

**IASSID Executive Meeting
Minutes
Friday January 9 and Saturday January 10, 2009
BMA House, London, England**

Present: Glynis Murphy (Chair), Vianne Timmons, David Felce, Phil Davidson, Jan Blacher, Neil Ross, Bob Davis (via videoconference for part of Friday), Keith McVilly (via teleconference for part of Saturday), Helene Ouellette-Kuntz (Secretary)

Regrets: Giorgio Albertini

Commencement: January 9, 2009 at 13h45

1. Approval of the Agenda

The agenda approved with the following modification: Item 12 moved after item 4

2. Previous Minutes and Matters Arising

The minutes of the Executive Meeting held April 13 and 14, 2008 in Charlottetown, PEI were approved with the following corrections:

- a. Delete (sp?) on p. 1
- b. Change G. Alberto to G. Albertini and delete (sp?) on p.2
- c. Change Medcap to Mencap on p. 5
- d. Change 1,011,953 Euros to 101,195

Motion to approve the Minutes made by N. Ross, seconded by P. Davidson; all in favour.

Matters arising were discussed resulting in the following actions to be taken:

- a. H. Ouellette-Kuntz will send information documents shared with new members at the last Congress to N. Ross to post to the website.
- b. Liaison with other organizations will be done by K. McVilly
- c. D. Felce will establish a dialogue with Research Centers regarding their expectations related to benefits of membership

- d. N. Ross will update the website listing of Council members to include designated roles on the executive and to indicate who is representing members at large, research centers and member organizations. H. Ouellette-Kuntz will provide the information.
- e. N. Ross emphasized the need for a Web Editor who is a member of Council in addition to a paid Web Master who provides the more technical assistance and serves as a back-up. H. Ouellette-Kuntz will verify that this requirement for this appointment by the President from those already on council (as recommended by N. Ross in 2008) is reflected in the next revision of the by-laws.
- f. H. Ouellette-Kuntz to confirm with H. Lantman (past VP- SIRG Coordination) regarding the documentation received and decisions made regarding the DS application for Affinity Group and/or SIRG status and copy R. Davis (new VP – SIRG Coordination) on correspondence. It was felt that syndrome-specific groups are best integrated in IASSID as affiliated organizations and/or Affinity Groups as is Down Syndrome International (affiliated organization). R. Davis will communicate the council's decision to the group through Roy Brown. [addition: DS was given Affinity Group status by the Council in 2008]

3. President's Report

The President did not have a separate report to present at this time.

4. Treasurer's Report

P. Davidson provided unofficial figures of balances in the US (\$520,362) and French (145,762 EUROS) accounts. He reported that he has been in constant communication with the past treasurer (M. Janicki) for the smooth transfer to the treasury. To facilitate the transition the same accountant will be used for this year. Registration as a not- for- profit organization in State of Wisconsin has been renewed.

Laura Robinson, a colleague from Rochester, is assisting with database management and paperwork. **A memo will be sent to council members regarding the functionalities of the membership list in the next month.** There are still some issues with the website regarding payment of registration fees but P. Davidson and N. Ross are working very closely on these. Once registrations are received and a new membership database compiled, membership services are the responsibility of the Secretary.

P. Davidson will be meeting with JPPID and JIDR publishers in the next few months. **1st subscription list will be sent to publishers in the next few weeks to publishers** (nearly 200 already received).

A document, entitled IASSID Finance Committee, prepared by P. Davidson and distributed with the agenda was discussed. It was decided that the following committee membership would be presented to Council for approval:

P. Davidson (Treasurer)

N. Ross (Web Editor, Correspondent, IASSID Europe Bank Account)

M. Janicki (Past Treasurer)

R. Davis (SIRG VP)

G. Murphy (President)

[called upon when needed: Joseph Klarberg, AG Edwards (Financial Consultant)]

H. Ouellette-Kuntz will request electronic vote from council members for the immediate constitution of this committee.

The circulated document also presented information related to the relation between IASSID Europe and IASSID. This was discussed at length resulting in the motion that IASSID Europe be dissolved, that the bank account be re-titled IASSID and that N. Ross remain the signing officer on the account for the time being.

Moved by N. Ross, seconded by P. Davidson; all in favour

G. Murphy will discuss the motion with VP responsible for Europe before the decision is finalized and acted upon.

SIRG and Academy funds -Attachment II 'Revised Dues Allocation Policy December 2008) was presented by P. Davidson. It was moved that the policy be implemented for 2009 upon submission to the Treasurer of a report of financial accounts from each SIRGs and the Academy.

