



**38th Congress of the International Society of Paediatric Oncology
September 18 – 21, 2006, Geneva Switzerland
Annual General Assembly of SIOP Europe**

Date: – Tuesday, September 19, 2006
Time: 18.45-20.30
Location: Room 1 of the CICG Geneva

MINUTES

1. Opening
Prof. G. Henze opens the meeting and welcomes all SIOP members present.
He notes that he is happy with this year's meeting as there are a god number of participants at the paediatric sessions.
2. Minutes of the SIOP Annual General Assembly, September 17, 2004 held at SIOP 2004 in Oslo, Norway
AV comments about the incomplete AGM participation list. He suggests to do a head count and then list the names. A head count is done and 17 members are present.
Otherwise the minutes are approved as a correct record.
3. Report from the President (G. Henze)
Prof. Henze notes on the following:
Terms of officers:
In 2006 several officers will end their terms. For this reason two new Board members are needed. The membership was asked to send in nominations and three names wre received: R. Ladenstein, A. Zoubek and M. Buyukpamukcu. If these people all wish to stand for election a ballot will be held in the near future.
In addition, a President-elect has to be nominated. The Board has received the nomination of Prof. K. Pritchard- Jones. More nominations can still be sent.
FECS:
There have been some new developments in FECS. At present there are 6 full member societies (ESMO, ESSO, ESTRO, EACR, EONS and SIOP Europe) and a number of associate member societies.
It has been discussed and decided in FECS that a change was to be made in the oncology scene in Europe, and that the Federation had to be changed into an European Cancer Society (ECS), not based on society membership, but on individual membership. The reason behind this was more or less to be a better counterpart to ASCO. One of the changes would be that FECS would also be open for other diciplines.
The societies more or less agreed to this change, and SIOP Europe's main reason to be included is that they need to have political representation in Europe.

ESMO decided at a later stage to retain their name and to become the European Society of Multidisciplinary Oncology, and to also become open for other disciplines.

This decision would cause competition between the ECS and ESMO, which is now a point of discussion between the member societies.

FECS Special Project Fund – Application SIOP Europe

SIOP Europe and EONS decided to send in an application of a collaborative project on how to improve the collaboration between nurses and doctors. This application was approved by FECS. Project co-ordinators are G. Perilongo, F. Gibson, P. di Giulio and M. Jankovic. The project will be a 3-year project and FECS has granted Euro 76.000 to accomplish this.

SIOP Europe activities in Europe:

In October 2004 there was a meeting of SIOP Europe representatives, ICCCP representatives and a Member of Parliament, Mr. P. Liese. This was a very successful meeting at which 32 members of parliament were present. This large number of parliament representatives was quite unusual and all seemed interested to help. No concrete proposals have yet been received. To be followed up further.

Directive on clinical trials:

On May 26, 2005 there was a meeting of the SIOP Europe Clinical trials committee and the representatives of the major European clinical trials. Prof. K. Pritchard-Jones will report on this meeting in more detail, but it was a very satisfying meeting.

Other issues:

SIOP Europe and SIOP International: The Board of SIOP Europe wish to make of SIOP Europe the umbrella organisation of paediatric oncology in Europe. SIOP Europe is on one hand related to SIOP Int., and on the other hand, they are their own independent society. This is quite a complex situation and is still to be discussed further.

SIOP Europe and ESO: SIOP Europe have been in contact with ESO, Dr. A. Costa, and it was decided to co-operate with ESO in the organisation of a masterclass to be held in 2006.

ECCO13: Prof. Henze notes that in the ECCO13 Scientific Committee the following members were represented: M. Stevens, C. Patte, G. Perilongo and himself.

He notes that there were many good non-paediatric sessions of high quality and with an interesting programme at ECCO, that are relevant for paediatric oncologists.

He thanks the people that were involved in the organisation of the paediatric sessions and notes that the paediatric sessions were well represented at ECCO.

No questions were raised.

4. Report from the Treasurer (G. Perilongo)

Dr. Perilongo reports on the finances of SIOP Europe. This overview was approved by the

SIOP Europe Board.

