

Minutes of the SSIEM Council Meeting

Held on 1st March 2004 at 11 a.m. at the National Hospital for Neurology, London

Council Members Present:

Guy Besley	Eli-Anne Kvittingen
Ubaldo Caruso	Jean-Marie Saudubray
Mick Henderson (secretary)	Graham Shortland (treasurer)
Cornelis Jakobs	John Walter (chairman)
Philip Lee	

2004. 1. Apologies for absence

There were no apologies for absence

2004. 2. Minutes of previous meeting held on 5th December 2003, London

The minutes were agreed to be a true record, and were endorsed as such by John Walter.

2004. 3. Matters arising from previous meeting

There were no matters that are not be covered by the agenda.

2004. 4. Web Site

Prof Kim Bartlett will be invited to the next council meeting to discuss the website. Prior to that Mick will write to Kim inviting him to submit ideas for modernising the site. Council would like the site to have renewed and more attractive appearance but would also like to discuss the possibility of some new features, a search facility and sitemap for example.

2004. 5. Future meetings

(a) The Netherlands 2004

The second announcement with registration forms and abstract submission details has now been circulated to the membership.

There was discussion about the relationship between meeting organisers and sponsors. In the second announcement the programme lists three sponsored satellite meetings as being part of the main programme. This is a departure from previous SSIEM meetings and may give the false impression that the SSIEM has participated in their organisation and endorses the nature of the discussions. Council felt that these meetings should be advertised separately from the main programme, either with flyers in the delegate bags or possible an additional page in the programme. This will be amended in the final version of the Amsterdam programme.

Cornelis reported problems in the construction of the meeting website. The electronic version of the registration form is not yet ready to use. There appear to be liaison problems between the meeting organisers and the SSIEM website managers who have been asked to build the new site.

Abstracts for the dieticians meeting be submitted in the normal way to the meeting organisers but will then be passed onto Anita McDonald for selection. Selection for the main body of

abstracts will be made by a panel of three judges, Cornelis, Guy and a physician from Amsterdam.

Council expressed the view that prizes should be awarded as usual. There will be one for the best presentation during 'late breaking news' and one for the best poster. The judges will be Jean-Marie, Graham and a scientist from Amsterdam.

Graham advised that personal liability insurance be purchased for the duration of the meeting.

(b) France 2005

A scientific committee has been formed with the remit to produce the scientific programme. The topics will concentrate on the theme of therapy for inborn errors of metabolism.

Details of the draft programme will be available for discussion at the next council meeting.

A suggestion was made that Prof James Leonard be invited to deliver the Komrower lecture on the topic of regional / international variations in the organisation of clinical metabolic services.

It is appreciated that there will have to be close liaison with the dieticians group to avoid unnecessary overlap. Council raise the question of whether it will be useful or necessary to hold a separate dieticians meeting given the likely interest of dieticians in the main programme.

Jean-Marie will discuss these matters with Anita McDonald, the convener of the dieticians group.

The PCO will be commissioned to build the website and have also expressed willingness to handle abstract submission.

(c) International Meetings the questionnaire

A questionnaire was circulated to the membership by e-mail and publicised in the Newsletter as agreed at the previous meeting, min 2003.28 (f).

Returns have so far been received from 220 members. Malcolm will be requested to repeat the mailing and the full response will be examined at the next meeting of council.

(d) International Meeting, Japan 2006

No further news about the meeting at this stage.

(e) Hamburg 2007

No further news about the meeting at this stage.

(f) Lisbon 2008

No further news about the meeting at this stage, Cornelis and John will conduct a site visit this Spring.

(g) International Meeting 2009

There are indications that the SIMD are preparing to organise this in the USA as anticipated.

2004. 6. Training Programme

Prof James Leonard will be invited to the next meeting to give a report.

2004. 7. Treasurer's report

Graham Shortland presented a summary report of the current financial balance sheet. There are currently 1025 members of the society of whom approximately 1000 have paid this year's subscription.

The loan of £6,000 to the Australian Society as assistance to fund the set-up costs of the Brisbane ISIEM has been returned to the SSIEM.

2004. 8. Publications report

Guy Besley presented the following report:

I am pleased to report that the first issue of the Journal for 2004 (Vol 27 No 1) is now published. Members can read it online and hard copies should be available shortly. A number of changes to the format will be seen. The design to the front cover now longer carries the characteristic red text, which has been a feature since the Journal was founded in 1978. We now have blue design, which I feel is less dated. There are also a number of changes to our editorial board, many members of which have served since 1978. Eight members have stood down, allowing us to bring in some fresh blood. The following have retired: Maria Barbara Cabalska, Mike Connor, Fleming Güttler, Eric Harley, Jean-Marie Saudubray, Olli Simell, Keiya Tada and Doug Turnbull. I thank them all for their support over the years. New members include: Cornelis Jakobs, Viktor Kozich, Ertan Mayatepek, Jan Smeitink, Johan van Hove, Ed Wraith and Johannes Zschocke.

