
- Access to new drugs for TYA;
- Psychological specificity in TYA with cancer;
- Consent, assents and ethical aspects in TYA with cancer;
- Fertility preservation;
- Sexuality, cancer and TYA;
- National groups and pathways of care in Europe.

There was also a very interesting multi-professional workshop with TYA cancer survivors where they could provide their views.

The objectives of the meeting were:

- To create a European multidisciplinary framework and network for TYA cancer;
- To promote and develop TYA multi-professional education;
- To improve the access to clinical trials for TYA;
- To develop a European TYA research initiative;
- To promote healthy lifestyles in TYA population and cancer survivors;
- To establish links to patient and support organisations.



*Multiprofessional workshop chaired by I. Lewis, R. Lorenzo, P. Olsen, T. Grew, A. Kogan, A. Cook.
Credits: A. Lescure*

We think that TYAs with cancer deserve the best of both worlds: medical expertise from paediatric and adult oncology, age-appropriate facilities and expertise, peer support, education and training.

We believe in a Europe-wide project on TYAs with cancer as a tool to overcome many of the barriers which different countries are facing locally. Partnerships and joint working serves TYA patients in many ways, including availability of trials, and perhaps recruitment.

Dr. Alvaro Lassaletta

Organisers: L. Brugières (Villejuif, France), F. Doz (Paris, France), V. Laurence (Paris, France), S. Morgan (Leeds, UK), R. Riccardi (Rome, Italy), D. Stark (Leeds, UK).

Speakers: N. Boissel (Paris, France), L. Brugières (Villejuif, France), S. Davies (TCT, UK), U. Dirksen (Muenster, Germany), J-C. Dupont (Paris, France), A. Ferrari (Milan, Italy), D. Hobin (Birmingham, UK), I. Lewis (Liverpool, UK), R. Lorenzo (Madrid, Spain), S. Morgan (Leeds, UK), P. Olsen (Aarhus, Denmark), A. Pacey (Sheffield, UK), S. Piperno-Neumann (Paris, France), R. Riccardi (Rome, Italy), E. Seigneur (Paris, France), S. Smith (TCT, UK), D. Stark (Leeds, UK), F. Tirode (Paris, France), M. Wilhelm (Stuttgart, Germany).

More information:

[ENTYAC course website](#)

EUROPEAN Cancer Congress 2013

The Paediatric Track, Regular Registration Rate and Late-breaking Abstract Submission



*Be part of the unique multidisciplinary 17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress, the premier cancer congress in Europe, and don't miss the outstanding the Scientific Symposia of the **Paediatric Track** led by SIOPE. The SIOPE General Assembly and several not-to-be-missed SIOPE events will also take place in Amsterdam. **SIOPE members save money on registration** and present your data! See you there!*

Take advantage of your SIOPE membership !

SIOPE members can attend the **European Cancer Congress** at a reduced rate

Be part of the world-renowned multidisciplinary **17th ECCO – 38th ESMO – 32nd ESTRO European Cancer Congress**, the premier cancer congress in Europe presenting the latest, ground-breaking and practice-changing data. The European Cancer Congress will take place from 27 September to 1st October 2013 in Amsterdam (The Netherlands) and is held **in partnership with SIOPE** and the other ECCO founding members.

The **Paediatric Track** led by SIOPE includes some outstanding Scientific Symposia about cancer in Teenage and Young Adults (TYA), the empowerment of survivors of childhood and adolescent cancer, targeted drugs and personalised medicine in paediatric oncology and, last but not least, the future of paediatric oncology in Europe. The first day of the congress' Paediatric Track will be the 28th September 2013, and already some not-to-be-missed symposia are scheduled, like the following:

- Cancer in Teenage and Young Adult, Chair: S. Bielack (Germany) on Saturday, 28 September
- Empowering Survivors of Childhood and Adolescent Cancer, Chairs: L.J. Hjorth (Sweden), K. Pritchard-Jones (United Kingdom), Monday, 30 September
- Targeted Drugs and Personalised Medicine in Paediatric Oncology, Chairs: G. Vassal (France), M. Schrappe (Germany), Monday, 30 September
- The Future of Paediatric Oncology in Europe, Chairs: A. Biondi (Italy), R. Ladenstein (Austria), Tuesday, 01 October

SAVE THE DATE: SIOPE General Assembly, Sunday, 29 September, 18.15-19.15

SIOPE members are also invited to attend the annual **SIOPE General Assembly** during the congress on **Sunday 29 September, 18.15-19.15**. The General Assembly is the ideal opportunity to meet colleagues from different countries in person, AND exchange and debate ideas to help SIOPE build upon its successes for the term ahead. At the General Assembly, SIOPE's activities of the last 12 months are discussed, the objectives and strategies for the near future are outlined and especially this year, after the change in the SIOPE membership model, several updates will be communicated to the new SIOPE members. A Reception for SIOPE members will be arranged after the General Assembly.

