



PenCRU & Family Faculty

making childhood disability research  
more relevant, useful and accessible

## PenCRU News April 2023, Issue 39

Here's a brief round-up of what's been happening at PenCRU this term...

### Healthy Parent Carers research project



We are starting a new research project looking at the best ways to measure the effectiveness of the Healthy Parent Carers programme,

and to ensure a wide range of parent carers feel able to access the programme. The project is funded by the National Institute for Health and Care Research.

You can find out more and get involved [here](#).

We're delighted to welcome Caomhán McGlinchey and Phill Harnies to the PenCRU team as

researchers on this project.

Caomhán is an educational psychologist and former science teacher living in Devon. Phill is a children's physiotherapist with a special interest in child disability. He lives in London so zooms in to our meetings.

### Healthy Parent Carers update

HPC is being implemented and talked about across the UK!

Bel and Fleur were joined by Marie Leddy, an HPC Assistant Trainer from Newcastle, when they exhibited HPC



at the National Network of Parent Carer Forums conference in Bristol. They were in high demand from interested forum reps.

Bel and Gail have just completed another round of training for facilitators from Kids charity in East Yorkshire. The next programme starts at the end of April and will be training new facilitators from LOOK charity,

Positivitree in the Wirral, and Parent Carer Forums in the Bournemouth, Christchurch and Poole areas.

If your organisation is interested in training facilitators then do get in touch with us. [Healthyparentcarers@exeter.ac.uk](mailto:Healthyparentcarers@exeter.ac.uk)

We love hearing from facilitators and participants on the programmes. Here is a recent quote from Rebecca, a participant on the Sunderland Parent Carer Forum course:

*"I was hesitant about joining this course at first, the first few sessions were particularly difficult for me as an isolated parent carer. Stepping out of my comfort zone was scary. Within a few sessions this eased, as I got to know the other parent carers and the facilitators more my confidence improved and I felt like part of a group, which is something I haven't felt since becoming a parent carer."*

## Cerebral Palsy Research

PhD student Fatema Shamsaddin has started her research project:

How does strength training help improve brain-muscle connection in Cerebral Palsy?

She is looking for participants who are:

- Children with CP,
- Age: 5-12 years old
- Able to walk with/without assistive devices

There's more information [here](#).

If you think you could help with her research please get in touch with Fatema.

[F382@exeter.ac.uk](mailto:F382@exeter.ac.uk)

## The Parrot trial

We are partnering with Liverpool and Australia on this project to assess whether prophylactic antibiotics help children

with neurological impairment at risk of lower respiratory tract infection. They are currently looking for participants.

More info on the [Parrot website](#)



## Other opportunities to be involved

We have several research projects that Family Faculty members can get involved in.

- Stretching and strengthening trials for children with cerebral palsy
- Assessing how nurse training programmes prepare children's nurses to care for children and families
- Children and young people with brain injury, epilepsy, autism or ADHD online interviews to understand their experiences of attending activity groups.
- Join an advisory group for a new research project on ADHD

Get in touch with Bel if you'd like more info on these. [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

## Publications

Three recent publications are from our epilepsy and sleep research studies and one from the Reset study, both are available open access to read:

Al-Najjar N, Bray L, Carter B, Castle AP, Collingwood A, Cook G, Crudgington H, Currier J, Dietz KC, Hardy WAS, et al (2023). **Changing Agendas on Sleep, Treatment and Learning in Epilepsy (CASTLE) Sleep-E: a protocol for a randomised controlled trial comparing an online behavioural sleep intervention with standard care in children with Rolandic epilepsy.** [BMJ Open, 13\(3\)](#).

Carter B, Bray L, al-Najjar N, Piella AT, Tudur-Smith C, Spowart C, Collingwood A, Crudgington H, Currier J, Hughes DA, et al (2023). **The impact of parent treatment preference and other factors on recruitment: lessons learned from a paediatric epilepsy randomised controlled trial.** [Trials, 24\(1\)](#).

Merrick H, Driver H, Main C, Ryan P, Kenny W, Richmond C, Allard A, Bola K, Morris C, Parr JR, Pearson F, Pennington L, Resetting Services Team (2023). Impacts of health care service changes implemented due to COVID-19 on children and young people with long-term disability: A mapping review [Developmental Medicine & Child Neurology - Wiley Online Library](#)

You can see all our publications [here](#)

Best wishes from the team

*Chris, Bel, Fleur, Caomhán and Phill*

[pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

[www.pencru.org](http://www.pencru.org)

[www.healthyparentcarers.org](http://www.healthyparentcarers.org)

