



SIOPE General Assembly Meeting

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1. Opening

Professor A. Biondi opened the meeting and welcomed all the presents. The proposed agenda was agreed.

2. Minutes of the SIOPE General Assembly, held on 19 September 2006 in Geneva, Switzerland

The Minutes of last meeting were agreed and approved.

3. Report from the President (A. Biondi)

Professor A. Biondi gave notice to all those presents of the end of his presidency. He expressed his great gratitude to the rest of the board members, explaining that a great progress of SIOPE has been achieved during the two years of his presidency.

Professor A. Biondi further addressed three items that SIOPE could take into account for the future strategy-building: 1.) offering better coordination for the pediatric oncologists within the pan-European network; 2.) closing the knowledge gap between the eastern and western Europe; 3.) designing a more concrete road map for carrying out the SIOPE future activities. (see appendix 1)

Offering better co-ordination for pediatric oncologists

Professor A. Biondi noted that there was still a great room for improvement for strengthening the influence of the pediatric oncologists in Europe. In the past, there was a long history of carrying out independent projects in the field. However, within the lately developed pan-European network, professionals who work in the pediatric field feel the need to collaborate under a common frame and to speak with one voice to the policy-makers in the European institutions.

Clinical trials in childhood cancer

Professor A. Biondi noted that Survival of children with cancer shows continued improvement but less so in Eastern Europe, where entry into clinical trials is less common. Therefore, clinical research is an integral part of daily clinical practice among the majority of

European paediatric haemato-oncologists (national and European clinical trial networks). It also means that the majority of their workload now falls under the scope of the EU Clinical Trials Directive.

The long term vision is to have an umbrella organisation for childhood cancer in Europe. This would draw on the existing expertise to provide a common structure for collaborative working and a common interface to provide information and links for health professionals, parents and patients, pharmaceutical companies and other organisations.

SIOPE Europe has coordinated two very informative meetings of existing multinational clinical trial groups and national organisations working in the field of childhood cancer in Europe, in May 2005 and March 2006 and a third one is already planned in October, 2007.

The main conclusions from these meetings were that we face many challenges in common to continue our previous level of clinical research activity and that we wish to have a more unified voice for the childhood cancer research community in Europe to solve these problems. It was clear from these meetings that SIOPE Europe has been given a mandate to act as a unified voice for childhood cancer in Europe.

The proposed actions for further developments of SIOPE activities are as follows:

- 1.) Amendments to SIOPE statute to incorporate legal entities (i.e national study groups) or informal networks (European clinical study groups) as SIOPE members.
- 2.) Promote SIOPE visibility at EU levels (EMEA, DG research etc)
- 3.) Promote a stronger administrative and scientific support to SIOPE initiatives (transfer of the SIOPE office in Bruxelles and hiring of new staff members)
- 4.) Activate and support Training Courses in partnership with ESO, ESH and EHA.
- 5.) Promote the contacts with members (new website)

With above the current activities of SIOPE, Professor A. Biondi was positive that SIOPE would follow a proper road-map for its future developments.

Introduction of the SIOPE New Membership

It was agreed that individual members for SIOPE will still come from the European residents of the SIOPE International. However, there is another type of membership to be developed: the association members. It was decided that SIOPE is going to develop its membership in the direction of group membership. The professional associations can apply for membership as an entity.

Special Thanks to Professor Kathy Pritchard-Jones

Professor A. Biondi specially thanked to Professor K. Pritchard- Jones for her efforts on developing and maintaining the relationship between SIOPE and the European institutions.

Recent Development of SIOPE

Professor A. Biondi introduced the recent developments of SIOPE: Professor R. Riccardi will further foster the collaboration between the education & training committees and other institutions. More training and courses are planned to be organized. Professor K. Schmiegelow will further develop the lately founded website of SIOPE.

A clearer road map has been developed and the feeling towards it was considered positive. Professor A. Biondi thanked everybody for their support during his presidency.