Other key SIOPE-related meetings will also take place:

- **SIOPE Society session**, Saturday 28 September 2013, 16.00–18.00
On this occasion, the **SIOPE Lifetime Achievement Award** will be granted to a distinguished paediatric oncologist, whose eminent work, dedication and scientific excellence in enhancing the research, treatment and cure of children with cancer in Europe has been widely recognised by our community.
- **SIOPE Board Meeting**: Sunday 29 September, 12.00-13.30.
- **Meeting of the European Clinical Research Council for Paediatric Oncology (ECRC)**, Monday 30 September, 17-20.

Don't forget the **congress key dates**:

- 6 Aug 2013: [Regular rate registration closes](#)
- 7 Aug 2013: [Late breaking abstract submission deadline](#)
- 15 Aug 2013: [Housing reservation closes](#)
- 20 Sep 2013: [Late rate registration closes](#)
- 27 Sep - 1 Oct 2013: [Congress](#)



More information:

[SIOPE website](#)

[ECC 17 website](#)

Paediatric Cancer Research at the INTERFACE

The ‘Paediatric Cancer Research at the INTERFACE’ symposium celebrating the 25th anniversary of the Children’s Cancer Research Institute, co-organized with the ENCCA and ASSET projects, will take place on 7-8 June 2013. The aim of this meeting is to update and discuss cutting edge biomedical research areas of relevance to future paediatric oncology.



You are invited to participate in the “Paediatric Cancer Research at the INTERFACE”-symposium celebrating the 25th anniversary of the Children’s Cancer Research Institute, co-organized by CCRI, ASSET (Analysing and Striking the Sensitivities of Embryonal Tumours) project and ENCCA. The aim of this meeting is to update and discuss cutting edge biomedical research areas of relevance to future paediatric oncology.

The symposium will take place on the **7th and 8th of June 2013** at the historic venue of the Austrian Academy of Sciences in Vienna (www.interface2013.at).

In association with this event, on **June 6th**, 2013 ENCCA is organizing a symposium on “**Clinical Research in 2013: Burning Issues**” that will take place in Vienna at the Festival Room of the Sigmund Freud Private University Vienna. The program is available at www.encca.eu. Looking forward to meeting you in Vienna!

More information:

[Interface website](http://www.interface2013.at)

Treasurer's Corner

May 2013

Dear colleagues,

I would like to use this opportunity to update you briefly on the status of the new SIOPE membership – through national societies. Several membership reforms have been received through national societies, the largest fraction stemming from the Nordic countries and their consortium – NOPHO. This is due in particular to their very efficient automatic and secured online portal for members. We expect more membership applications from other countries, as some countries are collecting the forms from their members in a non-automated procedure. Obviously, it will take longer than expected until the membership fees can contribute significantly to the management cost of SIOPE. On the other hand, the attendance of paediatric oncologists at the last European Cancer Congress in Stockholm and the generous support derived from that is reason for optimism. Hopefully, the well-developed and impressive Paediatric Oncology Track at this year's European Cancer Congress in Amsterdam in September (27 September – 1 October 2013) will attract even more paediatric oncologists.

In March, SIOPE participated in a very promising proposal responding to a call of the European Commission's DG Sanco on centres of reference in paediatric oncology in Europe. You can read about the contents of this challenging task [here](#). Let's keep our fingers crossed!

Last, but not least, three young paediatric oncologists have successfully applied for participation in the 2013 Flims workshop. Congratulations! Dr. Karsten Nysom and Dr. Petra Temming, having no financial support for this yet, are granted a SIOPE scholarship to realise their participation.

I wish all of you a sunny springtime! And thanks for promoting the SIOPE membership!

Best regards



Martin Schrappe, MD

May, the 'Month of the Brain'

May 2013 has been named the 'European Month of the Brain'. This year, the EU invested up to €150 million for research in neuroscience and human cognition. Among brain diseases, brain tumours are enormously affecting children: we take therefore this opportunity to highlight the efforts made in raising awareness and empowering paediatric brain tumour patients.



Every year, the month of May is dedicated to the research and treatment of brain diseases, showcasing the latest achievements in the field and urging a more decisive effort to combat brain diseases: one out of three Europeans is likely to be affected by brain-related illness and, of all diseases, brain disorders present Europe's largest health and socioeconomic burden. The European Commission is therefore encouraging national authorities to optimise resources to enhance brain research and healthcare.

