

## Minutes of the SSIEM Council Meeting

Held on 7<sup>th</sup> February 2003 at 11 a.m. at the National Hospital for Neurology, London

### Council Members Present:

Guy Besley	Graham Shortland (treasurer)
Mick Henderson (secretary)	Kurt Ulrich
Cornelis Jakobs	John Walter (chairman)

### In Attendance:

James Leonard

### 2003. 1. Apologies for absence

Apologies were received from Ubaldo Caruso, Philip Lee and Jean-Marie Saudubray.

### 2003. 2. Minutes of previous meeting held on 6<sup>th</sup> December 2003, Manchester

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

### 2003. 3. Matters arising from previous meeting

2002.26; guidelines for sponsors. It was agreed that Cornelis would collaborate with Philip Mayne in drawing up these guidelines.

### 2003. 4. Annual Meeting 2002 Dublin

Philip Mayne was unable to attend this council meeting but it was agreed that he should be asked to attend the next meeting in June.

### 2003. 5. Future meetings

#### (a) International meeting 2003

- Abstracts. Guy reported that arrangements were in hand to handle the submitted abstracts in collaboration with Kim and Neil as had happened for recent SSIEM meetings. The abstracts would appear as a dedicated volume of the Journal. They would also be sent electronically back to the ICIEM organizers to be published locally for distribution at the meeting.
- The organizers have allowed time and space for SSIEM meetings as requested. There will be a meeting of the council and corresponding members at midday on Wed 3<sup>rd</sup> September and the AGM at 2:00 on Thursday 4<sup>th</sup>.

#### (b) The Netherlands 2004

Cornelis Jakobs reported that Dr Tom DeKoning had been invited to join the organizing committee. He is the new Chair of the Dutch IEM society.

Neil Hamilton will be asked to make the link from the SSIEM website to that of the Amsterdam meeting more prominent.

Cornelis will supply an advance advertisement for the meeting to be published in the July Newsletter

**(c) France 2005**

A draft agreement between the proposed PCO and the local organisers has been referred to council for comment by Jean-Marie. This was felt to be satisfactory.

Council would like to see the establishment a full committee to support Jean-Marie in the role of local organiser.

**(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 will visit Hamburg in late March to facilitate a choice in collaboration with Kurt.

**(f) Lisbon 2008**

No further news about the meeting at this stage.

**(g) Future International meetings**

John Walter circulated a letter on December 31<sup>st</sup> 2002. It was behalf of the Chairs of the four major international societies, the SSIEM, SIMD, JISIEM and ASIEM. The text of which was as follows:

*'There has been continued debate within the various societies as to the best arrangements for future international symposia. The agreement that these meetings should be organized in turn by the major inborn error societies has been welcomed but the lack of any formal constitution for the International Congress Committee remains a concern.*

*In view of this, discussions have been held between the presidents of the SIMD (Tony Velazquez), the ASIEM (Bridget Wilcken), the JSIEM (Yoshikatsu Eto) and the Chairman of the SSIEM (John Walter). We confirm that the following schedule for the international meetings has been agreed:*

2003 ASIEM Brisbane Australia

2006 JSIEM Tokyo Japan

2009 SIMD site to be confirmed

2012 SSIEM site to be confirmed

*Each society will take full responsibility for the organization of their meeting and this includes the financial liability (both for any loss or surplus). It is expected that the organizing society will consult widely as to the scientific programme and enable the other societies to hold business meetings as appropriate.*

*Individual societies must make their own decision as to whether they will hold a separate meeting in the year of these symposia but it is agreed that if they do, these should be on a date and of a size that will not undermine the success of the international meeting.'*

All agreed that this seems a very reasonable and equitable arrangement. In view of the statement made in the final paragraph it was decided that there will not need to be a ballot of the membership, as resolved in minute 2002. 27. Council will decide on the necessity for such meetings nearer the time.

A response had been received prior to the meeting from Roberto Giugliani pointing out that the proposed list of venues and organizers omitted the Latin American Society.

Council expressed the hope that the Latin American Society could collaborate with the SIMD in organising the 2012 symposium.

### **2003. 6. Training Programme**

James Leonard reported that questionnaires had been sent out to prospective training centres in Europe and that some replies had been returned. Germany was particularly keen to proceed with an inspection. Cornelis explained that Holland also was keen to be fast tracked. James commented that Holland Germany and the UK were likely to constitute the first round of inspections. It was pointed out that one critical requirement for recognition as a teaching centre was that there should be at least two, suitably qualified, full time consultants.

There are models for the inspection of clinical training programmes within the UK that could readily be emulated. For example that in use by the clinical immunologists. CESPI will be satisfied to see moderate progress.

TEAM (Transfer of expertise on adults with rare metabolic diseases) Study. This is a project to develop a series of review papers and training sessions for clinical staff. It is based in the University of Utrecht. The SSIEM has been asked to collaborate by the project leaders, Prof Barrientos and Prof W. de Valk. Philip Lee and Jean Marie Saudubray are actively involved in the project. Council will wait for their reports before making any decisions about possible involvement.

### **2003. 7. Treasurer's report**

Graham Shortland presented a summary report.

The society is on course for a neutral budget this year. The final account from the Dublin meeting has not yet been received but it has been indicated to be in positive balance.

Membership has been steadily increasing and now stands at 1047 of which 945 have paid for the current year.

Statement of Risk for the Charity Commission; it has been decided to include the following phrase in the registration forms for future meetings: 'fees will not be refunded in the event of cancellation of the meeting due to unforeseen circumstances'.

### **2003. 8. Publications report**

Guy Besley presented the following report:

As reported at the last Council meeting, there have been delays in publication dates though last year. This has been due to a shortfall in the numbers of acceptable manuscripts. The submission rate remains fairly steady. The knock-on effect has been that the final issues to volume 25 (2002) have overrun into 2003. Issue 7 has recently been published and members' copies should have been dispatched by now. The final issue is currently being assembled.

Conscious of these problems I have asked Mike Gibson to try to elicit some review papers for the future. As far as the Dublin meeting is concerned all review manuscripts are now in. Of the 20 speakers approached 16 have produced manuscripts, 2 had declined early on 1 has failed to respond and 1 was unable to meet the deadline due to other commitments. I think this will produce a very useful review issue. It should be published in the next few months.

Arrangements seem to be progressing well for the publication of abstracts for the International meeting this year. Neil Hamilton has sent the pro-forma we have used in the past. Publications will be both by Kluwer here and by a local printer/publisher in Australia. Since the SSIEM is not organising this meeting, I am not sure what the response will be to invitations to submit a review article to the Journal from this meeting, but I hope we can publish a significant number. I will be getting the contact details from Bridget to approach speakers. She had not mentioned anything about a publication when inviting speakers. This may be something we should consider for the future when meetings are organised outside the SSIEM. We may not be able to depend on the usual review issue.

### **2003. 9. Web site report**

Kim Bartlett and Neil Hamilton will be invited to attend the next meeting of council for consultation with respect to the website.

### **2003. 10. Secretary's report**

Mick Henderson had nothing additional to report.

### **2003. 11. Any other business**

There was no other business.

### **Date and time of next Council meetings**

Friday 20th June 2003

Friday 5<sup>th</sup> December 2003

*Dr MJ Henderson*

*Honorary Secretary, SSIEM*

*7<sup>th</sup> February 2003*