Moved by D. Felce, seconded by J. Blacher; all in favour.

Contracting authority – The Treasurer expressed concern about not knowing of contracts IASSID has signed. All were reminded that contracts can only be signed by one or more of the officers: president, president elect, treasurer, secretary.

Request from Wiley-Blackwell to increase subscription rate for JIDR from \$52US to \$54US. The amount was deemed reasonable and the increase will be passed along to members in 2010 as a direct cost such that membership with the journal will increase by \$2US.

ITEM 12 – report on SIRG Coordination

R. Davis noted that he assumed his VP role in November. He will set up a teleconference with heads of SIRGs to go over changes to financial matters, will liaise with the Academy and report to the Executive and Council in June.

At this time, R. Davis left the meeting (videoconference).

5. Secretary’s Report

- a. Practical matters: H. Ouellette-Kuntz reminded everyone of the website set up for Council documents and requested that in the future, **agenda items and attachment be sent at least 1 month before meetings to allow for the preparation and distribution of materials in sufficient time for review by all members of the Executive and Council.**
- b. Committees for 2008-2012: H. Ouellette-Kuntz noted that the association’s by-laws call for several committees to be constituted and approved by Council. The role and membership for each committee were reviewed. There was agreement that our by-laws stipulated committee sizes that would hinder their effectiveness. Hence, the executive will recommend that some positions on committees remain vacant until the next Assembly when revisions to the by-laws will be proposed. **The executive recommended that the following individuals be approached by the Secretary to determine their willingness to serve on the listed committees. If they are agreeable, the committees will be presented to Council for approval in June** (with the exception of the Finance Committee which will be voted on electronically over the next month).

Articles and Bylaws Committee:	
As per by-laws	Proposed for 2008-2012
Member of Council (Chair)	K. McVilly (chair)
Member of Council	H. Ouellette-Kuntz
Member of Council	Vacant
Member of Council	Vacant
Member of Council	Vacant
Programme Committee:	
As per by-laws	Proposed for 2008-2012
President Elect (chair)	President Elect (chair) - V. Timmons
President	President - G. Murphy
Secretary	Past-President - D. Felce
Treasurer	Treasurer - P. Davidson
Member of Council	Vacant
Member of Council	Vacant
Member of Council	Vacant

Membership Committee:	
As per by-laws	Proposed for 2008-2012
Treasurer (chair)	Secretary (chair)- H. Ouellette-Kuntz
Member of Council	Treasurer - P. Davidson
Member of Council	VP membership - G. Albertini
Member of Council	Vacant
Member of Council	Vacant
Member of Council	Vacant
Nomination and Election Committee:	
As per by-laws	Proposed for 2008-2012
Member of Council (chair)	Past-President (chair) – D. Felce
Member of Council	President – G. Murphy
Member of Council	President Elect – V. Timmons
Member of Council	Vacant
Member of Council	Vacant
Awards and Recognition Committee:	
As per by-laws	Proposed for 2008-2012
Member of Council (chair)	K. McVilly (chair)
Secretary (ex-officio)	Secretary (ex-officio)- H. Ouellette-Kuntz
Member of Council	E. Emerson
Member of Council	L. Mayo
Member of Council	C. Vlaskamp
Non-Council member – biomedical science	A. Cooper
Non-Council Member – behavioural science	M. Guralnik
Non-Council Member – educational science	L. Cohen
Publications Committee:	
As per by-laws	Proposed for 2008-2012
Member of Council (Chair)	VP – Publications (Chair) – J. Blacher
Member of Council	Treasurer – P. Davidson
Member of Council	JIDR Editor – T. Holland
Member of Council	Member of Council with Experience as Editor – D. Felce
Finance Committee:	
As per by-laws	Proposed for 2008-2012
Treasurer (Chair)	Treasurer (Chair) – P. Davidson
Outgoing Treasurer	Outgoing Treasurer – M. Janicki
Council Member	VP SIRG – R. Davis
Council Member	President – G. Murphy
SIRG Coordination Committee:	
As per by-laws	Proposed for 2008-2012
VP SIRG Coordination (Chair)	VP SIRG Coordination (Chair) – R. Davis
Treasurer	Treasurer – P. Davidson
Secretary	Secretary – H. Ouellette-Kuntz
One representative from each SIRG	One representative from each SIRG (to be named)

Site Selection Committee (for 2016 Congress):	
As per by-laws*	Proposed for 2008-2012
Treasurer	To be determined at a later date
Secretary	
One VP	

*The President shall have full discretion in the appointment of members and number of members to the committee, however, the mandated members shall include those listed.

