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**Extended Board meeting**

**Thursday8 October 2015**

**Room 1.61**

**8:00 – 17:00**

**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), Stewart Kellie (SIOP Continental President for Oceania), Michael Sullivan (SIOP Continental President Elect for Oceania), Gilles Vassal (SIOP Continental President Elect for Europe), Eric Bouffet (SIOP President Elect), Michael Capra (SIOP 2016 LOC Chair), Juan Quintana (SIOP Continental President for South America), Oleg Chestnov (WHO VP NCD), Andreas Ullrich, Menno van Hilten, Perry Gil-Ran (Kenes), Susanne Wollaert (KAW), Lorraine de Montmollin (KAW)

**1. President Report**

1.1 Welcome

Giorgio Perilongo welcomed the participants and thanked them for joining.

1.2 Communication

1.3 Approval of minutes from the last SIOP Extended Board meeting

The last minutes of the Extended Board meeting held on 26th May 2015 were approved.

**2. Secretary Report**

Paul Rogers presented the membership report.

Giorgio Perilongo said that creating a virtual community would be a project.

Paul Rogers explained that one of the developmental goals was to increase membership benefits to encourage increased membership of SIOP. He said that efforts were to provide additional educational materials. He said he was hoping the updated website would provide the improved benefits expected by SIOP members.

He explained that the issue of SIOP aging membership demographics had been addressed with the Young Investigators initiative. Perry Gil-Ran added that the 2015 congress attendance of less than 50 age was 50%.

Paul Rogers explained that SIOP was discussing with IPSO and PROS on how these societies could be more embedded within SIOP. He said that a merger wouldn’t be an option as yet, but that IPSO might consider a joint membership category.

**Elections:**

Paul Rogers congratulated Eric Bouffet for his election as President Elect. He explained that the Secretary position would be up for election next year and that the elected Secretary would start as Secretary Elect as of SIOP 2016 Congress in Dublin.

He explained that François Doz and Angelika Eggert would end their term as of SIOP 2016 Congress and Steven Hunger would then take the lead as scientific Committee chair. He added that two members of the scientific committee would be elected in 2016 and would begin their terms at the SIOP 2016 Congress. He explained that in order to stagger the elections and to increase the numbers of members of this committee, there would also be one more member elected after SIOP 2016 and another after SIOP 2017.

It was reported that Gregory Reaman would remain Treasurer for an additional year until the congress of 2018 to stagger the election and turnover of the Executive Board members.

**Sosido:**

Paul Rogers encouraged all to use Sosido as it was a good tool for SIOP. He explaining that the Sosido digest was featuring SIOP contributed manuscripts. He added that IPSO was also subscribed to Sosido.

**3. Treasurer Report**

Gregory Reaman presented the financial report for the fiscal year 2014/2015. Gregory Reaman presented the income and expenses statement of SIOP for the year 2014-2015 (1st August 2014 to 31 July 2015). He noted that the total income for the year was € 295 340 and the total expenditure was € 373 386.He raised SIOP was currently using its reserves. He suggested reducing the expenses despite the upcoming budget showing an increased income. He said SIOP should look into potential external fund raise if SIOP wishes to continue supporting all current projects. Gregory Reaman raised that the 2012 congress income was still to be received. It was explained that in case the congress revenue exceeds 100 000 euros, the split would be 66% SIOP and 33% Kenes. Giorgio Perilongo asked the Executive Board if the budget was approved. All approved.

Giorgio Perilongo explained that Kenes was in the process of merging the two contracts.

**4. Committee Reports**

**4.1 Scientific Committee**

François Doz presented the numbers for SIOP 2015 Congress. He said that 1049 abstracts had been submitted. He said that 103 had been selected for poster discussion and 257 for orals.

François Doz raised that there was a need to increase the number of parallel lunch symposium and suggested to do breakfast symposium to increase the number of options. He said that actions should be taken to arrange such meeting for SIOP 2016 as sponsors would then be closing their budgets for the upcoming year. He said that St Baldricks would be included in the programme for SIOP 2016 Congress as it had been agreed on the principle to have symposium at lunch break and that the topic and the speakers were selected. It was also explained that two research awards would be given by St Baldricks in memory of Bob Arceci.

