



**36th Congress of the International Society of Paediatric Oncology (SIOP),
September 16-19, 2004, Oslo, Norway**

**Annual General Assembly of SIOP Europe – Friday, 17 September 2004
from 12.30 to 13.30 at the Vika Cinema Sal 3, Oslo, Norway**

MINUTES

1. Opening

GH welcomes all members present and asks if anyone has additions and/or changes for the agenda. It is noted that there was a mistake in the newsletter. This will be corrected. Apologies are made by GH and KS.

2. Minutes of the SIOP Annual General Assembly, September 23, 2003, Copenhagen, Denmark

These are approved without any remarks.

3. Report from the President (G. Henze)

SIOP Europe now has their own statutes. These are in the final stage of being registered. The status of SIOP Europe is rather complex as on the one hand SIOP Europe is a continental branch of SIOP International and on the other hand SIOP Europe is an independent society. This was required in order to be a full member of FECS. SIOP Europe is represented in FECS by M. Stevens, former President of SIOP Europe and treasurer of FECS and by GH himself. The role of SIOP Europe in ECCO (the congress organised by FECS) has increased as well and paediatric oncology is quite well represented in this meeting.

From the ECCO meetings SIOP Europe receives their only regular income. The membership fees of members of SIOP Europe go to SIOP Int. No other income is received. This money is spent on management by the board, scholarships for ECCO and for other meetings such as Flims.

One activity planned is to apply to the FECS Special Project Fund. This is money available for joint projects from 2 member societies. SIOP Europe will submit a proposal together with the European Nursing Society (EONS) on the organisation of educational meetings in Europe, especially with the new member states in central and eastern Europe.

SIOP Europe has now also a relationship with the European Union. This was thanks to Mrs. K. Vandendael from FECS. One of the topics discussed was the new directive on clinical trials. In this respect SIOP Europe will be able to meet with some representatives of the European Parliament later this year (October 2005). During this meeting SIOP Europe, together with the parents and nurses, will be able to explain who SIOP Europe are and what the problems are for paediatric oncology, caused by the new directive.

Also linked to the problems related to the new European directive on clinical trials, SIOP Europe has established a Clinical Trials Committee, chaired by Kathy Pritchard-Jones. This committee had a meeting yesterday. Prior to the establishment of this committee, SIOP Europe had sent a survey to the various national societies and groups on how they conduct clinical trials. SIOP Europe is trying to get in closer contact with these groups and societies in relation to clinical trials, but also in order to establish what the role for SIOP Europe could be.

Re. Education and training, J. Mann will report on the activities of this committee later in this meeting.

SIOP Europe newsletter: The first SIOP Europe newsletter was produced (with a printing error to be corrected). This will appear twice yearly and will provide information on SIOP Europe.

GH then says "Goodbye" to Micheal Stevens, who is stepping down from the Board. He thanks M. Stevens for his contribution and notes that he has been very active and made SIOP Europe really visible in Europe. Andrea Biondi is selected as the new President-Elect.

A.J.P. Veerman congratulates SIOP Europe with the newsletter. He notes that the logo is very similar to the SIOP logo which could create confusion.

J. Mann asks if it could be considered to have a page of information by the Education & Training Committee in the newsletter. GH and KS note that this is very much appreciated and in future the ETC report will be included.

As final item GH notes that A. Navajas is also stepping down from the Board. As she is not present, she will get her certificate later.

R. Kebudi notes that the lack of SIOP members at the ECCO meetings is due often to the almost clashing of these meetings. GH notes that in the year of the ECCO meeting, SIOP is not meeting in Europe. SIOP is meeting in Europe only every 4 years. However, FECS is considering having an annual meeting. If this will be the case, it will be unavoidable that there will be clashes. SIOP Europe is trying to make the paediatric programme at ECCO as interesting as possible and also aims more on the younger people in SIOP who are not able to travel to far destinations.

4. Report from the Treasurer (G. Perilongo)

GP notes that SIOP Europe is in good shape financially. The money from SIOP Europe should not stay in the bank, but is to be invested.

From ECCO12 the income was Euro 91.935. This sum is to be divided over 2004 and 2005.

