



ECR meeting of the SIRG PIMD in Glasgow

Monday 5th August 2019

**Room M401, George Moore building, Glasgow Caledonian University,
Cowcaddens Road, Glasgow, G4 0BA (map attached)**

9:00 Welcome with coffee and tea

9.10 Opening of the ECR meeting, introduction SIRG PIMD and introduction round

10:00 – 11:00 Presentations of Early Career Researchers

1. Anna Rensfeldt Flink: *Inclusion of children with PIMD in studies: experiences of and reflections on formulating inclusion criteria.*
2. Ann Dhondt: *Analysis of early communicative behaviours of young children with significant cognitive and motor developmental delays.*
3. Esther Atlan: *Qualitative analysis of interactions initiated by students with PIMD and direct support workers in educative context*

11.00 – 11:30 Coffee Break

11:30 – 12:30 Presentations of Early Career Researchers

1. Linn Johnels: *Children with PIMD: Intervention study targeting school staffs' responsive strategies using interactive music activities and multisensory storytelling.*
2. Karen Laing: *How do classroom teachers and occupational therapists work across professional boundaries to support students who have profound intellectual and multiple disabilities?*
3. Siméon Lahije: *Stronger Together: to enhance family quality of life of families with a child with profound intellectual and multiple disabilities.*

12:30 – 14.00 Lunch and networking with PAMIS staff and family carers (www.pamis.org.uk) – The only UK organisation that works solely with people with profound and multiple learning disabilities and their family carers for a better life

14.00 - 17:00 Selection of visits and group discussions to choose from

- **SENSE Scotland visit to Touchbase, 43 Middlesex Street, Glasgow G41 1EE**

TouchBase is one of Sense Scotland's biggest contributions to developing a community. It offers a variety of registered group services or 1:1 support including access to expressive arts, music and drama. It's also a place for the wider community.

<https://www.sensescotland.org.uk/what-we-do/touchbase-a-sense-of-place/>

- **Exploring resources**

- **Multisensory storytelling** offers the opportunity to connect with those who find it difficult to communicate verbally. A range of stories have been developed to enable the voice of lived experience and access culture. Some of our stories deal with sensitive issues, such as growing up and separation anxiety, while other stories tell folk-tales. In addition, sharing personal digital stories can support service design, training and consultation. These have been effective in changing policy and attitudes around people with PMLD. Maureen Phillip, PAMIS senior family support and development director, has spent the last 25 years developing this approach and now provides training and development in multi-sensory storytelling to support communities to be inclusive. Come and discuss the models and approaches and share ideas for future collaborations
- **Pat Graham** a family carer consultant and chair of the PAMIS Board has spent a lifetime researching the representation of people with disabilities in picture and story books. She has developed a substantial and fascinating historical resource which she will share and discuss with participants. Pat and PAMIS are keen to consider how to develop this project. Come and share your thoughts and ideas.
- **Postural Care** –Appropriate and person centred postural care supports people to protect and restore body shape by adopting symmetrical postures, particularly in lying. Habitual destructive postures compromise body shape, muscle tone, motor performance and function of the vital organs as a consequence of reduced internal capacity within the abdomen and thorax. These complications cause suffering and premature death. PAMIS are co-chairs the Scottish postural care strategy group. We have developed a network of family carers who are equal partners in the delivery of postural care training. The co-produced model of training is supporting a culture change in partnership working. Come and meet the team of families and staff who are developing this approach and share approaches and ideas regarding the reduction of postural deformity.
- Open space – bring your own topic for discussion with colleagues and PAMIS family carers.

19:00 -...: Social Dinner