

# **IASSID SPECIAL INTEREST RESEARCH GROUP PERSONS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES**

## **Minutes of the Meeting of the SIRG PIMD Council held at the 3<sup>th</sup> IASSID European Regional Congress on Friday 22<sup>th</sup> October, in Rome (Italy)**

### **1. In remembrance of Prof. Dr. Han Nakken**

The 23<sup>th</sup> of July 2010, Han Nakken passed away. We will remember him as a person with great dedication to research and practice, and to persons with PIMD. At the World Conference in Helsinki, in 1996, he set up the plan to start a SIRG PIMD. It started as a small group at the Seattle 2000 conference. Han would be proud to see how many people attended the SIRG in Rome. At the IASSID congresses, there is now a whole program on people with PIMD, with many attendants, a lot of enthusiasm and interesting contributions. Thank you, Han, for your enthusiasm, your willingness to discuss with students, and your dedication to practice. We will never forget you.

### **2. Minutes SIRG-meeting Cologne**

The minutes of the meeting of the SIRG PIMD held on Thursday 24<sup>th</sup> September 2009, in Cologne, were approved.

### **3. Board of the Special Interest Research Group on Profound Intellectual and Multiple Disabilities**

Normally, the board members would be (re)elected at this SIRG PIMD meeting in Rome. Carla and Loretto decided that it would not be appropriate to hold a re-election without a proper announcement and a transparent procedure. A proposition will be made by the current board and this proposal will be send out to the members by e-mail and through the newsletter.

### **4. News from the sub-committees**

Since the SIRG PIMD meeting in Cologne, September 2009, five subcommittees were founded. It is time for a first evaluation.

#### **1. newsletter committee**

- coordinators: Juliet Goldbart, Krysti DeZonia

Juliette and Krysti have done excellent work on the newsletter. Many thanks as well to Brooke Trayer, a parent who helps in making the newsletters.

We should add a family section to the newsletter. In a user-friendly layout and language, we can make clear how study results are of interest for families (implications). And of course, for practitioners as well. It is important to put families in the mailing list. Our general starting point is that parents are equal members and are the most knowledgeable with regard to their own child with PIMD.

The newsletter is up to now predominantly a medium of transferring information. More content-based articles are needed. The newsletter is not only meant for transmission of information. Every research or project, even if it's still in progress, is interesting for the newsletter. The more information and the more international, the better!

It would be interesting to translate the newsletter into other languages. But there's a need for translators.

New contact persons for providing information for the newsletter are welcome (let Krysti know)!

## 2. **young researchers committee**

- coordinators: Annette van der Putten, Vera Munde

Many thanks to Annette and Vera. There was an interesting meeting of young researchers in Groningen, in June 2010. This has proven again that it is motivating for young researchers, as well as for their supervisors, to meet regularly. We keep the plan to meet once a year.

## 3. **parents committee**

- Coordinators: Loretto Lambe, and ....???

Loretto stresses the great importance of increasing the attendance of parents in IASSID meetings. Since funding is the problem, we should think about ways to find money. We should think about using SIRG-budget for this. We might set aside a figure for these parents, not just for their subscription in meetings and travel costs but also for the respite care for their child with PIMD.

It's important to know that funders often ask for learning outcomes. So, in applying for funding, we should stress how parents benefit from attending meetings like IASSID congresses. It should be shown how they feel strengthened and empowered by contact with researchers, practitioners and other parents. Jenny Whinnett is a perfect example of how a parent can contribute to the academic discourse. She already gave a presentation on this at the parents meeting in Cologne (September 2009). She will now write down her experiences in an article too, to be published in the next newsletter.

Sometimes universities (e.g. in Scotland) also provide money for this cause. David Felce should also be reminded about special conference fees for family members and family carers.

Anyone who has other ideas about possible funding or about how to involve parents, should e-mail these to Loretto.

Anneleen reports about the meeting of practice-oriented organizations in July 2010 in Leuven. Abstract from the newsletter:

In Europe, there are several practice-oriented organizations who work together with people with PIMD and family members and/or direct support workers. Some of these organizations have already participated at IASSID SIRG conferences and Round Tables, but certainly not all of them. For this reason, a European meeting was organized in Leuven, Belgium, on the 7<sup>th</sup> and 8<sup>th</sup> of July 2010, where all practice-oriented organizations known to us were invited. CESAP, NEXE FUNDACIÓ, APF, AP<sup>3</sup>, AIR/AIRMES, Multiplus, Platform EMG and INS HEA were present, as well as researchers from the universities of Liège, of Cologne, of Leuven and Genève. PAMIS, Leben Pur, CRMH and the University of Groningen were excused but were kept informed by mail.

At this meeting, all the organizations presented themselves and formulated their expectations concerning European cooperation. The organizations who were interested in working together on research concerning people with PIMD, were stimulated to become a member of the SIRG-PIMD.

Finally, we also brainstormed on a common European project, in which these organizations, parents, professionals, researchers and trainers cooperate. In January 2011, a second meeting will take place in Paris to discuss this further.

To simplify the exchange of information and experiences, we decided to create a website (<http://www.multiplus.be/euronet.php>) where all the organizations can upload interesting information. The login is *multiplus*, the password is *Europimd* (mind the capital!). Read the report on the July meeting to get more information about this initiative.

If other practice-oriented organizations, known to you, could be interested to be involved in these meetings, please inform Multiplus (info@multiplus.be).

**4. new membership committee** – coordinator ms Chen

We should keep people aware of ticking on the SIRG PIMD box when inscribing for IASSID. The travel costs from Asia to Europe are immense, this is a problem. But the idea of an Asian Round Table is certainly a possibility for the future. In the meanwhile, maybe there is scope for videoconferencing?

Maybe we should think about adding a link to the SIRG newsletter or to IASSID on social network sites to let know that we are existing?

**5. pre-conference committee** – coordinators: Juliet Goldbart and Carla Vlaskamp

There wasn't a preconference in Rome. There were too many applications for preconferences and the one for the SIRG PIMD was not retained. Unfortunately, Carla and Juliette were not informed about this. But they already have the confirmation there will be a preconference in Halifax, Canada.

**5. Any other business / miscellaneous**

Jean Ware notices that it should be mentioned to the Central Board that the IASSID congresses should be at cheaper places. Touristic cities like Rome are extremely expensive.

Asia-Pacific 3<sup>rd</sup> Regional IASSID Conference, Tokyo, Japan, August 2013: There will be a symposium on people with PIMD, in English. Our Asian colleagues would like to cooperate with the European researchers and parents. There is a Japanese parent organization who would like to get in contact, but the English language is a hindrance and they cannot pay the travel costs to Europe. So maybe some SIRG-members can visit them in Japan? A translator can be arranged.

It was suggested the next Round Table would be in Taiwan. Because of the financial climate and because most SIRG-members are from Europe, this is not an option for now. Information on where the next Round Table, in 2011, will take place, will be sent out. The 2011 Round Table will be in Europe at an easy accessible and not too expensive place, the 2013 Round Table can be arranged in cooperation with a conference in Australia. The possibilities for video conferencing will be considered (e.g., looking for an accommodation that makes this possible).

The next IASSID World Congress will be in 2012 in Halifax. Maybe we can organize a Round Table in Australia too; this would be easier for the Asian and Australian people.

Interesting publications: see newsletter.

It's important to keep on trying to share resources. Multi-sensory storytelling is a good example of joint research. We should elaborate this kind of joint research, more exchange is necessary.

We are reminded of the interesting publications of SLD experience, of which Jean Ware is the editor. PMLD-link is also very interesting.