It was asked to review the classification of congress delegates in order to better understand the attendance breakdown.

He asked that the scholarship process be sorted out in the handbook.

He raised that it would be important to ensure that SIOP Congress and Continental meetings would not compete and suggested that the Continental meeting focus on Education and the international Congress on science.

He reported that he was happy to see that the Young Investigators group was growing and outlined that this was a great initiative.

**4.2 Global Advocacy**

Gabriele Calaminus reported on the SIOP Advocacy activities.

She said that the goals of this committee were to

* Lobbying for childhood cancer on the global platform to
* To increase awareness on the political level for the situation of children and adolescents with cancer, in cooperation with other supporting organisations/foundations e.g. Sanofi Espoir Foundation
* To make childhood cancer a notifiable disease
* To work together in conjunction with CCI at the WHO platform to reach out to its member states and as final goal to achieve a resolution for Childhood and adolescent cancer at the WHA
* To achieve NGO status at WHO
* To elaborate the possibility of setting up an independent fund

She explained that SIOP Advocacy group had been working on increasing the awareness on the political level for the situation of children and adolescents with cancer in collaboration with other supporting organisations and foundations such as Sanofi Espoir foundations.

She said the committee had been working with CCI to prepare the World Health Assembly, enabling to add Childhood and adolescent cancer on the global agenda. In parallel, SIOP is working on the registration of SIOP as an NGO in official relations with the WHO.

Gabriele Calaminus explained that the Russian Federation, in partnership with other countries (Germany, Philippines and Russia) had used the 2015 WHA as a platform to elevate the fight against childhood cancer and avoidable childhood deaths as a top global health priority. She explained that the objective of this event had been to demonstrate that childhood diseases must not be neglected within the Non-Communicable Diseases Agenda, which at present, primarily focuses on adults between 30 and 70 years of age.

Gabriele Calaminus reported that the SIOP/Sanofi Espoir Foundation Annual Nursing Awards for Paediatric Oncology Nurses had been awarded to Nurses who submitted applications in the field of Education or professional practices improvement.

She reported that a strategic meeting on Childhood cancer had been held to define concrete actions, following the WHA 2015 discussion.

She explained that September was the International “Childhood Cancer Awareness Month” and that a poster had been created by SIOP Nurses to celebrate “Paediatric Oncology Nurses Day” on September 8th.

She presented the Advocacy Dinner aiming to discuss how to improve access to care for children worldwide.

Oleg Chestnov asked how SIOP and WHO should go from there.

Menno van Hilten raised that it was very important to remind that this was the opportunity to implement a programme to reduce mortality of child under the age of 3. Andreas Ullrich explained that the first opportunity to pass a resolution at the WHA would be in May 2017, and that this would require an approval during a pre-meeting in January 2017. He said that consequently ministers of health would need to submit a letter asking this to add this on the agenda by September 2016. He explained that this letter should mention what is the current situation in their countries and then propose some suggestion. There was a discussion on which countries could be supporting with this letter. It was said that Russia and Ghana would be supporting.

Oleg Chestnov explained that SIOP and WHO would complement themselves as SIOP creates bottom up information flow when the WHO works in top down strategy, i.e. that SIOP has data and knowledge of the situation on the field that are crucial to take this resolution to the next step.

Oleg Chestnov suggested to select six or seven countries to implement programmes and to measure results. Paul Rogers said that adaptive protocols were very important and that some were already in process.

Gregory Reaman outlined that he was happy to see the commitment from the WHO and ensured Oleg Chestnov that SIOP willing as well. It was agreed that SIOP would open a fund dedicated to the WHO –SIOP projects.

Akira Nakagawara asked about the involvement of UICC in this project. Oleg Chestnov said they wouldn’t be involved in this project. Gabriele Calaminus urged the Continental Presidents to take part to this project.

