

Minutes of the SSIEM Council Meeting

Held on 20th June 2003 at 11 a.m. at the National Hospital for Neurology, London

Council Members Present:

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

In Attendance:

Kim Bartlett	James Leonard
Neil Hamilton	Philip Mayne

2003. 12. Apologies for absence

There were no apologies.

2003. 13. Minutes of previous meeting held on 7th February 2003, London

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

2003. 14. Matters arising from previous meeting

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

2003. 15. Annual Meeting 2002 Dublin

Philip Mayne outlined some of his recommendations for future meetings.

- All liaison and financial negotiation with sponsors should be conducted by the local organising committee and not the PCO.
- There should be standardisation of the sponsorship categories. This will be defined in the sponsorship guide being prepared by Philip and Cornelis.
- Strongly discourage the organisation of alternative events by sponsors
- Wherever possible sponsors, posters and coffee need to be located together.
- Organisers need to be aware that there can be problems with equipment belonging to sponsors. There may need to be an advance delivery address. And it needs to be made clear when all equipment has to be removed and whose responsibility that is.
- Ensure that sponsors have their own insurance for goods and third party claims.
- Be clear about local requirements or regulations that will affect sponsors displays, e.g. health and safety, height and weight restrictions.
- Be prepared for an e-mail storm, nearly 3,000 for Dublin.
- Be advised to apply for CPD/CME accreditation early.
- Useful to have a conference information stand to greet delegates at the airport.

- Clarify which delegates are paid for by the symposium and which by central SSIEM funds.

Council ruled that from now onwards SSIEM will pay for the attendance (travel and registration) of the officers, treasurer, secretary and chair. Other council members have their travel costs met as does the chair of the SIMD. The local meeting will not be expected to pay any of these costs.

The meeting will pay for the production of the abstract book.

The Final Report from the Dublin meeting will be posted on the website shortly.

2003. 16. Future meetings

(a) International meeting 2003

The agenda for the council and corresponding members meeting will be sent out in July.

(b) The Netherlands 2004

Cornelis Jakobs reported that the first announcement will be ready to distribute in the autumn. A draft of the scientific programme was distributed and discussed.

(c) France 2005

Jean-Marie reported that a local organising team was now formally established and constituted as a not-for-profit organisation. A draft budget had been set. A website was being created.

The main topic is proposed to be therapy of IEM, a review of advances over the past 40 years marking the career of Jean-Marie.

(d) International Meeting, Japan 2006

No further news about the meeting at this stage.

(e) Hamburg 2007

There are two potential sites each of which have advantages. Mick and John visited Hamburg in March and inspected the venues with Kurt. It was decided that the best venue was the Congress Centre. This had all facilities, to a high standard, under one roof. There was ample space for the posters which was close to a large area ideal for the trade show. So the sponsors will not be isolated from the main meeting. In addition the Congress Centre has an 'in house' PCO which will make facilitate organisation. Accommodation will be in a variety of nearby hotels.

(f) Lisbon 2008

No further news about the meeting at this stage.

(g) International Meeting 2009

(h) 2010

An advertisement for potential hosts of this meeting will be sent out in the Feb Newsletter next year. The bids will be discussed at the June council meeting.

Future International meetings

John Walter had received an invitation from a commercial company, Kenes International, to act as the long term PCO for all future SSIEM meetings. Council felt that this was not a good idea since the local organisers are different each year and they must have the freedom to choose the PCO with whom they feel that can work best with.

2003. 17. Training Programme

James Leonard reported that an outline plan for the criteria that will form the basis of inspections has been drawn up by ETAC, The Education and Training Advisory Committee. It is available from James and can be e-mailed to interested parties. Requests for inspection will only be acted upon when received from national bodies, i.e. not the individual laboratories themselves. It is hoped that the first inspections will take place this Autumn. Probably starting with Paris then Dusseldorf and Prague. The inspection teams will comprise one member nominated by the SSIEM and a local (same country) paediatrician who is not affiliated to the institution being inspected. Documents explaining the remit and operational methods of ETAC are to be posted on the website in due course.

A request had been received to create a link from the SSIEM website to that advertising a training course being organised by a commercial organisation. Council agreed that this would be facilitated if the meeting in question was endorsed by the Society. The criteria for such endorsement were discussed and described in minute 2002.17 of last year's June council meeting. It was agreed that this could be made more clear if the minute could be refined into a set of guidelines that could be posted on the website. Mick will liaise with James on this issue. Meeting organisers would be invited to submit details of their meetings to ETAC for approval on behalf of the Society.

- TEAM initiative (refer to min 2003.6)

Philip attended a TEAM meeting in February and explained to council the overall ambition of the EU funded project. The intention is to establish a series of training courses in adult metabolic medicine across Europe. The TEAM organisers have asked for the support of the SSIEM. Council agreed to give full support to the initiative, but will ask that any meeting programmes be submitted to ETAC for accreditation before the SSIEM name can be used in association with them.

2003. 18. Treasurer's report

Graham Shortland presented a summary year end report.

The overall balance shows a surplus of £478,000. The bulk of this is held in reserve as a contingency against the liability of failure of future meetings.

Council accepted the final accounts for the year 2002 as submitted with the exception of one correction from the accounts for the Dublin 2002 meeting. The figure of £10,706 listed as 'interest' on page 9 should be described as 'other income'.

It was requested that the turnover in future from the annual symposium should be included and emphasised as this constitutes the bulk of the financial risk to the SSIEM as a charity.

Three travel scholarships for Brisbane have been awarded so far. An additional three applications have been returned with requests for more information. It was decided that in future an advertisement for scholarships will be placed in the Journal.

Membership stands at 1047 with 945 having paid.

Council thanked Malcolm Heron for compiling the accounts.

