



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible



PenCRU News December 2022, Issue 38

Hello

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

Family Faculty Festive Fun



Join us on Zoom for Festive Fun on **Thursday 15th Dec at 10am**. If you let us know you are coming and email us your address we'll send you a party pack. Last year we enjoyed Bel's Christmas quiz, Christmas bingo and opening our party boxes.

Family Faculty Fun Day

It was a treat to meet so many of you in person at Paignton Zoo. Sorry to those of you who couldn't make it. We know that some of you live just too far away, but we still want you to know we appreciate your involvement in the Family Faculty.



'Elfy Parent Carers



In September the team went to London as finalists in the NHS Confederation-AHSN Innovate Awards. Healthy Parent Carers was 'Highly Commended' in the 'Innovation Helping Address Health Inequalities' category.



Congratulations to **Marie Leddy** who has come on board as an Assistant Trainer with Bel. Gail Bedding is also joining the team of trainers. Welcome Marie and Gail!



This term Bel and Marie have trained 4 new pairs of Lead and Assistant Facilitators from Sunderland Parent Carer Forum and the North Yorkshire and Humber branch of the Kids charity.

Sunderland are about to start delivering their first programme to parent carers. Loving the goody bags they are sending out!

Bedford and Exmouth facilitators did some 'top up' training so they could run the programme in person. Exmouth started off in the local park when the weather was good.

Another facilitator training course starts on 26th January and will run for 7 Thursdays. There is still space for another pair to train, so get in touch if you want to book on. healthyparentcarers@exeter.ac.uk

We always love hearing back from participants and facilitators. Here are some recent quotes:

"I would have gone under if I hadn't been doing my CLANGERS"

Anon facilitator



"Everyone needs time for themselves and many SEN parents struggle to do this. However this programme will help you find those breathing spaces and moments to do this, I whole heartedly recommend this course for any parent carer."

Kirsty, Bedford



Meet the PhD Student

PenCRU supports several PhD students in Exeter and around England all focused on childhood disability. In this issue we meet Fatema, a paediatric physiotherapist from Saudi Arabia.

"My name is Fatema Shamsaddin, I have Undergraduate and Masters degrees in physiotherapy.

Although it is well-known that physical training is beneficial for children with cerebral palsy, it is still not clearly understood how their bodies adapt to training. Therefore, my research is focusing on studying the changes that occur in the legs muscles and brain-muscle connection following one of the commonly used training approaches by paediatric physiotherapists, strength training. Understanding how the body adapts to training could help improve the current clinical practice for children with cerebral palsy."

If you would be like to be involved in Fatema's research do get in touch with her fs382@exeter.ac.uk

Resetting a Space for Parrot playing Chess?



Yes we love acronyms!

The CHESS project **CH**ildren's **E**arly **S**elf-care **S**upport launching in Newcastle have asked for the Family Faculty's help informing their research.

CHES is a new way to support self-care of young children with neurodisability from age 12 months to around 5 years, across different conditions and difficulties.

Self-care means developing skills and independence in everyday activities, like using the toilet, having a bath, and getting dressed. It also means getting involved in the activities by making choices, joining in with routines, and coping with problems by finding individual solutions.

We will investigate whether CHES is better than the usual self-care support provided by therapists and can save the NHS money.

If this sounds like something you'd be interested in getting involved with or if you have any further questions, please let us know. We will create a list of people interested in becoming a member of the CHES Working Group and will arrange a meeting early next year. pencru@exeter.ac.uk



The Parrot trial is now recruiting participants. They are looking for children with neurological impairment at risk of lower respiratory tract infection. More info on the [Parrot website](#)

You can still take part in the **Reset study**, a research project finding out what impact the changes in services during the pandemic had on our children's health and wellbeing. More info [here](#)



Members of the Family Faculty attended a **SPaCE project** meeting in which they shared with the team how the Covid-19 pandemic and transitions back after lockdowns had affected their children's mental health and their own mental health. Their input will help to shape the analysis of data from the Mental Health of Children and Young People national survey, and will feed into planning for the next round of that survey. More info [here](#)

Publications

This [paper](#) has just been published in collaboration with researchers in the Netherlands and Canada. 'Exploring the "how" in research partnerships with young partners by experience: lessons learned in six projects from Canada, the Netherlands, and the United Kingdom'. *Research Involvement and Engagement*, 8(1). Nguyen L, van Oort B, Davis H, van der Meulen E, Dawe-McCord C, Franklin A, Gorter JW, Morris C, Ketelaar M (2022).

Wishing you all a happy and healthy Christmas and New Year.

Bel, Chris, Alice and Fleur

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www.pencru.org

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