**4.3 Website & Communication**

Paul Rogers reminded all that a survey had been circulated to members to better understand their needs before initiating the renewal of the website. He said that the website & communications committee comprised of various SIOP groups. It had been created to build a new website format that would be more interactive and with more educational content. Susanne Wollaert said that the consulting participation from Yuri Quintana had been very beneficial for all technical aspects.

Paul Rogers said that a conference call had been held with St Jude who said they would focus on educational content and therefore had no issues with SIOP posting its own material on the SIOP website.

**5. Kenes Report**

5.1 Objectives & Goals Status

Giorgio Perilongo reminded all that the objectives & goals document was created to guide the SIOP Executive Board. He reminded all the essence of this document:

* To advocate globally for children with cancer and their families
* To focus on future research needs and encouraging young professionals in paediatric oncology to join SIOP
* To improve SIOP’s visibility by enhancing our internal and external communications
* To increase the SIOP membership to have a vibrant society which understands and fulfils the needs of its members
* To explore possible partnerships with societies sharing the same mission and vision and elaborating a common agenda

5.2 Policy Registry

Giorgio Perilongo explained that the policy registry had been prepared by Isabel Mortara to ensure to keep track of strategic decisions made by the Executive Board.

5.3 Repository

Susanne Wollaert explained that the online repository was giving access to all documents of SIOP to the Board of Directors (minutes, financials documents).

5.4 Membership

Susanne Wollaert explained that the option to sponsor a member had been put in place so that anyone can cover the fees of another member when renewing their own membership.

5.5 Terms of Reference

Paul Rogers explained that each committee now had term of references.

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

**6.1 Africa**

Mariana Kruger reported on the Africa Continental branch (see report). She introduced Lorna Renner as upcoming Continental President for Africa.

**SIOP 2015 Congress organisation:** Mariana Kruger explained that she had been supporting the organisation of the scientific programme together with a pre-congress workshop.

**Twinning programme**: She explained that the twinning programme between South Africa and Cameroon was going well. She said this programme was sponsored by WCC and BT Thyer trusts.

**Treatment protocols**: She explained that the Neuroblastoma one was the first, Retinoblastoma was at its early stages.

**Collaborative PODC nephroblastoma protocol:** She said that a report would be presented during SIOP 2015.

**SIOP 2016 meeting in Zambia**: she explained that Zambia was very slow at responding so the planning will be challenging. She said she would report with a list of issues to the board. Andreas Ullrich said that the WHO could arrange to facilitate the government approval.

Paul Rogers said that Africa had the greatest need for improvement and that SIOP should support as much as possible.

**6.2 Asia**

Akira Nakagawara ported on the Asia Continental branch (see report). He introduced Chi Kong Li as upcoming Continental President for Asia.

**Annual SIOP Asia Congress:**

Akira Nakagawara said the SIOP Asia would now be held yearly. He reported that SIOP Asia had been held in Amman, Jordan and that SIOP Asia 2016 would be held in Moscow, Russia and SIOP Asia 2017 in Bangkok, Thailand. Oleg Chestnov said he could provide its support for the upcoming meeting in Moscow.

**ICCD, February 15th**: He explained that in 2015, in collaboration with CCAJ (Children’s Cancer Association of Japan), SIOP had shared over 20,000 cards with the posters warning early detection and T-shirts in Japan.

**Asian Paediatric Haematology& Oncology Group (APHOG):** Akira Nakagawara explained that the APHOG was growing and met during SIOP Asia 2015 to work on their structure and activities.

**6.3 Europe**

Gilles Vassal reported on the Europe (SIOPE) Continental Branch (see report). He said that Martin Schrappe would be the upcoming Continental President for Europe.

**SIOPE Strategic Plan: A European Cancer Plan for Children and Adolescents:** Gilles Vassal explained that SIOPE had finalised its Strategic Plan to increase the cure rate and the quality of survivorship for children and young people with cancer via 7medical and scientific objectives that was presented at the European Cancer Congress in Vienna, September 2015 and during the SIOP 2015 Congress.

**European Advocacy:** He explained that a group named *Members of the European Parliament Against Cancer* (MAC) would organise a joint SIOPE – MAC event at the European Parliament to cover topics listed in the strategic plan.

