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**Extended Board meeting**

**Wednesday 22 October 2014**

**SIOP Board Room - ELGIN, Sheraton Centre Toronto Hotel, Toronto, Canada**

**12:30-13:30**

**Minutes**

**Attendees:**

Giorgio Perilongo (SIOP President), Gabriele Calaminus (SIOP Immediate Past-President), Paul Rogers (SIOP Secretary General), Gregory Reaman (SIOP Treasurer), François Doz (SC Chair), Mariana Kruger (SIOP Continental President for Africa), Lorna Renner (SIOP Continental President Elect for Africa), Akira Nakagawara (SIOP Continental President Elect for Asia), Chi Kong Li (SIOP Continental President Elect or Asia), Stewart Kellie (SIOP Continental President for Oceania), Michael Sullivan (SIOP Continental President Elect for Oceania), Gilles Vassal (SIOP Continental President Elect for Europe), Lisa Diller (SIOP Continental President Elect for North America), Silvia Brandalise (SIOP Continental President Elect for South America), Valérie Kuffer (KAW), Susanne Wollaert (KAW), Lorraine de Montmollin (KAW)

**Agenda:**

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| --- | --- | --- |
| **Item** | **By** | **Est. time** |
| 1. **Welcome**
 | **Giorgio Perilongo** | **1** |
| 1. **Communication**
 | **Giorgio Perilongo** | **2** |
| 1. **Approval of minutes from the last SIOP Extended Board meeting**
 | **Giorgio Perilongo** | **2** |
| 1. **Report from SIOP President**
 | **Giorgio Perilongo** | **10** |
| * 1. SIOP Goals and Objectives
 |  |  |
| 1. **Report from Presidents of SIOP Continental Branches**
 |  | **40** |
| * 1. Africa
	2. Asia
	3. Europe
	4. Latin America
	5. North America
	6. Oceania
 | Mariana KrugerAkira NakagawaraGilles VassalSilvia BrandaliseLisa DillerStewart Kellie |  |
| 1. **Miscellaneous**
 | **All** | **5** |
| 6.1 Next Extended Board meeting |  |  |

1. **Welcome**

Giorgio Perilongo welcomed the participants and thanked them for joining.

1. **Communication**

Giorgio Perilongo introduced Susanne Wollaert who will be replacing Valerie Kuffer as SIOP Secretariat Manager and Perry Gil-Ran as Senior Account Manager.

1. **Approval of minutes from the last SIOP Extended Board meeting**

The minutes from the Extended Board meeting held in Amsterdam, May 23, 2014, were approved.

**4. Report from SIOP President**

**4.1 SIOP Goals and Objectives**

Giorgio Perilongo presents the SIOP Goals and Objectives to the Continental Presidents.

**5. Report from Presidents of SIOP Continental Branches**

**5.1 Africa by Mariana Kruger**

***1. New President-elect***

Our new president-elect is Dr Lorna Renner from Ghana, who was elected unanimously. We are very excited about her future term and shall support in every way we can. She will participate as president-elect from October 2014 in Toronto, Canada and take office in Cape Town in October 2015. She is a general paediatric oncologist, familiar with the challenges of paediatric oncology in Africa. She is active in leading the first joint nephroblastoma clinical trial in Anglophone Africa.

***2. SACCSG Meeting (South African Children Cancer Study Group)***

Our current chair is Dr Monica Vhaithilingum and the secretary is Dr Jennifer Geel. We had our annual meeting 12-13 September 2014 in Cape Town. The meeting was well attended and the focus of the meeting was the treatment of histiocytosis, as well as harmonization of treatment protocols in South Africa. Dr Jan-Inge Hente from Sweden was our invited expert and added very useful and practical advice regarding the management of the spectrum of histiocytosis in countries with limited resources. Another focus for the meeting was the update regarding the spectrum of molecular genetic abnormalities, presented by Dr Lizette van Rensburg from South Africa. A new website for the SACCSG has been launched at this meeting (http://www.saccsg.co.za/).

The first ever tumour registry paper is being finalized, which will be the first dedicated report regarding the incidence of childhood cancer in Africa. The first national treatment protocol is recruiting and treating children with retinoblastoma(PI: Mariana Kruger) and we hope to soon have a national treatment protocol for nephroblastoma as well (PI: Janet Poole).