Professor K. Pritchard-Jones was introduced as the SIOPE new president as of 25 September 2007 and as the chair for the rest of this meeting.

4. SIOPE Clinical Trials (K. Pritchard-Jones)

Professor K. Pritchard-Jones expressed her gratitude on this new responsibility. A report on the current activities of Clinical Trial Committee was firstly delivered.

What has been done?

Two meetings have been conducted – the meeting with national trial group and the meeting with the parents group in Europe. From the meetings, it was found that the professionals share the same problems and it would be much easier for the professionals to work together to find solutions to these problems. It was considered necessary to have a unified voice for a stronger strength.

Contacts to the parents were also made. The SIOPE CTC group was invited by the EU institutions and other European institutes such as EMEA for consultations on relevant issues.

The topic on Pediatric priority drug list is still to be developed.

Regarding the topic on ethics of clinical trials in children, the SIOPE CTC group is trying to encourage consultations of the EC/Clinical Trial Facilities Group (CTFG). The first submission of SIOPE opinion was submitted in September 2005.

Regarding the topic of the Commission consultation paper, SIOPE has delivered its first response. The European Commission has asked SIOPE to follow up the consultation process. SIOPE has been given a seat during the coming meetings.

Professor K. Pritchard-Jones was pleased to inform all those present that SIOPE will take a more active role in terms of consultation for the European policy-makers during their decision-making process. The next meeting scheduled would be the one taking place on the 3 October 2007 with the European Commission. For further developing SIOPE's political role, it is considered to be necessary that SIOPE has to unify as a single voice for its members.

Professor K. Pritchard-Jones also gave a briefing on the topic of FP7 funding. SIOPE has been trying to facilitate the cooperation between the groups on the relevant issues.

What Next?

A general and crucial question was raised: what can SIOPE offer to the SIOPE member?

5. New Structure of the SIOPE Office

The New SIOPE Office

The new SIOPE scientific coordinator - Ms. Samira Essiaf and the new SIOPE administrator – Ms. Jocelyne Wang were introduced to all those present. Ms. S. Essiaf's main tasks will be to facilitate the interactions/collaborations within the committee members and among the different working committees and to be the desk for the current bylaws. Ms. J. Wang's main tasks will be to run the office administration and maintain / develop the databases, the new SIOPE website and memberships.

With this new office structure, SIOPE is determined to offer more efficient and effective services to its members. An EU lobbying link and cooperation with other groups will also be further developed shortly. Professor K. Pritchard-Jones proposed to check with other group members in the coming meetings to see what more needs to be done in the future.

Revision of the SIOPE Statutes

Professor K. Pritchard-Jones also gave a briefing on the lately revised SIOPE statutes. The major modifications from the previous version are as follows:

1.) the change of the name

The full name of SIOPE – SIOP Europe will remain the same. However, there will be a new acronym: SIOPE. A new logo will also be produced soon after.

Professor T. Eden asked to be informed on the design of this new logo.

2.) membership

Members' voting right will not be changed. As a member of SIOPE, members have the right to vote for all sorts of important decisions for the organization's future. Members also obtain the right to elect the board members.

The eligibility to become a SIOPE member has been revised. Not only the physical individuals, but also professional entities which are involved in the European pediatric research, are entitled to apply for the SIOPE membership.

3.) different categories of membership

Two different categories of the memberships were introduced. As for the physical individuals, all SIOP International members located in Europe will be automatically identified as the SIOPE members. Currently, SIOPE will not start working on the recruitment of individual members.

A new type of membership was introduced to the members: the group membership. The professional groups located in Europe can apply for this new type of membership.

Professor K. Pritchard-Jones again explained SIOPE's willingness to assist every professionals working in the field. There is obviously a need to have a common template, in order to organize relevant activities more efficiently and effectively.

No membership will be charged in this case.

Professor K. Pritchard-Jones asked the assembly to give a mandate to the Board to finalise the membership categories and statutes in agreement with SIOPE International. This was agreed unanimously by all voting members present.

