

Minutes of the SSIEM Council Meeting

Held on 9th December 2005 at 9 a.m. in Ground Floor Seminar Room, Institute of Neurology,
Queen Square, London

Council Members Present:

Cornelis Jakobs (chairman)	Philip Lee (secretary)
Ubaldo Caruso	Jean-Marie Saudubray
Mike Champion	Isabel Tavares de Almeida
Guy Besley (JIMD editor)	Graham Shortland (treasurer)
Nenad Blau	Jutta Gaertner
Johannes Zschocke (JIMD editor)	

In Attendance:

Rene Santer

2005. 29. Apologies for absence

No apologies for absence were received.

2005. 30. Minutes of previous meeting held on 10th June 2005, London

In the corresponding members section, there was an error about Dr Tom de Konig - he has only done one term and therefore will not be replaced. The minutes were otherwise agreed to be a true record, and were endorsed as such by the Chairman.

2005. 31. Matters arising from previous meeting

Mick Henderson, former secretary, sent flowers to express our gratitude for Eli-anne Kvittingen service to the Society over many years; and subsequently Council send condolences to her family and colleagues following her sad death.

Prof van den Berghe is to be replaced as corresponding member. A proposal from the Belgian Society is awaited.

Action Phil Lee to contact Prof van den Berghe

It was felt that the precise role of corresponding members needs to be clarified. This will be discussed at the next Council meeting.

There was a discussion about the place of the Chief Editors of the Journal of Inherited Metabolic Disease within Council in view of transitions occurring and the presence of two Chief Editors. It was agreed that only one named Chief Editor could sit on Council although any of the others could be invited to attend. Johannes Zschocke will therefore have a place on Council. In this transition period, the out-going editor, Guy Besley, will sit on Council for a further one year.

2005. 32. Paris 2005

Jean-Marie Saudubray gave very detailed feedback on the Paris meeting held in September. A total of 1,287 people participated in the congress (30% more than the previous meeting in Amsterdam), of whom only one third were SSIEM members. Participants came from 32 different European countries and 36 non-European countries. It was noted that there is an increasing

number of emerging countries being represented who previously had not attended the congress. 20 different sponsors supported the meeting, providing 200,000 Euros (25% of the total income).

Looking at the congress budget, 50% went on the scientific programme, 40% on catering and the social programme and 10% on secretariat and administration. There was a surplus of 53,000 Euros. The costs of the meeting are certainly increasing and therefore this needs to be borne in mind for future meetings. Clear contracts with sponsors were drawn up prior to the meeting which made it clear what they were able to get for their support. This will act as models for future meetings.

There was discussion about the ERNDIM meeting which on this occasion was borne by the SSIEM organisers because of the higher than normal costs. However, Council felt that ERNDIM should contribute to the cost of their meeting as they do have their own income.

The Chairman had had a meeting and subsequently a letter from SHS and Genzyme (the two platinum sponsors) expressing their joint concerns about the meeting. It was felt that their letter expressed a mixed role of sponsor and participants which was inappropriate. Ubaldo Caruso felt that complaints from sponsors about the local management of the congress should be addressed to the local organisers as well as the SSIEM Chair. Council had previously made it clear that there were to be no satellite meetings during the congress and the sponsors contracts were very clear about exhibition space. The Chairman will respond on behalf of the SSIEM.

Action Cornelis Jakobs to write to SHS & Genzyme

There were some hiccoughs with abstract handling as usual, particularly with multiple submissions. It was felt that a single company to deal with abstracts at each congress would be helpful.

Action Guy Besley to contact RCPCH

Action Nenad Blau to discuss with SSIEM webmaster

Dietitians had two meetings this year: one 'nutritional meeting' incorporated into the whole meeting and a further closed meeting for themselves. The responsibility for these meetings is with the local organiser who should liaise with dietitians (both local and international) about the contents.

Late Breaking News: if possible one or two slots should be kept aside for very late breaking news that is the most topical. This worked very well this year, but it was appreciated that this would not always be possible.

Prizes: because of difficulty in judging, it was agreed by Council that there would be no prize for posters in future, but two prizes for oral presentations (winner and runner-up) most likely drawn from the late-breaking news session.

Poster CD-ROM : this had been produced by Jim Bonham with the possibility of distributing it to all attendees and members after the meeting. There were some concerns about author permission and patient consent. It was agreed by Council to invite Dr Bonham to attend the meeting in February to discuss.

Action Phil Lee to invite Jim Bonham

Membership numbers: it was suggested that membership registration forms be sent out with future congress registration forms to try to increase membership numbers.

The Chairman thanked Prof Saudubray for all his hard work and endeavours in organising such an enjoyable and worthwhile meeting.

2005. 33. Future Meetings

- 2006 - no new information on the programme for the Tokyo International meeting had been received by the SSIEM

- 2007 - Hamburg

Rene Santer presented the current plans. A local organising committee has been established as well as a scientific committee drawn from throughout Germany. The first announcement was distributed in Paris. The venue is a large congress centre in the centre of Hamburg able to seat 1500 people for plenary sessions. There are 4 rooms available for parallel session. There is almost 1000m² for breaks/lunch and exhibitors.