***3. Trainees from Africa training in South Africa***

There are currently two trainees from Africa, training in paediatric oncology at two universities (University of Cape Town - Malawi, Stellenbosch University – Rwanda). Another trainee from Cameroon will join Stellenbosch University in January 2015 and 2 trainees from Ghana will join University of Cape Town in January 2015, strengthening South-to-South collaboration.

***4. POUs in Africa***

Twenty-nine countries in Africa have at least one paediatric oncology unit. The GFAOP (Francophone) paediatric oncology units are located in 11 countries (Algeria, Burkino Fasso, Cameroon, Cote d’Ivoire, DRC, Madagascar, Mauritania, Morocco, Mali, Senegal, Togo) and participate in the clinical trials for nephroblastoma, retinoblastoma, ALL, Burkitt lymphoma and Hodgkin lymphoma.

The collaborative trial for nephroblastoma, involving 5 Anglophone countries, is open and recruiting patients (Cameroon, Ethiopia, Ghana, Malawi, Uganda). Cameroon paediatric oncology units in the Baptist Mission Hospitals (Banso, Mbingo, Mutengene) are active in recruiting and treating children with Burkitt lymphoma, Retinoblastoma, Hodgkin lymphoma and Kaposi sarcoma in clinical trials. World Childhood Cancer provide support for local human resources and Beryl Thyer Trust (UK) provide the financial support for the chemotherapy drugs. A new paediatric oncology unit (1 ward with 10 beds) is in the planning phase for Mbingo hospital, which will become the main treatment center for the Baptist Mission Hopitals. The local parent organization is very active in pig- and chicken farming to supplement meals for parents and provide assistance with hospital fees and out-of-pocket expenses. Publications from Africa are increasing and there are more than 20 all ready for Africa in 2014.

***5. SIOP 2015 in Cape Town, South Africa***

The LOC under the leadership of Dr Alan Davidson is active in the planning of the upcoming conference in Cape Town in 2015. Theme will be 21st centure priorites for childhood cancer. Sponsorship is actively sought to ensure that there are enough scholarships, especially for African colleagues to attend the conference and especially the pre-congress education workshop. The conference venue is excellent and in the center of town with very good accommodation available nearby. The scientific program will be discussed at the upcoming SIOP scientific meeting, where after the keynote speakers will be invited. The social program is being finalized and will be very exciting. CHOC, the local parent organization, will assist with the parent and survivor program.

***6. Major concerns and advocacy issues***

The new essential drug list (EDL) drug list for South Africa does not include the essential chemotherapy drugs. This is of major concern, since this may also influence other African countries to do the same. At the moment we are all advocating for the inclusion of these drugs in the official South African EDL.

***7. Resources for research in Africa***

“Research ethics in Africa: a resource for REC members in Africa.” Editors: Mariana Kruger, Paul Ndebele, Lynn Horn: Of particular interest may be the chapters regarding clinical trials and children as research participants from an African perspective. This book is available as a free ebook under:

<https://africansunmedia.snapplify.com/product/9781920689315>

**5.2 Asia by Akira Nakagawara**

***1. Current status of the clinical pediatric oncology in Asia***

Asia is a huge continent comprising of very heterogeneous regions spanning from high- to very low-resources countries. In the high resources countries in Asia like Japan, South Korea, Taiwan, Hong Kong, Singapore and Jordan, the cure rate of childhood cancers is relatively high, that is very close to the level in US and Europe. However, the system for the long term follow-up of the survivors is still premature. In such countries, the ratio of the number of pediatric oncologist and that of pediatric surgeon is going to be high with a little variety. They already have the system of pathological and molecular diagnoses with the tissue bank. The registration of the patients is relatively good but not perfect. In the middle resources countries in Asia like Thailand, China, India and some other countries, the cure rate of pediatric cancers is gradually increasing. However, it is largely different among the regions. The socio-economical conditions within the country strongly affect the results. In those countries, the pediatric surgeons together with the pathologists have more power to treat the patients with solid tumor than the pediatric oncologists have. The infrastructure of diagnostic and therapeutic systems as well as tissue bank is not enough in those countries. In the low-resources countries in Asia like Laos and Cambodia, there is a large lack of infrastructure for diagnosis and treatment. Many patients are dying without receiving any diagnostic nor proper therapeutic services. The number of hospital is deficient. More seriously, the medical staffs including physician and nurses trained for pediatric oncology are largely lacked, rather absent. One of the key persons in the Laos Cabinet told me that they want to ask the developed countries to educate and train the Laos medical staffs to send back to the home country. Then, they can make the necessary system within the country, that is the most important thing to be done, he said.