International collaboration among experts active in the field of brain diseases is essential to increase the availability of information and to improve scientific knowledge of this complex organ. More than 50 [thematic events](#) and conferences are taking place during this 'Month of the Brain', and the European Commission is organising two major conferences, in Brussels (14 May) and Dublin (27-28 May), together with the Irish EU Presidency.

Brain tumours are one of the main types of paediatric cancer in Europe and the second leading cause of cancer-related death in children under 20. More so than any other cancer, brain tumours can have life-altering psychological, cognitive, behavioural, and physical effects. However, there is hope: not only researchers are making progress in understanding brain tumours and finding innovative cures, but awareness-raising on the need to ensure brain tumours are diagnosed early has become increasingly well-known and referrals are being improved, which leads to significantly better clinical outcomes, and can even save children's lives.



Among the several initiatives taking place at the European and national level is [HeadSmart](#), which focuses on early diagnosis of childhood brain cancers. While UK-based, awareness of the importance of this initiative has increased all over Europe. The campaign objective is to reduce the time needed to diagnose a brain tumour, thereby improving its diagnosis, treatment and cure, by enhancing symptom awareness amongst the general public as well as professionals.

More information

[European Commission website](#)

[HeadSmart initiative](#)

The Clinical Trials Regulation: SIOPE's position

The paediatric oncology community calls for a pragmatic approach to trial governance for children and adolescents with cancer in Europe. Fair risk categorisation, fair insurance for academic institutions and fair and proportionate transparency measures are required.

SIOPE welcomes the proposal by the European Commission for an EU Clinical Trials Regulation, which encapsulates changes that will address many of the concerns and limitations of the EU Clinical Trials Directive (2001/20/EC).

We particularly support and welcome:

- The introduction of the single Portal for application for clinical trial authorisation;
- The co-sponsorship model;
- The requirement for the establishment of national indemnity schemes;
- The recognition that not all clinical trials pose an additional risk to subjects compared to treatment in normal clinical practice.

However some areas remain a major concern as they put into question our ability to successfully re-build academically-led and sponsored clinical trials for children and young people with cancer.

SIOPE calls for:

- 1) **FAIR and proportionate risk categorisation of childhood cancer trials** where the use of medicinal products is often outside the terms of the marketing authorisation (off-label use), but based on high-level expertise, standard practice and decades of success
- 2) **FAIR insurance** for academic trials treating children with rare diseases **secured through 'national indemnity schemes'**
- 3) **FAIR and proportionate transparency measures**, with provisions for reasonable and secure reporting that protects young cancer patients and their personal data

To enhance and optimise paediatric clinical research through the EU Clinical Trials Regulation, SIOPE and ENCCA will continue to call for legislation that **reflects well the realities of academic research and can help improve research for young people with cancer in Europe.**

Risk categorization

The 'low intervention clinical trial' category in the CTR is a very welcome step forward allowing proportionate application of regulatory control over clinical trials.

In paediatric oncology (and in many rare diseases), the vast majority of drugs involved are used in standard clinical practice outside their marketing authorisation ('off-label use'). We remain very concerned that **in the context of 'off label use' of licensed medicinal products, there will be fundamental differences between Member States in the interpretation of when the 'low intervention clinical trial' category applies.**

Insurance

We believe that the introduction of national indemnity schemes will be a major facilitator for the future growth of non-industry sponsored clinical trials. Academia-driven clinical trials should be encouraged because they serve as fundamental cornerstones to improving standard practice and hence to improve and optimise a patient's treatment and care. National indemnity schemes will be a particularly critical issue for the



academia-sponsored trials that are not categorised as low intervention trials and therefore will have an insurance requirement, which is often disproportionate to the risk posed to the patient and/or trial and prohibitively expensive to academic and publically-funded Institutions.

Transparency

The SIOPE community supports the need for transparency of clinical trial results but only after appropriate public consultation. Any regulatory or governance requirements that codify these principles should be drafted with great care and consulted on widely to prevent any unintended adverse consequences.

We support the disclosure of trial summaries, as proposed in the draft legislation. But criteria for what a summary should contain in a reasonable format should be detailed, but not based upon the ICH E3 guidelines, which, as per the attachment, are completely outdated.

Raw data should not be included in the summary. SIOPE believes that the protection of the patient and patient data are essential. For those that had a life-threatening disease like cancer during their youth, this is particularly sensitive as they try to live a normal life once cured. As 80% of patients with paediatric cancer survive, protecting patients' personal data is extremely important.