

# Profound Multiple Disabilities

Contributed by Administrator  
Thursday, 16 April 2009  
Last Updated Friday, 17 April 2009

## Mission

The SIRG has as its founding principles:

- Provide a focus for the worldwide exchange and dissemination of research and practice, as well as networking, in the field of persons with profound multiple disabilities. Individuals with profound multiple disabilities form a heterogeneous group. The 'core group' consists of individuals with such profound cognitive disabilities that no existing standardized tests are applicable for a valid estimation of their level of intellectual capacity and who often possess profound neuromotor dysfunctions like spastic tetraplegia as well. Apart from profound intellectual and physical disabilities, it has been demonstrated that they frequently have sensory impairments. Individuals with PMD form a physically very vulnerable group of persons with a heavy or total dependence on personal assistance for every day tasks, 24 hours a day. The SIRG/PMD brings together researchers and practitioners with different disciplines and from different countries.
- Promote cross-national, multidisciplinary collaboration in the area of persons with profound multiple disabilities. The ultimate aim of the group is to improve the quality of life or and services for people with profound and multiple disabilities, their carers, and their families.
- Provide a framework for the collation of information relating to the research interests, expertise, and publications of group members. Within the overall process of collaboration, the views and contributions of nonprofessionals, including people with intellectual disabilities and their families and friends, are a fundamental component, and will be given the priority they deserve.

The SIRG works by means of a newsletter, a mailing list, and two-yearly round table conferences. The group also makes several contributions on the European and World Congresses of IASSID. Membership

Membership is open to persons with an interest in any facet of research or application related to persons with profound intellectual and multiple disabilities:

- researchers in the psychological, educational and medical fields;
- teachers, therapists, professionals in schools and services for persons with profound multiple disabilities;
- family members or other significant persons in the lives of persons with profound multiple disabilities;
- representatives of volunteers or service organizations.

Contactperson .

For information on joining the SIRG/PMD, contact the SIRG Secretary,

Bea Maes at [bea.maes@ped.kuleuven.ac.be](mailto:bea.maes@ped.kuleuven.ac.be)

or write to

Bea Maes  
IASSID SIRG/PMD Secretary  
Centre of Disability, Special Needs Education and Child Care  
University of Leuven  
Vesaliusstraat 2, B-3000 Leuven  
Belgium

## Board members

Carla Vlaskamp, PhD (University of Groningen, the Netherlands), co-chair and  
IASSID Council Representative from the SIRG/PMD E-mail: [c.vlaskamp@ppsw.rug.nl](mailto:c.vlaskamp@ppsw.rug.nl)

Loretto Lambe, PhD (White Top Research Centre, Dundee, United  
Kingdom), co-chair E-mail: [l.lambe@dundee.ac.uk](mailto:l.lambe@dundee.ac.uk)

Han Nakken, PhD (University of Groningen, the Netherlands), past chair E-mail:  
[h.nakken@ppsw.rug.nl](mailto:h.nakken@ppsw.rug.nl)

Bea Maes, PhD (University of Leuven, Belgium), secretary E-mail: [bea.maes@ped.kuleuven.ac.be](mailto:bea.maes@ped.kuleuven.ac.be)

Barbara Fornefeld, PhD (University of Köln, Germany), member E-mail: [b.fornefeld@gmx.de](mailto:b.fornefeld@gmx.de)

Mats Granlund, PhD (University of Stockholm, Sweden), member E-mail: [mats.granlund@ala.fub.se](mailto:mats.granlund@ala.fub.se)

Paul Pagliano, PhD (School of education, Townsville, Australia), member E-mail:  
[paul.pagliano@jcu.edu.au](mailto:paul.pagliano@jcu.edu.au)

Knut Slåtta ( Torshov Resource Center for Special Education, Oslo, Norway),  
member E-mail: [knut.slatta@statped.no](mailto:knut.slatta@statped.no)

Mary Arnold (Ark Regional Services), member E-mail: [maryarnold619@hotmail.com](mailto:maryarnold619@hotmail.com)

Anne Brown ( White Top Research Centre, Dundee, United Kingdom ), member E-mail:  
[helenanne.brown@virgin.net](mailto:helenanne.brown@virgin.net)

\*For more information, updates and documentation  
please consult : [www.sirgpm.d.be](http://www.sirgpm.d.be)