***2. SIOP activity***

***1) SIOP Asia 2014 in Seoul***

The SIOP Asia meeting was held in Seoul from April 17th to 19th, 2014. More than 300 people attended from 22 countries. The program was much more attractive than before by introducing more scientific programs. It was very impressive that the activity of pediatric oncology in South Korea is very high. It was also so good that the SIOP President, Dr. Giorgio Perilongo, joined it and gave some important messages to the participants. He also joined the SIOP Asia General Assembly and the APHOG core members meeting, and discussed together how to activate SIOP Asia and APHOG in the future. The minutes of the APHOG meeting is attached.

***2) ICCD***

The celebration of ICCD on February 15th, 2014, was very successful in many Asian countries. In Japan, CCAJ (Children’s Cancer Association of Japan) collaborated with SIOP Asia for

celebrating ICCD. More than 20,000 cards with the posters warning early detection were distributed all over Japan and the red ballooning in the park was performed for the first time in the Chiba city.

**3) HP of SIOP Asia**

Since I have moved from Chiba to Saga, renewal of the HP has been a little bit delayed. It will be reactivated soon.

**4) Paper of the report from the continental president of Asia**

I am so sorry for the delay to complete the paper. It will be finished by the end of coming December.

Tentative Title: “Asian challenges for children with cancer”

**5) Importance of collaboration between SIOP Asia and APHOG**

During the SIOP Asia meeting held in Seoul in April, 2014, we had the APHOG session for 3 hours and discussed about how to activate it. We could have many fruitful discussions, that are attached in this file. The current problem is how to get financial supports.

**6) Venue of SIOP Asia meeting**

# Changed: Bi-annually -> Annually

2014: April Seoul, Korea

2015; April Amman, Jordan

2016: Moscow, Russia

2017: Thailand

2018: Main SIOP Congress in Asia

**3. New Continental President-elect of Asia**

Dr. Chi-Kong Li (Hong Kong)

**4. Suggestion for the future**

a) Activation of the annual SIOP Asia meeting:

* Stimulation of exchange program
* Focused topics
* Work together program
* Prizes etc.

b) Clarify the more specific goals to be pursued in Asia:

We will discuss about this issue at the meeting of SIOP Asia 2015.

What about money needed?

c) How to collaborate with survivors and parents?

 ICCD and others?

d) Communication among the members through ICT:

 HP, TC, smart phone, U-tube, DVD, etc.

f) Tight collaboration with APHOG:

* Registration
* Tissue bank
* Protocols
* Datacentre
* Long term follow-up

**5.3 Europe by Gilles Vassal**

*Kindly refer to separate PDF report which has been send this document*

*Main items reported:*

* General Assembly of SIOPe to be held on 23 October 2014 in Toronto
* Advocacy work for protection of research data launched
* Giorgio Perilongo (GP) added that advocacy activities from SIOPe and SIOP Advocacy group could create synergies and common education activities could also be done
* Gabriele Calaminus stated that SIOP should be a communication platform to gather all activities. SIOP should not get involved in projects that are not owned by SIOP. SIOPe representative should be member of the Advocacy group.

Gilles Vassal asked that during the last board meeting in Amsterdam common goals to implement to all regions where discussed and inquired about the status of this matter.

**5.4 Latin America by Silvia Brandalise**

The SIOP-LA administrative office, inaugurated on Feb. 25, 2014 in Campinas, São Paulo (Brazil) is working mainly with 2 goals:

**1) The Educational Program** related with early childhood cancer diagnosis. Next November, 21-22th there will be performed a course "When to Suspect about Cancer in Children" directed to Medical students, primary care pediatrics and physicians, nurses and biomedical areas professionals/students. The SIOP/UICC/ICCCPO folder (recently translated and printed) will be reinforced and strengthened at this opportunity. From December 2014 till February 27, 2015, there will be held the second Summer Intensive Program (POE Program) for the undergraduate students coming from different health areas. This is a vacation period for them, with a full-time period (10-12 weeks), offering an unique opportunity to participate on research, laboratory activities, radiology, pathology training in order to stimulate them for basic or translational or clinical research in this field.

**2) A Political Action.** The strategy underway gains relevance of childhood epidemiological profile in Brazil, to conquer space in the political and technical agendas in all the government spheres. The knowledge about the unchangeable mortality rates (around 53%) of childhood cancer over the last 3 decades in Brazil, allowed the opportunity to call the attention of the National Health System to be aware of this problem and try to delineate/ establish priorities and to allocate resources in a directed way for a positive modification of this scenery in the country. Another political strategy was officially directed on August 2014, to the Brazilian Union Accounting Court to define Childhood Cancer as a Highly Relevance Theme for 2015-2016, to gradually increase the cure rates to additional 30% more.