GP informs the members on the income and expenses of SIOP Europe:

Status in January 2004 is Euro 196.000+

In September 2004, the amount is Euro 150.000+

About 48.000 was spent on liabilities. A specification is shown to the participants.

The fiscal year is from January to December. In February a budget was established, based on income and expenses of the previous year and on the projections of the coming year. The expected income for 2004 comes from the ECCO12 meeting, which is Euro 91.935. This money was to last for 2 years. So the income for 2004 is actually Euro 48.000. GP notes about the expenses in 2003: secretarial costs; Board activities, Statutes, ECCO12 fellowships, Nurses activities, Bank charges etc. Based on this, the budget of 2004 was set, with some new expense items.

Actual income for 2004:

ECCO12 2003: Euro 47.967,50

Bank interest : Euro 1.282,15

Baxter Germany: Euro 1.500

Actual expenses in 2004 as of 05-09-04:

ECCO12 costs: Euro 1.977,13

Board meeting costs: Euro 9.886,13

Estimated costs:

not planned

Euro 10.000

SIOPE secretariat:	Euro 14.176,--	Euro 16.128
2003 ETC costs :	Euro 165, 23	not planned
2004 ETC costs:	Euro 1.209,62	Euro 5.000
Trial Committee :	-	Euro 5.000
Miscellaneous:	Euro 863,88	Euro 500
ECCO 12 scholars:	Euro 16.181,47	Euro 13.000
Nurses:	-	Euro 5.000
Flims fellowships :	Euro 5.000	Euro 3.000
Bank charges:	Euro 523,10	Euro 400

As it looks now, there will be a negative balance at the end of 2004.

GH asks if there are questions or remarks:

D. Walker compliments GP with the clear financial overview and notes that it shows that the money is spent more than SIOP Europe actually has, but in this early stage, this is a good thing as you have to invest and look ahead.

D. Walker also asks if there is a relation between the number of participants per society and the money paid to the societies. M. Stevens notes that the profit of the ECCO meetings is allocated among the 6 full member societies by a formula based on a standard fixed amount and a variable component which is proportional to the number of the members of the member societies that attend ECCO. About 10.000 people attend the ECCO meetings, but only 40% are signed up as members of the full member societies of FECS. So many participants do not register as being a member of one of the 6 societies. Usually there are about 90 SIOP Europe members only, so this is very small in relation to the number of the participants of the larger full member societies.

M. Stevens notes that if there will be an annual ECCO meeting, this formula will change and it will become interesting to see what happens. A lot of politics is involved in this.

K. Pritchard-Jones notes that we have to stimulate many young members and trainees to go to ECCO. KS notes that the paediatric oncology programme is improving every year and should attract more members every time.

A. Veerman asks how it is arranged in case ECCO makes a loss; will the 6 societies then have to pay a part as well. M. Stevens notes that the chance of a loss is quite minimal, and if there is one, FECS has a large liability fund that can cover a loss if it happens.

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

KS notes that the SIOP Europe profile is changing because there are specific issues that SIOP Europe needs to address, such as equal access to high quality medical standards; education, clinical trials etc. SIOP Europe therefore collaborated with the other 5 member societies in a project on continuous medical education, which was published in a booklet.

The General Assembly offers the possibility that the Board can meet with the members and is the opportunity for the members to give the Board feedback on what they expect from the SIOP Europe Board.

6. Education and Training; Training Courses; Accreditation (W. Kamps)

As the Chairman Dr. W. Kamps is not able to be present, Prof. J. Mann reports in his place.

JM reports on the following:

Accreditation of training centres: After having written and published the paediatric oncology training programme, the ETC has been working on the accreditation of training centres. Criteria for accreditation have been agreed upon, but no system for visitation of centres has yet been written. Some systems are already in place or are being developed in a few countries like the UK, Netherlands and France. CESP felt that they could manage the organisation of this visitation system also for paediatric oncology. However, this was considered by the ETC as an unrealistic ambition. CESP has now agreed that where a country or grouping of countries have set up a satisfactory visitation system looking at training provided in centres, they will accept that system. The ETC feels that this is the route that paediatric haematology and oncology should take. The role of the ETC is to oversee the accreditation systems and make sure that they are to the accepted standards rather than personally undertaking visits as a group or through CESP. This means that smaller countries need to co-operate. The Nordic countries are already working

on this. This model could hopefully followed by other countries.

