



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible

Family Faculty Meeting

23rd March 2021 1:30pm Zoom

Attendees

Family Faculty: Kevin, Sharon, Lynn, Julia, Julie, Annette, Ian, Sean, Nicole, John, Hannah, Mary

PenCRU: Chris, Bel, Annette, Alice, Fleur, Phil

Apologies: Rachel, Karen, Lin, Ursula, Faye, Ruth, Antonia, Sarah, Mary

Welcome and icebreaker, ground rules

Overview and funding update: Chris is busy applying for several grants so we can continue our work in the years to come.

Healthy Parent Carers Programme Update

- Charities: Charities are engaged in the roll out of the programme. We've had interest from NHS commissioners nationwide.
- Online adaptation of manuals: Several manuals are involved and they all need adapting to online delivery. Bel and Annette have been working hard on this.
- Activities have been trialled by a Family Faculty subgroup. Many thanks to them, their help has been invaluable. Some people prefer an online course as they can access the training without leaving home. So going online offers opportunities as well as challenges. The principles of the programme are so strong they transfer across the online barriers. Access to the course is widened with it being online but others would prefer to meet in person.
- The aim of the programme is to make parent carers more resilient to life's challenges.
- Involvement in the development of the programme has been therapeutic in itself for some faculty members.
- We recently presented to a group of SEND managers. Kate presented [her story](#) about the benefits of HPC that she has experienced and was very well received.

Update on PhDs

Do contact us if you're interested in being involved in any of these projects. For a full list see the [Annual Report 2020](#).

- Phil Harniess is a paediatric physiotherapist studying the effects of early engagement of therapy with babies with cerebral palsy in London. He interviews families and therapists after the sessions to see what works best.
- Rebound Therapy- to improve chest health in children with neurological conditions.
- Foot and ankle problems in children.
- Botulinum toxin use in children with cerebral palsy.
- Outcomes for children following lower limb orthopaedic surgery.
- The DoMore study looking at exercise for wheelchair users.
- Occupational therapy in schools for SEN children.
- Neuromuscular functions following training in children with cerebral palsy.
- Respiratory fitness and function in children with complex neurodisabilities.

Other Research Projects:

ICoN Study: Neurological surgeons and bowel nurses think many children can be more continent if intervention is early. Sufficient number of accessible toilets in the community is important. Over 600 parent carers took part, many of those in the South West.

Hospital Communications: The University of Exeter are using our project with their trainee nurses. It has also been used in Portsmouth. Our manual is very accessible so easily used by trainers. The programme is also about to be delivered on Zoom.

Parrot Study: Prophylactic antibiotics to prevent recurrent lower respiratory tract infections. Led by a team in Liverpool, research has been slow during the pandemic as there have been fewer respiratory infections.

Intensive Interaction: A way of communicating with children with profound learning difficulties. Project on hold at present as the leaders aren't available.

Further Comments:

HPC project is particularly notable, especially Kate's story. The HPC project spreading nationally has the potential to make a big impact for parent carers.

We're looking forward to being back together again in person, but appreciative of the technology that brings us together. Thank you to everyone for coming; your input is invaluable.