The Childhood Cancer Registries distributed in a large number of countries in Latin America, under the leadership of Dr Florencia Moreno (Argentina) is growing. The Parents/Patients Educational activities of the Continental Latin America SIOP started in 2013 with the focus on behalf of the cancer patients and families. Translation to the Portuguese language, from different foreign parent’s associations were done by volunteers and printed. Electronic distribution of the booklets was provided to SOBOPE and to all the pediatric oncology services in the country. There were translated till now about 50 different topics concerning childhood cancer.

Concerning fellowships from other Latin American countries in Brazil, it is fully provided, with no costs for nurses, medical doctors and biologists. The SOBOPE (Brazilian Society of Pediatric Oncology) is underway to standardize the up-to-date medical diagnosis and care for children with cancer. For the Health Ministry we worked on the Acute Myeloid Leukemia in children Guidelines, recently published all over the country.

Finally, we are convinced that SIOP and WHO political pressure should be done at this moment in Brazil and eventually, with other Latin American country with not acceptable mortality rates from childhood cancer. Enclosed are attached 2 previous reports.

**5.5 North America by Lisa Diller**

**1) SIOP North America membership**

According to the SIOP website, there are 123 US members and 42 Canadian members. That number might change, given the current meeting in Toronto. We look forward to reaching out to new members, and are having a meeting on Friday, October 24th in order to brief our membership about activities, and create connections between members. I respectfully invite the members of the Board to attend this meeting, and have issued invitations to you by email.

**2) SIOP North America meetings and member activities**

SIOP North America does not meet as a group under the SIOP banner; many North American members are a part of other professional organizations based in the United States and Canada. These include the Children’s Oncology Group

(COG), American Society of Clinical Oncology (ASCO) and American Society of Pediatric Hematology/Oncology (ASPHO). Because of the connection between ASPHO and SIOP, a plan has been made to use the ASPHO meetings as a site for gathering SIOP members. This will likely just be a social gathering, and has not yet occurred.

Children’s Oncology Group remains the main source of activity in clinical trials in the United States and Canada, but trends have included more international trials, and more international COG memberships of Centers outside North America, including Australia and Switzerland. Travel to COG, ASPHO and ASCO, as well as disease-specific international meetings (ANR, CTOS, Histiocyte Society) remain priorities. Many of the North American members see SIOP as an opportunity to learn about pediatric oncology in terms of global health and implementation in resource-limited countries.

**3) Global oncology**

One of the main interests expressed by the members of SIOP North America who participated in the meeting of the group in London was to learn about and participate in Pediatric Oncology activities in resource-limited countries. There was an interest on the parts of the members to find out how and where they could help and how to make those connections. For that reason, we embarked on a project to catalogue current activities of the members, their institutions, and institutional and individual willingness to provide expertise both locally and internationally. The preliminary work is attached, and will be updated after this meeting. In collaboration with the IT team at SIOP and with Paul Rogers, we will attempt to post this “offering” as a dynamic part of the SIOP website. In addition to this effort, the SIOP North America group has pursued developing a Global Health Special Interest Group (SIG) for ASPHO. This group comes directly out of monthly teleconferences of our membership, and was created in collaboration with our hematology colleagues.

Of note, the inaugural meeting of the SIG will take place at the annual ASPHO meeting in Phoenix, and will include a strategy session and sessions on twinning and global sickle cell interventions. We will also invite a representative from a resource-limited country to offer a presentation on their program. Lisa Diller reported on the North America region. Membership of North America is over 200. They will meet during the 2014 congress.

**5.6 Oceania by Stewart Kellie**

**1) New SIOP Oceania President-elect**

SIOP Oceania welcomes Dr Michael Sullivan who was elected unanimously as new Continental President for Oceania. Dr Sullivan’s election will become effective from the October 2014 SIOP AGM in Toronto and he will act as President-elect until the October 2015 AGM in Cape Town. Michael recently relocated from Christchurch, New Zealand to take a leadership role in solid tumours and neuro-oncology at the Royal Children’s Hospital, Melbourne. Michael is well known and respected on both sides of the Tasman Sea separating Australia and New Zealand and is a prominent member of the SIOEL Liver Tumour initiatives.