**Paediatric Platform (new drug development):** Gilles Vassal explained that the CDDF-SIOPE-ITCC was multi-stakeholder paediatric platform for discussion and to identify solutions to improve the development of new oncology drugs. He said that the 2016

CDDF-SIOPE-ITCC-ENCCA conference was planned to share progresses and discuss proposals based on the outcome of this online discussion.

**ExPO-r-Net (access to care & research):** Gilles Vassal said that SIOPE was a partner of the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment. Working from technical solutions for cross-border paediatric oncology tumour boards, to the development of the Survivorship Passport initiative.

**Education and training**Gilles Vassal explained SIOPE had started a collaboration with ESMO on the needs of TYA, and a new E-Learning module on Cancer in Adolescents and Young Adults has been launched on an educational online platform provided by ESMO. Andreas Ullrich said that the WHO was already in relation with ESMO. He said they had created a committee for emerging countries, following three action points in developing three surveys (access to drug, essential medicine, and human resources).

**6.4 Latin America**

Juan Quintana reported on the Latin America Continental Branch (see report). He said he would be taking over Silvia Brandalise who will be stepping down after SIOP 2015.

**Paediatric Oncology Course (PEOp):** He explained that the main activity for SIOP Latin America had been the PEOp course for students coming from various Universities and Institutions in Brazil. He said this had been a full-time training program. He said the course was based on St Jude POE program. He added that CCI Early Childhood Cancer Diagnosis Chart had been distributed in Portuguese to 300 Paediatric Institutions and Societies all over Brazil.

**SLAOP Meeting:** Juan Quintana explained he had led the SIOP Latin America meeting held in Chile.

**6.5 North America**

Paul Rogers reported on the North America Continental Branch on behalf of Lisa Diller (see report). He said that the major decision made during SIOP 2014 Congress had been to focus on help providing training and education in LMIC and thus have created a group within PODC. He explained that an email had been sent to SIOP members from North America to see if they would be willing to go there for training.

**6.6 Oceania**

Stewart Kellie reported on the Oceania Continental Branch (see report). He introduced Michael Sullivan as the upcoming Continental President for Oceania.

**Outreach and Twinning Activities**

Stewart Kellie explained that Australia and New Zealand aside, the number of paediatric oncologists were very low, but that SIOP members were involved in twinning programmes to palliate this situation. He raised the challenge of sending back highly trained doctors back to LMIC.

**Annual Scientific Meeting:** He said that the theme of the 2015 ASM held in Fremantle in June 2015 had been ‘Difficult Diseases, Difficult Situations’, aiming to address the challenges of providing high quality care and meeting expectations of patients and families. He said that the next Neuroblastoma would be held in Cairns in 2016.

**7. Report from SIOP Nursing Group**

Pernilla Pegert, Christina Baggott, Rachel Hollis joined the meeting.

Christina Baggott raised the issues discussed within the Nursing committee. She said that the nurses committee had no incentive to become a member to attend the congress as Nursing members have no discount rate. She suggested to modify the fee structure so that the nurse’s membership could leverage from the congress.

Christina Baggott presented the nurses committee activities.

**My Child Matters Awards in paediatric oncology**: she explained that the Sanofi Espoir

Foundation had provided ten awards for nurses to enhance the care of children with cancer in low and middle income countries.

**Standards of paediatric oncology nursing practice**: Christina Baggott said that an “Evidence Based Practice Committee” had been created and would meet during SIOP 2015 to help disseminate the guidelines created by other nursing or multidisciplinary organizations throughout the world.

**SIOP 2015 nursing component of scientific committee**: she raised that Linda Abramovitz and Zainu Brownhad worked on the content of the Education Day in conjunction with the local organizing committee to promote communication and

Information exchange between nurses.

**Nursing research**: She said that Faith Gibson created group of nurse researchers, named the “Virtual Faculty” to review SIOP past congresses’ abstracts and that their findings had been published in PBC in July 2015 and that the group would meet again during SIOP 2015 to define future projects.

