

Minutes of the SSIEM Council Meeting

Held on 1st February 2002 at 11 a.m. at The National Hospital for Neurology and Neurosurgery, Queens Square, London

Council Members Present:

Guy Besley	Philip Lee
Mick Henderson (secretary)	Kurt Ulrich
Cornelis Jakobs	Graham Shortland (treasurer)

In Attendance:

Neil Hamilton

2002. 1. Apologies for absence

Apologies were received from Kim Bartlett, Ubaldo Caruso, Philip Mayne, Jean-Marie Saudubray and John Walter

2002. 2. Minutes of previous meeting held on 30th November 2001 London

The minutes were agreed to be a true record and were endorsed as such by Mick Henderson.

2002. 3. Matters arising from previous meeting

There were no matters arising that were not covered by the agenda.

2002. 4. Annual Meeting 2002 Dublin

- The second announcement with registration forms and calls for abstracts will be distributed to the membership within the next two weeks. These documents will also be available from the website. The website, www.ssiem-dublin-2002.com has had over 600 recorded visits.
- The programme was circulated for discussion. 21 of the invited speakers have sent written confirmation of their acceptance to attend. Two more have yet to be identified. One to give a clinical presentation on the treatment of childhood hyperlipidaemia and one to discuss the IEM applications of protein tandem mass spectroscopy. Various suggestions were made which will be followed up as soon as possible.
- A budget has been produced and agreed between the local organisers and Dr Shortland. The cost of registration, including standard accommodation in University rooms, will be approx. 700 EUR.
- There was some discussion as to whether the meeting was open for individual parents to attend. Some parents have attended past meetings, but usually as representatives of parent groups. It was the view of Council that the meeting is open to all; it would be impractical and unfair to vet the individual applications for registration.

2002. 5. Future meetings

(a) International meeting 2003

- Following the decision taken at the last Council meeting John Walter wrote to the local organising committee making the following offer: that the SSIEM will provide £6,000 as a loan for an initial financial float. In addition a further £6,000 will be set aside to subsidise travel grants for SSIEM members to attend the conference. £6,000 will be used to subsidise the production of an abstract issue of the JIMD. Bridget Wilcken has replied and expressed the gratitude of the organisers for this offer of help. Malcolm Heron has been instructed to organise a transfer of funds. Travel costs for Council members were discussed. It was reiterated that Council members will have their travel costs met by the Society. It was also agreed that the Society would meet the registration costs of the three officers, Chairman, Secretary and Treasurer, who must all be there for the AGM. It was further agreed that Malcolm Heron would be paid to be present in order to man the member's desk and offer administrative support.
- Concern was expressed that there did not appear to be any progress with establishing a formally constituted International Committee to oversee the future organisation of such meetings. If this is indeed the case then it was suggested that the SSIEM table a proposal to the other major Societies to create and constitute the International Committee between them. A number of representatives, e.g. two, per organisation could be elected to sit for a fixed term. It was hoped that the first meeting of such a body could take place at Brisbane next year.

(b) The Netherlands 2004

Cornelis Jakobs reported that he is busy forming the local organising committee. Final preparations were in place to appoint the professional conference organiser. This should occur within the next two weeks.

(c) France 2005

Progress is being made but nothing definitive to report yet.

(d) International Meeting

No further news.

(e) Hamburg 2007

No further news.

(f) Standard Procedure

Following the agreement at the last meeting an advertisement has been placed on the front page of the February Newsletter explaining the new procedure to the membership. This invites bids from members willing to host the meeting six years from the summer of this year, i.e. 2008. The bids will be circulated in advance and considered by the council and corresponding members meeting at the AGM in Dublin. A provisional decision will be made subject to a satisfactory visit by two Council members, or suitable delegated members.

2002. 6. Treasurer's report

Graham Shortland presented a summary report on the current financial position which remains very healthy. There are assets of £338,000 in total. Some of this surplus will be used to

subsidise member's attendance at the annual meeting. There will be more of a differential between the registration costs of members and non-members.

The surplus from the Prague meeting totaling £46,950 has been transferred to the Societies main account.