**2) ANZCHOG and SIOP Oceania.**

SIOP Oceania does not meet as a group under the SIOP banner, but all SIOP Oceania members are a part of a larger regional professional children’s cancer organisation called the Australian and New Zealand Children’s Haematology and Oncology Group (ANZCHOG). ANZCHOG is the umbrella multidisciplinary group representing all professional groups involved in clinical care, clinical trial management, clinical and laboratory research, education and advocacy involving children’s cancer in our region. Member ship is free and includes virtually all regional SIOP members. Late autumn and early winter in the southern hemisphere is the time of year that ANZCHOG holds its annual scientific meeting. This is a highlight on our regional paediatric oncology calendar and brings together a strong multidisciplinary workforce in excess of 200 delegates to discuss a range of scientific, clinical trials, nursing practice and psychosocial topics. The 2014 ANZCHOG was hosted in Sydney by the Sydney Children’s Hospital from 19 – 21 June on the theme of ‘Improving patient care – from bench to bedside’. International invited faculty included Prof Steven Joffe, paediatric oncologist and bioethicist from Pennsylvania, USA, Prof Andrea Patenaude, a clinical and research psychologist from Boston, Prof Dario Campana from Singapore, Sharon

Savage MD from the Clinical Genetics Branch of the NCI, USA and Dr Leonard Sender, an oncologist who practices across the age spectrum with a particular focus on AYA issues. The meeting attracted wide attendance for Australian and New Zealand centres. An important challenge facing SIOP in Oceania is maintaining and building multidisciplinary interest beyond mostly mid-level or senior paediatric oncologists. Cost of membership, distance and cost in attending the main annual meeting, the absence of a membership fee for joining ANZCHOG and the relative accessibility of ANZCHOG meetings present real limitations to building SIOP membership in this region. A second key area of influence and academic input is Oceania’s close linkage with COG (USA). All recognised paediatric centres in Australia and new Zealand participate in a diverse range of therapeutic, biologic, epidemiologic and observational studies and many centres regard sending oncologists, CRA’s, pharmacists and other multidisciplinary collaborators including surgeons and neurosurgeons to the annual COG meeting as a priority. SIOP faces significant challenges in retaining relevance and promoting its scientific and advocacy missions in this professional space.

**3) 2018 SIOP Annual Scientific Congress**

Bids for the 2018 main SIOP meeting will be invited from Asia, Oceania and Latin America. There is strong interest in bringing SIOP back to Oceania in 2018, particularly as it will be 7 years since SIOP was last hosted in Oceania (Auckland 2011) and one or more cities have expressed preliminary interest in hosting the meeting, together with substantial government subsidies on rental of conference infrastructure. In addition to written undertakings for a 85% discount on Sydney’s new waterside convention facilities currently under construction, y is rebuilding its massive waterfront convention centre and the 2018 meeting would fall within the first 12 months of scheduled opening and steep discounts are offered to secure advance bookings. In my capacity as SIOP Oceania President, I have received calls, but no written offers from Convention Centres in Cairns, Darwin and Adelaide all of whom are interested in promoting and hosting the Annual Congress in 2018.

**4) Advocacy**

Australia is a high income country and a country with a proud reputation of aid and defence of human rights internationally. During the past decade Australia’s commitment to international humanitarian efforts has gradually been wound back and we are no longer on track to meet our obligations specified in the Millennium Development Goals. One key measure, the under-5 years mortality, show that Oceania has one of the lowest rates of improvement of under-5 mortality, across the 22 year period of measurement worldwide. Much more work remains in improving paediatric health in general and paediatric oncology in the Oceania region, beyond Australia and New Zealand. More recently, our foreign aid budget is being reduced to fund Australia’s commitment to join a military coalition in the Middle East and our politicians have publicly linked the reduction in foreign aid to our support for an increased scope of military action. Progress in advocacy in regional countries faces greater obstacles than previously. Fortunately, our role as a site for training paediatric oncologists from South East Asia and South Asia has been preserved, as this role is largely supported by private philanthropy at most Oceania centres.

**6. Miscellaneous**

**6.1 Next Extended Board meeting**

GP said that we might not have the face to face May meeting for cost reasons. The next face to face meeting would therefore be held in Cape Town congress.

**Action(s):**

* Continental reports to be posted on the website.
* Africa Report: Twinning programmes to be put on the SIOP website.

**Decision(s):**

* Giorgio Perilongo explained that there will not be another face-to-face meeting before Cape Town due to cost reasons.