Status as per 1 January 2005: Euro 117.419,69 (in SIOP Europe account)
Euro 20.000 (in money market funds)

Expenses:

SIOP E Board meetings	Euro 4.525,50-
SIOP E Secretariat	Euro 8.160,- -
SIOPE Educational And Training Ctte	Euro –
SIOPE Clinical Trial Ctte	Euro 1.954,73-
Miscellaneous	Euro 1.471,88-
ECCO13 scholars	Euro 16.570,23-
SIOP E Nurses	Euro 420,43-
SIOPE Special Project	Euro 2.504,-- -
Bank charges	Euro 138,80-
Overexpenses 2004	Euro 12.195,75-

Income:

Interest money market funds	Euro 1.556,12+
Income miscellaneous	Euro 791,-- +

Status as per 30 October 2005: Euro 71.825,74 (in SIOP Europe account)
Euro 20.000 (in money market funds)

Prof. Perilongo notes that if all budgeted expenses are spent, the debt will be Euro 29.027.

There is a tendency in increasing activities and thus expenses. As the income remains more or less the same every other year, this is a problem to be addressed. We have to either limit the expenses or and look for alternative sources of money.

He notes that due to the amount of Euro 76.000, which has been provided by FECS for the Special Project, and to the income from ECCO13, SIOP Europe does not have to be pessimistic, however, we have to be careful in spending.

A. Biondi adds that in order to expand the activities of SIOP Europe, we cannot rely solely on the income from the ECCO meetings. A fundraising strategy is needed. Another issue to be discussed is als the membership fees of SIOP. At present SIOP Int. receives the fees of all members, including the members of SIOP Europe. This has to be discussed by the two Boards.

Prof. A.J.P. Veerman (Treasurer of SIOP Int) comments that for paediatric oncology fundraising is difficult. Only a small number of pharmaceutical firms would be interested and only if they feel if they get anything in return from paediatric oncology. He proposes to discuss the issue of fundraising together and hen divide the gains made.

M. Stevens disagrees with A. Veerman and notes that SIOP Europe is truly European oriented. In order t obtain sponsorship from European companies or organisations, you need European goals/aims to attract sponsorship.

He notes that the membership fees paid by members from Europe should go to SIOP Europe and SIOP Int. should find another format to work in. This could be more of a federation.

A. Veerman notes that this is an interesting point of view. It would be just the other way around of what FECS is now doing. Prof. Perilongo agrees with A. Veerman and notes that this way of thinking would divide SIOP Int. This was not the initial idea of creating SIOP Europe.

M. Stevens notes that SIOP Int. would never address European issues (clinical trials etc). K. Pritchard-Jones notes that if SIOP Europe would not exist, another entity or group would become the umbrella organisation of paediatric oncology in Europe.

A. Veerman notes that he fears that these developments might cause SIOP Int. to disintegrate into various continental organisations. It was however, the goal of SIOP Int. to cover the whole world.

G. Henze notes that at present it is becoming clear that SIOP Europe is getting a different role and is undergoing a unique process within oncology developments in Europe. He suggests to discuss this issue in the coming Board meeting of SIOP.

A. Veerman notes that it should indeed be discussed at the next Council meeting.

A. Veerman asks the Board how SIOP Europe will be organised within the new European Cancer Society? Will the members have to pay fees? G. Henze notes that this will be the case, but that these will only be low fees.

Irrespective of what will happen, SIOP Europe will continue to exist and acknowledges the problems that might arise from this issue.

M. Stevens notes that the fees will not be high, but will be around Euro 30.

A. Biondi notes that it should be discussed with SIOP Int. if these fees could be included in the SIOP membership fees.

K. Schmiegelow notes that there are many issues to be dealt with by SIOP Europe. He confirms that fundraising activities are needed and that SIOP Europe will need a mandate from the membership to work on this. Collaboration with SIOP Int. is important and should be followed up.

A. Veerman agrees and notes that the SIOP congresses made some money, which is being kept to cover a possible congress loss, however, fundraising is important and should be an activity of SIOP.

G. Henze concludes the discussion by noting that in order to be able to do fundraising, a vision is needed. This is to be determined first. A European COG could be such a vision. This is to be further discussed. Also if SIOP Europe wishes to be the only legal entity in Europe in the paediatric oncology-hematology community, what can we give back to the groups that are already existing? For this money is needed.

If SIOP Europe would be a European COG, then the European government should pay for this and take responsibility for this.

5. Report from the Secretary-General (K. Schmiegelow)

K. Schmiegelow notes that he has not much to add to the former discussion. He only notes that as there are many informal working groups in Europe which have no common information provider, the Board of SIOP Europe plan to expand the web site of SIOP Europe.