2003. 19. Publications report

Guy Besley presented the following report:

There have been delays in the publication of volume 26 (2003). This is partly due to the overrun of three issues from vol, 25 into the current year. The problem was highlighted in my last report and continues to result from a shortfall in acceptable manuscripts. The number of submissions remains fairly steady (159 in 2001, 138 in 2002 and projected 153 for 2003). But the acceptance rate is currently just less than 50% and although this has helped to improve our impact factor (1.79) the consequence is a lack of sufficient papers available to complete each issue. The editors and publishers have therefore agreed that as from next year we will return to 6 issues per year, as was the case up to 1998. In 2001 we dropped the Short Communications which contributed to the pressure on pages to complete 8 issues/year.

At present issues 1 and 2 for this year, have been published and are currently being distributed. Papers for issue 3 are ready and there are almost sufficient for issue 4. A supplement covering the homocystine meeting has also been published will probably be distributed with issues 1 & 2.

I feel there are a number of factors that have contributed to our current difficulties and intend to make some changes which I hope will improve the situation.

First, the Journal needs to operate a web-based manuscript submission system with facility to track progress and electronically send papers for review and processing. Such a system is now available through Kluwer and will accept submissions in a number of formats (Word, WordPerfect, RTF, PDF, JPEG etc). We have asked the publishers to set this up for us as a trial.

Second, it has been suggested that the editorial board should be reviewed. Many members have been on for many years. Historically they were appointed to represent geographical areas. I intend to write to all members suggesting that there should be a rotation of board members and that the role they play in supporting the Journal should change. I will propose that all board members should be expected to provide at least one paper or review each year. In addition I would recommend that we increase the number on the board and that we should focus more on individual areas of metabolism and to enlist a number of younger more active members. I would welcome suggestions from Council and perhaps corresponding members.

As far as the publication of abstracts for the Brisbane meeting are concerned, I understand that these are shortly to be sent to Kluwer who will publish copies for members and institutional subscribers. Delegates attending the meeting will receive copies published locally from electronic files that will be sent from Kluwer to the organisers. I have written to all invited speakers requesting review papers in the usual way, but since SSIEM was not involved with the original negotiations I do not have a feel as to how successful this will be.

Finally, at the recent business meeting with Kluwer, we learnt that the company was undergoing significant change. They have been bought over by a financial organisation and were joining with the German publishers, Springer. The owners are in the process of reorganising the whole operation. It appears that the Lancaster office that we deal with is to be closed as of the 30th June and that our contact for many years (Phil Johnstone) will no longer be an employee of Kluwer. Phil has been very supportive of the Journal and its production. Without his contact and expertise I feel there will be serious problems. Historically, contact with Kluwer in Dordrecht has been difficult and I feel that without Phil's input we need to consider alternative publishers for the future. In the meantime, I would recommend that we send a letter to Kluwer from Council expressing our concerns with these proposals for future production arrangements. Certainly, in the short-term the best arrangement would be for Phil to work as a freelance production editor and for us to continue to work through him. This has been a proposal but head office may not agree to this.

2003. 20. Web site report

Kim Bartlett and Neil Hamilton submitted the following report:

a Abstracts for Brisbane meeting

536 abstracts received electronically (including re-submissions) and processed. 456 were accepted. All corresponding authors were notified of receipt and where necessary asked to re-submit if the format was incorrect. No paper based submissions were received. The final database and text files have been sent to Kluwer and the editor-in-chief.

b Future procedures for abstract database

We suggest that in future the abstracts should be available on the SSIEM website accessed by means of unique abstract id (allocated by us) and the email address of the corresponding author. If there are any modifications necessary the authors would re-submit. The authors would thus be able to track the progress of their submission on-line.

We also suggest that in future the submissions should be made directly to us and not via a third party as this has caused some confusion.

c Journal of Inherited Metabolic disease

In accordance with agreed procedure the access password to the journal will be changed effective 1st July 2003. All paid-up members will be in receipt of the new password.

d ERNDIM database

The ERNDIM database of diagnostic laboratories will be modified to allow participating laboratories to inspect and modify as necessary the list of tests offered. This will be available prior to the Brisbane meeting. The laboratory information pages (as per BIMDG convention) will be converted and published by us. Any new tests proposed by the laboratories or any new laboratory wishing to participate will be submitted to the ERNDIM panel for approval.

e Transplant outcomes database

We propose to develop an on-line facility to register the complications and outcomes of transplantation in the treatment of MMA and PA. A full proposal will be submitted to Council as soon as possible (refer to 2003.23).

f Website home page and links

The basic SSIEM website has been maintained and new links added as appropriate.

2003. 21. Secretary's report

Mick Henderson had nothing additional to report.

2003. 22. Review of council and corresponding members

Dr Graham Shortland has completed one three year term of office and will be standing for re-election as Hon Treasurer at the AGM.

The following have completed two terms of office and so will have to stand down at the AGM: Dr O Elpeleg, Prof R Giugliani and Dr S Schweitzer. The Society thanks them for the support they shown in the last six years. John will contact the relevant national societies and ask for nominations for the replacement of these corresponding members.

2003. 23. Any other business

Database of clinical outcomes.

This was suggested by James. He would like to see the creation of a web based database to record adverse events during the course of therapy for IMD. This could be allied to the SSIEM homepage. He is particularly concerned to gather information in relation to post transplant complications in PA and MMA. Council approved the idea in principal and requested that a

working example be brought to the next council meeting. It was also felt that this could usefully be discussed at the AGM. It was acknowledged that before progress could be made it would be necessary to seek ethical (MREC) approval.

Date and time of next Council meetings

Friday 5th December 2003, The Board Room, National Hospital.

Dr MJ Henderson

Honorary Secretary, SSIEM

20th June 2003