Gilles Vassal congratulated them for their great work done by the committee. He raised that French nurses were not aware of this, most likely because of language barrier. He asked if there were activities for non-English speaking nurses. Rachel Hollis said that they were many options such as the posters project for Paediatric Oncology Nurses Day was translated in many languages. Andreas Ullrich said that there could be synergies with INCTR and IPOS who have similar activities and in official relations with the WHO.

Christina Baggott raised that standards were hard to implement and that a lot of resistance to change had been witnessed. Andreas Ullrich said that the WHO working group on patient safety could benefit from a presence of SIOP nurses.

Giorgio Perilongo said that the nurses should be included in the continental meeting programme. Chi-Kong Li said he would be happy to include it.

**8. SIOP - PROS Meeting**

No update for this meeting.

**9. SIOP – PBC Meeting**

- Peter Newburger via TC

Peter Newburger reported on the PBC Journal. He said that a special report had been published to honour Robert Arceci. He reported that Thomas Gross had been elected as Deputy Editor of PBC and that Daniel Wechsler Associate Director.

**10. SIOP Annual Meetings**

*10.1 SIOP 2018 Venue Selection*

Paul Rogers explained that the Executive Board had been looking at additional criteria for venue selection such as potential congress attendance and scientific expertise of the region. Following the selection criteria, Kyoto was considered by the executive board the most appropriate destination for 2018 congress. The Executive Board asked the Board of Directors to endorse this decision. All agreed. It was raised that SIOP 2018 would be the 50th SIOP congress. Perry Gil-Ran said that the suggested dates were 13-17th November 2018 as per congress center availability.

*10.2 SIOP 2015 LOC Update*

Perry Gil-Ran said that the attendance of SIOP 2015 was 1421 delegates, without onsite registration. He raised that the feedback was that there had been a good attendance of the Educational day.

*10.3 SIOP 2016 LOC Update*

Michael Capra said that the fund for scholarships was now secured by the tourism office. He said that the Presidential Dinner would be held on Day -1 instead of D-2 and that he would be an informal dinner with only those who are working to prepare the congress. Paul Rogers asked about the relation with the Destination Management Company (DMC) from Dublin. Perry Gil-Ran said that the DMC was working directly with the venue.

Perry Gil-Ran confirmed that as of 2016 the lunch would not be provided for free for delegates in order to save costs. He raised that the rental fee would be high compared to the rental fee of the Cape Town Convention Center.

*10.4 SIOP 2017 LOC Update*

Perry Gil-Ran said that the venue would be the Marriott, in the North West from Washington DC. Gregory Reaman confirmed that despite the venue being outside the city center, metro transportation to downtown was very convenient.

10.5 SIOP Congress Handbook

It was agreed that the Handbook would be modified with the changes suggested during and shortly after the SIOP 2015 Congress. François Doz said he would ask all comments to be sent and integrated in the document by November 2015 after which the document wouldn’t be modified until after SIOP 2017 Congress.

**11. SIOP Young Investigators (SIOP YI-NET)**

Saskia Gooskens, Anna Font-Gonzalez, Reineke Schoot, Heather Danysh

François Doz congratulated the team representing the Young Investigators Committee for managing the committee and developing its activities.

Heather Danysh said that one of the big achievement for the committee was the running the YI Educational Day. She explained it had taken a lot of time to plan and the attendance was very good. She added that one other achievement was to secure a sponsor for a collaborative event to promote international collaboration.

Reineke Schoot said that the meet the expert is always interesting for young people as general Education is still needed for Young Investigators. She said that learning the job of a publisher was very interesting. Heather Danysh said that SIOP was an International congress and therefore was bringing international perspective, enabling all to see things from the eyes of another perspective.

It was agreed that the Young Investigator would send a summary of the challenges they are facing to the Executive Board. Reineke Schoot explained that those were related to the composition of the committee members (i.e. only recipients of the YI award or open to all YI) and to the committee funding for future activities.

Paul Rogers suggested establishing individual partnerships with L&MIC Young Investigators and institutes.

**12. Any other business**

As there was no other business, the meeting finished at 18:00.