The social programme has been organised.

There is a contract with a local PCO. Budgeting has started and will involve discussion with the SSIEM treasurer. It will be based on 950 participants.

The theme of the scientific programme is 'Pathogenic mechanisms of disease. Focus on lysosomal disorders.' Lectures, speakers and sessions are taking shape well. There was a brief discussion about the possibility of poster walks or talks.

- 2008 Lisbon - the first local organising committee meeting is due to take place in January 2006. The first announcement for the meeting will be in Hamburg 2007.
- 2009 San Diego for the International Meeting: no news
- 2010 Istanbul : no news

2005. 34. Publications Report

Johannes Zschocke presented the plans for the new-look JIMD which will commence in January 2006. All communicating editors have been identified and agreed to be involved. The Short Reports and Case Reports will be printed in abstract only with the rest appearing on-line. There will be the opportunity to publish Data Reports. The structure for manuscript review is in place with an expected review time of 4-6 weeks. Accepted manuscripts will appear on line within a month and in print in the next edition.

Johannes Zschocke presented the chief-editors view on the new workflow for the review-process for articles in the new JIMD which was sent to the communicating editors (CE's). Cornelis Jakobs expressed his surprise that this workflow did not include any activity for the other formal editors Garry Brown and Mike Gibson, and asked whether both have seen and agreed upon this workflow.

A Euro account has been opened by Malcolm Heron so that monies between SSIEM and Springer can be dealt with more easily.

There was discussion about abstract handling for Tokyo 2006. It was assumed that they would be published in the JIMD although editors will not be involved in abstract selection.

The Council were very excited and impressed by these developments.

2005. 35. International Committee & Meeting

The Chairman had sent a letter to the Chairs of all four societies. There was only one positive response received from the Japanese Society to date.

Action Cornelis Jakobs to follow up other societies

2005. 36. Website Report

Nenad Blau reported that the new website was going well with positive responses from users. The webmaster was very pro-active and helpful. The main problem has been that the site has been inundated with emails, some of which were appropriate. It was agreed that the website would make it clearer which emails would get a response and which would not. Ubaldo Caruso

suggested clear categories should be devised and so messages could be sent to the appropriate person.

Action Nenad Blau to discuss with webmaster

There was discussion about the GA-I guidelines appearing on the SSIEM website. Council felt this was inappropriate and it would be better if they were published elsewhere and a link established between this site and the SSIEM website.

Action Phil Lee to reply to Dr Kolker

2005. 37. Training

John Walter was visiting Brussels on the day of the Council meeting but will be asked to report back in February at the next meeting.

Action Phil Lee to invite John Walter

2005. 38. Treasurer's Report

Graham Shortland presented the balance sheet and budget report. Currently there are 945 paid members - a fairly stable number despite attendances at the annual conference increasing. Despite professional fees being £2,000 overspent, there was £10,000 more income than expected and overall there was a surplus of £2,000 (excluding the Paris Symposium). The current assets of the SSIEM are £460,000.

Malcolm Heron has been paid by the SSIEM to help the treasurer and secretary at a rate of £800/month since January 2003 (=£13/hour). Council agreed to increase this to £900/month from January 2006 and were much appreciative of all his hard and efficient work. He plans to continue in his role until the end of 2009. It was felt that there should be plans for an SSIEM office to be established in view of the increasing work and intricacies of the society.

Action Phil Lee & Graham Shortland to put together list of office tasks needed

It was agreed that the SSIEM will pay for the Chairman, Secretary, Treasurer, all 4 JIMD Editors and Malcolm to attend the Tokyo International meeting. This will cover cost of registration, social events and travel.

Two new membership scholarships were approved for Birute Tumieni (Lithuania) and Maja Djordjevik (Serbia & Montenegro). It was felt that there need to be more applications for this financial support.

2005. 39. Secretary's Report

An application for an exchange grant was received from Christiaan van Woerden for 2310 Euros to travel from Amsterdam to Tenerife to work on the mouse model for primary hyperoxaluria type I. It was felt this was an excellent project which should foster good collaborations between the centres and should be approved. This is the fourth, and final, exchange grant given out in 2005.

The secretary's newsletter will now appear in each edition of the JIMD instead of as a separate publication.

2005. 40. AOB

The new Italian corresponding member has been discussed by the Italian Society and will be proposed by their president in due course.

Graham Shortland will have completed two terms as Treasurer and will stand down in September 2006. His replacement needs to be discussed at the next Council meeting.

Jean-Marie discussed a meeting organised by EurorDis, a group to support patients with rare diseases. He felt this was a group that should have links with SSIEM so that we could have some input into their meetings if they felt that were appropriate.

Action Phil Lee to contact Eurordis Chair

2005. 40. Date and time of next Council meetings

Meetings for 2006 in the Old Board Room of The National Hospital for Neurology, Queen Square, London, starting at 9am, will be as follows:

February 10th

June 16th

December 8th

Phil Lee

Honorary Secretary, SSIEM

Friday, 12th December 2005