R. Kennis and A. Veerman note that at present SIOP Europe is making free use of the SIOP Int. web site as being part of the society SIOP Int.

6. W. Kamps reports on the activities of the SIOP Europe- ESPHI Education and Training Committee:

W. Kamps notes that this committee was founded in 2000. At the time not all European countries were represented. However, at present the committee has liaisons with all European countries. The main activity of the committee was the development of a paediatric oncology training programme. This was approved by the national societies and UEMS. Paediatric oncology was therefore also recognised as a sub-speciality. The training programme was widely promoted and was also translated. At the moment it is implemented in the major European centres.

The current activities of the committee are regarding accreditation of training centres. In this respect surveys and visits are being undertaken by the committee.

Apart from this, the committee have been very active in education and is at the moment involved in the programme of the SIOP Europe – ESO masterclass.

G. henze thanks the Education and Training Committee for their achievements and involvement.

G. Vassal asks how the accredited training centres will be called and how are these recognised. These are recognised by the European Board of Paediatrics (EBP). The training courses are accredited by ACOE.

7. SIOP Europe Clinical Trials (Kathy Prichard-Jones)

K. Pritchard-Jones notes that there are many different ways to apply to funds for clinical trials. The main issue to apply to these funds is to use all European expertise so there is more chance to submit a successful application.

On May 26, 2005 representatives of many national groups and trial groups discussed the abovementioned issue and tried to identify the problem areas they encounter.

The main message from this meeting was that the best way is to speak with one single voice to the clinical trials facilitation group. A document to this group was submitted, but no feedback was provided so far from this group. K. Pritchard-Jones asks if the members agree that this document is published online. This is agreed by the membership present.

There will be another meeting with the national group and clinical trial group representatives on March 7, 2006. At this meeting there will also be representatives from paediatric activities in countries that have no national groups.

The meeting will be announced in more detail by e-mail to the members and national groups.

G. henze thanks K. Pritchard-Jones for all she has done so far. These actions will be very valuable for the future.

G. Vassal notes that at a meeting of the GFGCP held in Brussels on paediatric medicine regulation, an agreement was reached on a 6 month extension of the patent. This is to be in place by the end of 2006. EMEA is looking into this issue, however the EU is not prepared to fund an infrastructure for this. This has to be done by the national member states. This is a difficult situation.

8. Evaluation on meeting with Member of Parliament on October 27, 2004.

G. Heze notes that he already reported on this and that another small meeting for follow-up is desired.

M. Stevens notes that in two weeks there will be a launch of a new structure called “MEPs against cancer”. SIOP Europe is to be involved in this. Mr. P. Liese (the MEP with whom the meeting took place) was not involved in this, so perhaps he was not the right person after all. M. Stevens notes that the MEPs mainly listen to patients, so the importance of patient representatives in SIOP Europe is large.

9. Collaboration with nurses and parents

Nurses: A. Biondi notes that by taking part in the FECS Special Project, SIOP Europe is involved together with the nurses (EONS) in a research project which aims to improve the collaboration between nurses and doctors. Certain centres in Europe are involved in this project and it is a good opportunity to strengthen the relationship between SIOP Europe and the European nurses.

Parents: A. Biondi notes that SIOP Europe should make a strong connection with the Parents associations. G. Henze adds that M. Naafs of the ICCCPPO was also involved at the MEP meeting. It is suggested to make new contacts with the parents and patients associations and reinforce collaboration. Perhaps a meeting should be organised. This is to be further discussed on the Board and the members will be updated on this.

11. Any other important business:

It is noted that Prof. P.A. Voute has been given the SIOP Europe Award. His lecture will be on 2 November.

A. Veerman wants to compliment the Board with a very nice programme at ECCO13. He also feels that the e-mailing sent prior to the congress with the paediatric programme information was a good initiative.

No other questions or comments were made and the meeting was closed at 19.00.

Present at this meeting were:

S. Bielack
A. Biondi
C. Gidding
G. Henze
W. Kamps
H. Kosmidis
A. Navajas
O. Oberlin
G. Perilongo
J. Plaschkes
G. Popa
K. Pritchard-Jones
C. Sabado-Alvarez
K. Schmiegelow
J. Stary
M. Stebnicky
M. Stevens
G. Vassal
A.J.P. Veerman
P.A. Voute
E. Widing
B. Yalcin