- c. Membership Update: With the transfer of the Treasury and website issues, there was a delay in sending membership renewal notices and getting the registration process but all in progressing well now with over 200 new or renewed memberships for 2009.
- d. Letter to past council members: **H. Ouellette-Kuntz will draft a letter** to acknowledge past council and executive members for their contributions. **These will be sent to the members by G. Murphy.**
- e. Newsletter: A draft of the layout of the newsletter being prepared for distribution in February 2009 was reviewed. H. Ouellette-Kuntz has/will **request contributions from G. Murphy, V. Timmons, K. McVilly, R. Brown, JPPID Publisher, and T. Holland.** She will also include a report from this Executive meeting.

The meeting was adjourned for the day at 17h00.

The meeting resumed at 9:30 on January 10, 2009

6. Approval of the Agenda

The Agenda was approved with the following modification – item 11. b moved to first item and item 10 being deleted

ITEM 11.b Singapore 2009 Conference Update

K. McVilly reported that planning was on track. There has been a good response to the request for Abstracts (~250). He noted that the program could accommodate 180 to 200 presentations. An extensive group of reviewers (~50) are working diligently to set a standard for the conference and also provide constructive feedback to those who submitted abstracts. The review process is done electronically and the software used has worked very well. The possibility of incorporating the software on our website for use with other conferences appears worth discussing.

Financially, the event is expected to do well despite the limited success with fundraising to date. It was noted that the Singapore government offers a reimbursement for cost of professional organizer IF a set target for overnight accommodations is met. However, without more fundraising to offer scholarships, the cost of registration is high for people in the region. Various

avenues for fundraising were discussed including approaching the World Bank for support (**K. McVilly will follow-up with Olive Webb** – ASSID President who has contacts), Jerome Lejeune Foundation (**K. McVilly will send N. Ross materials for use in his next meeting with his contact**), pharmaceutical companies (noted they are best approached by a prescribing professional – **K. McVilly will discuss with his planning committee**), Wiley-Blackwell (could be approached to provide scholarship support in return for IASSID manning a booth for them at the Conference). The executive is willing to offer support for scholarships in order to provide reduction in registration fee for many local participants. **K. McVilly will submit a proposal.**

K. McVilly will ensure space for the following meetings including access to teleconference (and if possible videoconference):

Executive Meeting Wednesday 24th 9:00 until 13:00; 8 expected to attend; 2 in North America will join by tele/videoconference

Council Meeting Saturday 27th 13:00 until 18:30; up to 34 to attend; at least 2 will join by tele/videoconference

SIRG Coordination Committee Meeting date and time to be set by R. Davis; up to 11 to attend; at least 1 will join by tele/videoconference

K. McVilly left the meeting (teleconference).

7. Website Update

N. Ross reported that Damien Munch, a doctoral student in computer science, is working as our web master. A contract being developed with him will include providing technical support and back-up to the web editor. Membership forms on the website have been revamped, all links are now working properly. We were informed that our site is hosted in Manchester with a back-up in the US.

There is a need to start thinking about assigning a new web editor in the future.

8. Report on Publications

J. Blacher reported that she met T. Holland to be oriented to her role as VP responsible for publications.

a. Issues Regarding Sponsorship of Publications by IASSID were discussed. **J. Blacher will write to Vee Prasher** in follow-up to correspondence regarding a proposed book based on the 2008 World Congress Abstracts making it clear that the publication is not endorsed by IASSID and as such is not to display the Association's logo. The letter will be copied to G. Murphy and T. Holland.

b. Solicitation of books for IASSID – It was decided that while IASSID will endorse books which have been vetted by the Publications Committee, the responsibility for finding a publisher rests with the author(s).

c. Donation of JPPID back issues – **J. Blacher will direct M. Janicki to go ahead** via contacts established in Africa, South America, Eastern Europe to make the donations. Everyone is asked to send J. Blacher names of contacts that she will pass on to M. Janicki

d. Wiley-Blackwell discount offer – **H. Ouellette-Kuntz will propose to M. Janicki that the publisher prepare a notice** re: discount for books to include in our Newsletter. The executive had no specific books to recommend that the publisher announce.

e. Other – It has come to the attention of the Executive that a separate bank account may exist for JPPID. **P. Davidson will look into this and report back to the Executive.** It is felt that any moneys for JPPID should be sent to the IASSID account earmarked to JPPID.

f. D. Felce provided the following background regarding our two journals: Wiley-Blackwell owns ½ JPPID and ½ JIDR. Mencap owns the other ½ of JIDR while IASSID owns other ½ of JPPID. Tosinvest has provided support for JPPID.

g. The following were recommended to form the Publications Committee: J. Blacher (Chair), P. Davidson (Treasurer), T. Holland (JIDR Editor), D. Felce (past JARID editor- editorial experience).