From the Brisbane symposium, I have now had eight review manuscripts and two workshop reports submitted. These are all currently in press and may form the basis of the next issue. We also plan to publish, as a supplement, the proceedings of an International symposium on glutaric aciduria type I, recently organised by Georg Hoffmann. The funding for this publication will be from an independent source, not from our regular page budget.

The flow of manuscripts remains steady, but as always we would like to have more good quality full papers, rather than brief Case Reports. Processing of manuscripts has been much improved by the use of electronic distribution of proofs as pdf files. The next stage to improving the handling of manuscripts will be the introduction of an online submission of manuscripts, with online reviewing and tracking. We hope to have this up and running in a few months time, once all the editors have completed some training in its use.

2004. 9. Secretary's report

Mick Henderson circulated a draft proposal for an SSIEM exchange grant scheme as discussed under council minute 2003.29. The text of which is as follows:

SSIEM Exchange Grants

Proposal

The SSIEM would like to encourage exchange visits between institutions. There is no restriction as to age or seniority, but preference will be given to junior members in the event of over subscription.

Grants will be made available from August 2004 to a maximum value of £2,500 each.

The total value per annum of all grants will not exceed £10,000.

Process

Applications should be addressed to the secretary and will be judged by at least two committee members before a decision is made.

Applications will only be accepted from members of at least two years standing.

Each application will need to be supported by:

- Applicant's c.v.

- Application letter explaining benefit from exchange and proposed length of stay
- The names of two sponsors, one from the home institution and one from the venue.

Advertisement

SSIEM Newsletter

Metab.L

Council approved the proposal and the following amendments were agreed :

- applications also need to be supported by details of proposed expenditure
- details will be posted on the website, the adverts will refer to the website for more detail.
- Successful applicants must provide detailed financial summary with receipts and a brief written report to council on completion of period of study
- There will be two deadlines for the submission of applications each year. The first being June 1st

A preliminary advertisement was made in the February Newsletter. More complete details will be sent out in July. They will also be posted on the website.

2004. 10. Any other business

- A group has been established, lead by Prof George Hoffman, to define treatment guidelines for glutaric aciduria type 1. Prof Hoffman has written to The SSIEM requesting the endorsement of the Society for this project and requesting financial aid. Council felt that whilst this project was a very worthy cause there was anxiety with regard to endorsing guidelines that would be written without the direct involvement of The Society. There was also some concern about a possible precedent. The production of guidelines has been discussed before, see min 2003.34, and this is an issue of interest and concern to many of our members. It was therefore decided to propose at the AGM that a sub-committee, of council, be established with the remit of drawing up a protocol for writing guidelines. If guidelines were then established and the authors followed this protocol, the SSIEM would be in a position to endorse the resultant procedures. Council will request feedback from the corresponding members prior to the AGM on this point.
- Ubaldo expressed disappointment with the joint ERNDIM/SSIEM laboratory database. He complained that there were errors, inaccuracies and it was incomplete. He also questioned by what authority were entries accepted and requested the involvement of National Societies in the vetting process. Mick re-iterated that this whole process is the responsibility of ERNDIM. The SSIEM was asked to support the initiative with some limited set-up funding but has not become involved with the organisation of the database. Mick is however a member of the ERNDIM group that is organising this database. He explained that the current version is still very much in its infancy and contains data that was collected over six years ago. Laboratory directors have been given ample opportunity to update their entries before the database is given public access. It will take time to update the database with completely new assays and so will be incomplete initially. With regard to the admittance of laboratories to the registry, the decision was taken that unless there was clear evidence to the contrary, requests for inclusion would be accepted. A suitable disclaimer will be displayed on the front page. Users of the database will be encouraged to take into account participation in external quality assurance schemes.

2004. 11. Date and time of next Council meetings

The next meeting will be in the Old Boardroom, National Hospital on Friday 28 May 2004

The final meeting of the year will be Friday 12 November 2004, will be in the meeting room in No 7 Queen Square on the first floor. To obtain access to 7 QS the first to arrive will need to get a swipe card from the reception at the Institute of Neurology and also the key to the room. There is an entry phone in the meeting room so people who buzz at the door can be admitted by using this.

Dr MJ Henderson

Honorary Secretary, SSIEM

1st March 2004