The fees paid to Malcolm Heron were reviewed. It was decided that they will remain at their current level for a further year, i.e. £12 per hour representing about £750 per month. The officers recorded their continued gratitude to Malcolm commenting that he performs an essential role for the Society. His remuneration will be reviewed next year.

2002. 7. Publications report

Guy Besley informed council that issue 8 of the Journal was now ready for distribution. All requested review papers have been received from the Prague meeting.

There was some discussion about the publication in the Journal of papers that were transcripts of meetings other than those organised by the Society. Council had no reservations about these when they were subjected to the normal peer review process but was becoming concerned by the trend for complete collections of meeting reports to be submitted directly for publication. The editors, on our behalf, must maintain control of the material that is published.

2002. 8. Web site report

Some progress has been made with respect to on-line access to the Journal. Guy has been given appropriate passwords and been able to gain access via an intermediary connecting website. Although the process is a little clumsy, it works. The only thing that seems to be holding up the process of making this available to the members is a demonstration to Kluwer that the membership area of the site has adequate security and that access to the Journal will not be abused by institutions.

Neil Hamilton tabled a paper with suggestions for developments at the website.

- An electronic noticeboard accessible only from the member's area will be trialled for a year.
- Neil suggested that the Society consider improving access of the site for visually and cognitively impaired users. Some improvements to the logical layout will achieve these aims; radical changes were not felt to be necessary at this time. It was decided that the membership could be canvassed about the general ease of use of the site in the next Newsletter.
- It was suggested that Council minutes could be posted and made available in the member's area. This would help foster the view that decisions are made in an open environment, and would facilitate feedback encouraging debate. Minutes would only be posted after they had been ratified as an accurate record at the subsequent Council meeting. Before proceeding with this idea it was decided that the corresponding members should be consulted. It was also felt that AGM minutes could be posted. These could appear as soon as they are distributed in paper form to the members.
- New links have been created to the British Inborn Metabolic Group, the Garrod Society of Canada and three research trusts related to mitochondrial disease. Corresponding members will be invited to contact Neil with web addresses of other National IEM societies.
- There was discussion about the advisability of publishing recommended laboratory standard operating procedures. The majority view was that this would be difficult. The Society would be taking responsibility for procedures that were not always straight forward or without contention. Also they may not be relevant or appropriate in differing countries. It

was pointed out that a better idea would be to encourage laboratories to publish their own SOPs on the lab database that is to be created.

- It was suggested that members could be invited to post interesting case histories in the protected area. This idea was supported; it was felt that we need first of all to explore the confidentiality issues raised.
- It was proposed that a notice board be established in the public area of the site to carry brief messages advertising matters that might be of more general interest. For example positions vacant, studentships and grants, research proposals and requests for collaboration. It was felt that all items would need to be reviewed by at least one of the officers of the Society before posting.
- Laboratory database. A meeting is soon to take place between Mick, representing the SSIEM, Brian Fowler for ERNDIM and Neil who will design the pages and the links to the SSIEM site.

2002. 9. Secretary's report

Mick Henderson reported that the next Newsletter was about to be circulated. This has on the front page an advertisement for the new venue selection procedure for the annual meetings.

2002. 10. Summer School

Philip attended the meeting in Paris that discussed the arrangements for a second academy. It will take place in Nijmegen this Autumn.

There was a strong feeling that the SSIEM should take a lead in encouraging training and be pro-active in organising and facilitating schemes. The Society has some funds that could be used to initiate events. However, it was felt that the Society should be careful about becoming involved with meetings or events that had only one additional, commercial sponsor. It was decided that further progress could not be made without involving Prof James Leonard and Prof Jean-Marie Saudubray.

Practical things that could be achieved without difficulty include creating Fellowship grants to enable members to work in other institutions to widen their experience, learn new techniques or gain clinical experience and encouraging the advertisement on the website of meetings being planned by other, smaller national groups. There are often useful study days or workshops which may only be advertised locally.

2002. 11. Any other business

There was no other business

Date and time of next meetings

Friday 14th June 2002, The Old Boardroom, National Hospital for Neurology,
Queen Square, London (map available on request from the secretary)

Friday 6th December 2002, The Old Board room. **Please note change of date**

Dr MJ Henderson

Honorary Secretary, SSIEM

February 2nd 2002