Professor T. Eden suggested to charge membership fees from the association members, in order to expand the limited financial resources of SIOPE. He also noted that SIOPE Europe was entitled to apply to SIOPE International for financial support for its continental meeting (ie ECCO).

6. Education and Training; Training courses; Accreditation

The chairman of the SIOPE Education & Training committee, Professor Riccardo Riccardi, gave a presentation on the current activities of the committee.

He noted that for the topic of educational training, the aims of the committee are (see appendix 2):

- 1.) Regulations for adequate training of Pediatric Oncologist in Europe.
- 2.) Accreditation of training institutions;
- 3.) Training courses.

The main goal for the future developments of the relevant activities is to offer fewer training courses but with better quality.

Professor R. Riccardi also noted problems arising from the limited financial contributions which SIOPE could contribute in this domain. Given the limited financial resources, progress of the relevant activities are restricted. Therefore, SIOPE has to look for more funds for future development in this domain.

He used the coming pediatric oncology class as an example. For the coming ESO-SIOPE Pediatric Oncology Masterclass, ESO is due to contribute 40,000 euros to the program but SIOPE is only able to contribute 5000 euros. In order to cover the cost, Professor R. Riccardi had to look for other sponsors. At the end, he got another 10,000 euros from from Fondazione per il Neuroblastoma.

In agreement with A. Costa, the ESO President, this course name is defined as 'ESO-SIOPE Pediatric Oncology Masterclass.' The class will be held in Ascona, Switzerland in November 2008.

As for the coming ITCC programme, which will be held in March 2008, the SIOPE involvements will be to have the logo on the flyer and to advertise this event on the new website.

The notion to use the SIOPE logo for the scientific training courses was proposed. If an institution or an organization would like to use the SIOPE logo for their training activities, they have to write to the SIOPE Board first to see how it can be involved. The request for the use of SIOPE logo for scientific courses and the similar shall be presented to the SIOPE Board or to SIOPE/ESPFI ETC. A reply shall be followed within 30 days. Professor R. Riccardi used the coming ASPO event as an example of this kind of request. It will have the SIOPE logo on the flyer and will have the event advertised on the SIOPE website.

It is also proposed to organize different classes for different themes and not to have the same topics repeated each year. SIOPE also would like to get more involved in the organization of training courses focusing on tumor related issues.

7. SIOPE Website

Professor Kjeld Schmiegelow, the main designer of the new SIOPE website, gave a presentation on the on-going construction of the site. The structure of the site was introduced.

The website will be centrally administrated in Brussels by the SIOPE administrator Jocelyne Wang, under the supervision of Professor K. Schmiegelow, the webmaster of the site.

Members may submit information to be uploaded to the SIOPE administrator in Brussels with an instruction on where to place it in the section-tree. The administrator will structure and edit the information accordingly.

The new SIOPE website is to be the online platform for all members. The recent priority of the site is to revise and update the submitted contact information of the members. The final goal is to obtain an up-to-date database, in order to facilitate the information-exchange among the members and working groups.

An update of the site is to be sent to the members every three months.

Professor Tim Eden raised a question on the confidentiality of these contact info.

Professor K. Schmiegelow explained that there would be four different categories to access this new website: webmaster / administrator; board members; members, the public. The access to the contact information will be limited as 'members only'.

8. Financial report

The SIOPE Treasurer, Professor B. Morland gave a presentation regarding the overview of the SIOPE account to date.

He also noted that the situation of the account still needs to be clarified. The account details and reports were still held and prepared by Professor G. Perilongo, the former Treasurer of SIOPE. It was proposed and agreed that as soon as the SIOPE office will be registered in Brussels by the end of this year, an account should be opened in Belgium and all the SIOPE financial resources shall be transferred there.

9. Collaboration with nurses and parents

No reports were delivered.

10. Any other important business

Dr. P. Kurkure, the president of SIOP Asia, gave a presentation on the coming SIOP congress, which will be held from the 1 to the 4 November 2007 in Mumbai, India.