The ETC have not yet made any substantial progress on systems for appraising trainees, and this is the next activity for the ETC. The ETC have already looked at various documents used in the UK.

ETC composition: Regarding the composition of the ETC, at present there are 9 members at the committee. It has been decided that instead of having a more or less ad hoc arrangement of members, the ETC will have a representational system per (group of) countries in the future. Representation of the Nordic countries is done by K. Schmiegelow; Spain & Portugal by A. Navajas, Italy & Malta by G. Masera; Czech Republic & Southern Eastern block countries by J. Sary; Germany, Austria & Switzerland by U. Creutzig, Greece & Cyprus by H. Kosmidis; UK & Ireland by J. Mann and F. Hill, Holland & Belgium by W. Kamps, and France by F. Doz. This new composition should improve communication between the ETC and the educational organisations in the European countries.

Reports to CESP: The ETC has to report to CESP and the Board of Paediatric once or twice a year. This is done by W. Kamps.

Training courses: The ETC has tried to identify and promote over the last year training programmes/courses for trainees. In Italy there has been a successful course on paediatric haematology-oncology for 60 trainees, organised by the European Haematology Association, the European School of Haematology in association with SIOP Europe. This course will be repeated in 2005.

The ETC is also in negotiation with the European School of Oncology to set up similar courses on solid tumours. No dates are however available yet.

Standards for Training courses: The ETC is also planning to set standards for training courses which then can be endorsed and promoted in Europe by the ETC and SIOP Europe.

Application to FECS: The ETC had hoped to submit to FECS an application for EC funding from the Socrates Erasmus fund. However, it did not get submitted. The application is to be part of a survey of the educational activities of all member societies. It will be resubmitted next time.

Special Project Fund: JM asks GH if the application prepared by the ETC (W. Kamps) is the same as the one mentioned by GH. GH confirms that this is the same project.

Accreditation system by ACOE: This is still not yet working very well. The problems are more or less political. In due course these will hopefully be solved.

GH thanks JM and notes that this ETC programme was only started a few years ago and now so much has already been done and achieved. GH thanks JM for her large contribution in this field and her extremely good job. She receives an applause from the members.

SOL comments on the issue of accreditation of centres in small countries: this is a delicate issue. KS notes that it could be solved by having such a small centre affiliate for a certain period of time with a larger centre for training. No centre will however be excluded. JM notes that in the UK this system is already working and is quite acceptable.

D. Walker asks how all the expertise within SIOP Europe regarding clinical trials can be disseminated to Europe? Would there be the possibility for organising training courses on clinical trials in Europe as well? Does SIOP feel that there is a task there as well. GH notes that SIOP Europe already has several tasks and also has their own European situation and “developing countries” that need attention. This has priority now.

R. Kebudi asks if Turkey can be represented at the ETC as well. Dr. Kebudi is chair of the Turkish Pediatric Oncology Group and this group organises many educational events for paediatric oncologists. JM knows that at present the ETC had aimed at the EU countries only, but she will take this request back to the ETC. GH notes that this will be considered as SIOP Europe

should deal with all countries of Europe. This will be discussed by the Board. GH notes that Europe does not end at the EU and SIOP Europe wants to represent the whole of Europe. KS notes that each of the committee members has contacts with representatives of the European countries. In the next meeting it should be discussed who will then liaise with Turkey.

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

Kathy Pritchard-Jones reports on the following:

In January K. Pritchard-Jones, on behalf of the SIOP Int. Board, had asked the SIOP Europe Board if they could look into the issue of clinical trials, especially into those which carry the SIOP label, and to find out what this might imply for SIOP. The Board then asked her if she could take this on for SIOP Europe and she agreed to this.

SIOP Europe clearly represents paediatric oncology for the European Union, FECS and potential funding. There is huge expertise in Europe in relation to clinical trial committees in general, so not just the SIOP clinical trials.