9. Miscellaneous

In order to enhance accountability practices, the treasurer's expenses will require approval by the President. Furthermore, the President will be given the access code to the Bank of America Account.

G. Murphy will ask E. Emerson to prepare a report on WHO liaison (including our workplan) for presentation at the June 2009 Council meeting.

11. a. 2008 World Congress Report

G. Murphy distributed a report showing the number of paid registrants by country. She requested that P. Davidson and D. Felce go over the budget and final statement to ensure nothing has been missed. Slightly less than 100,000 Euros is expected in profit not counting 30,000 Euros in French account.

G. Murphy will prepare a report on the six research projects funded by IASSID.

11.b. Singapore 2009 Conference

A motion was presented by D. Felce, seconded by N. Ross to provide \$10,000 US in support of scholarships for the 2009 Asia-Pacific Conference; all in favour.

G. Murphy will notify K. McVilly and instruct P. Davidson re: transfer of funds.

11.c. Europe 2010

In the absence of G. Albertini, D. Felce reviewed minutes of two planning meetings held in Rome. Potential co-sponsors have been identified. As a regional meeting, it is important that the conference cover a breadth of topics; it is suggested that using SIRGs and Affiliate organizations to fill program ensures such breadth. The proposed structure of the event and dates are:

September 13 & 14: Academy pre-conference workshops;

September 15 to 17: conference in Grand Hotel Plaazza Carpegna;

September 18: Family Synthesis Day.

The organizing committee is comprised of: Giorgio Albertini, Matt Janicki, David Felce, Giampaolo LaMalfa, Fabrizio Fea, Manuella Galli and Claudia Conducci. **D. Felce will suggest the addition of Patricia Walsh to the committee to add a broader European presence and another person with experience organizing a European Conference for IASSID.**

Call for Abstract is expected to be in November 2009.

Conference language is expected to be English but it is unclear whether or not there will be translation.

It was noted that the conference dates conflict with Jewish holidays. **D. Felce will bring this issue to the attention of the Europe conference planning committee ASAP, to seek alternative dates.**

11 d. 2011 South America Regional Conference

It was noted that M. Malbran suggested Brazil with a focus on poverty and ID. **J. Blacher as VP for America will follow-up with M. Malbran and Liliana Mayo in order that a decision regarding where to hold the 2011 Conference in South America can be made at the Council meeting in Singapore.**

11.e. 2012 World Congress in Halifax

There is an urgent need for a visit to the venue and signing of the contract establishing the exact dates of the event. V. Timmons notes that June would be better than July for holding the World Congress. Before the June 2009 Meeting in Singapore, **V. Timmons will visit the site, confirm dates, establish a local organizing committee and develop a budget. She will also prepare a flyer to send to K. McVilly** for inclusion in the Singapore meeting conference package. [Addition: V. Timmons & D. Felce will visit the site on March 9, 2009; P. Davidson and H. Ouellette-Kuntz might join them.]

11.f. World congress 2016 venue

It is felt that it is too early to establish site selection committee.

13. Academy

- a. The report received from R. Brown was distributed.
- b. Formal Evaluation in 2009

As the Academy was a pilot project of IASSID, it will be evaluated this year in order to answer such questions as: Is having an Academy a good idea? Does it overlap with SIRG activities? How should it be done? What does IASSID endorsement of training activities mean? It was decided that two evaluators would be named to prepare a report for the Executive by December 2009. Shamus Hagerty and Patricia Noonan-Walsh were suggested. **G. Murphy will approach them.** A small honorarium will be offered to each in the order of \$2,500 US each.

14. By-laws: simplifying language

The by-laws committee will present a proposal to the Executive for changes to the by-laws including cost for hiring someone to re-write the document in clearer language.

15. Future Executive Meetings

Singapore June 24, 2009 (regrets: J. Blacher, H. Ouellette-Kuntz, D. Felce)

Halifax late October 2009

Rome Spring 2010

Rome September 2010

Reimbursement to Meetings: Executive: airfare, hotel and other expenses; Council: different for each meeting; P. Davidson will send information out to all.

H. Ouellette-Kuntz will build agenda for Council meeting based on previous one. To be sent out by June 1. Therefore agenda items need to be confirmed by May 1 and attachments received by May 15.

Adjourn 3:30 pm