KPJ is still working on the questions on what people want this committee to achieve and what it can achieve and the main thing is that duplication must be avoided. SIOP Europe has an opportunity to become the vehicle for providing a unified voice to the European Parliament and other regulatory authorities on behalf of children with cancer in Europe and on behalf of the clinical researchers. A meeting was held yesterday with members of several European national groups who had collaborated in a survey formerly sent out by SIOP Europe regarding the organisation of paediatric oncology and clinical trials in their country. At the meeting there was a general consensus that SIOP Europe should be the organisation to represent these groups at a European level.

There is close collaboration with the FECS executive director, K. Vandendael, who is organising a few reviews of the impact of GCP on clinical trials for academic oncology and is also organising a meeting with the European MEPs in Strasbourg in October. These are the first two steps to make, to make sure that SIOP Europe is there at the information and lobbying stage.

After these meetings it can become clearer how the clinical trials committee can move forward.

KPJ invited 8 people to take part in this committee. However, it is still at a very early stage. Needed is clarity from the members on what they want the committee to do. SIOP Europe will not aim to become a European COG.

KPJ notes that she received a helpful comment by D. Walker, noting that the clinical trials activity could provide a resource to help clinical trial committees to apply for EU funding, not just SIOP clinical trials. This could be any trial where groups work together among countries. This could be worked towards.

8. SIOP Europe Survey (M. Stevens)

MS notes that from the sounds he hears in SIOP Europe, SIOP Europe is emerging from a period of considerable uncertainty. SIOP Europe is getting in touch with the European colleagues in order to build up a better picture on what is going on in paediatric oncology in Europe. MS apologises in this respect to J. Stary, Czech Republic, whose answers did not get into the survey report due to an administrative error, and to the Serbian colleagues, who never received the survey.

However, the messages from the survey were in general that SIOPE needs an ability to relate to members throughout Europe and the best way to do this is through the national societies/organisations. Most European countries have national organisations, in various forms and most have been in contact with SIOP Europe regarding the survey.

Another item to emphasize is the importance of collecting good quality registry information about the patients we treat. There is an European Community initiative looking at cancer registration for children. MS hopes that this will bring forward some initiatives in that direction.

The clinical trials issue has also been informed in the survey and from the replies quite a good map has formed, showing that many countries are still using largely national or institutional protocols. The survey results form a baseline picture, which needs to be repeated regularly.

9. Meeting with Member of Parliament on October 27, 2004

GH notes that representatives of SIOP Europe, ICCCP and the nurses will meet with the MEP, Mr. Peter Liese in October. He was willing to organise a symposium with SIOP Europe in

Strasbourg.

An overview on the situation of paediatric oncology in Europe will first be given; then an overview of the organisation and centralisation of care of children with cancer will be presented. After this, the ICCCPO representative M. Naafs-Wilstra will present an overview of the parents and patients perspective. Then an overview of the clinical trials situation will be given (the clinical trials network, impact of the new directive on clinical trials etc). The contribution to the development seventh framework will also be discussed and finally Dr. G. Vassal will talk about drug treatment and the specifications of drug therapies in children.

After the presentations there will be a Questions and Answers session and in the afternoon possibly a press conference.

SIOP Europe sees this as an excellent opportunity to come into contact with the political authorities in the EU to present the aims and difficulties in paediatric oncology the actions we need for the future.

10. ECCO 13, Paris, France, 2005

GH notes that there will be 2 symposia: Brain tumours in childhood (problems and new concepts) and Bone tumours in childhood and adolescence – future directions.

There will be a teaching lecture on high dose chemotherapy for childhood solid tumours and there will be various paediatric clinical trial sessions. These will be on brain tumours, osteosarcoma and on malignant lymphomas. There will also be a joint session with the colleagues from adult oncology on adolescent oncology. In addition there will be the SIOP Award lecture.

11. Any other important business

The ECCO dates are asked for: October 30 to November 3, 2005.

GH thanks everybody for attending and wishes everybody a good meeting in Oslo. The meeting is closed.

Members present at the SIOP Europe General Assembly 2004 (incomplete as of non-returning of presence list):

**G. Henze
R. Kebudi
H. Kosmidis
S.O. Lie
J. Mann
G. Perilongo
K. Pritchard-Jones
K. Schmiegelow
J. Stary
M. Stevens
A.J.P. Veerman
D. A. Walker**