



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible

PenCRU Summer Newsletter July 2022 37th edition

Hello

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

Thank you to those of you who have been involved in our activities. We really appreciate your thoughts and suggestions to direct our work and keep it relevant to families. We understand that some of you can't be involved due to other commitments at this time, but do feel free to jump back in when you can. We're always pleased to welcome people however long they've been a part of the Family Faculty.

Healthy Parent Carers - going national

- This term Bel and Kevin have trained new pairs of Lead and Assistant Facilitators from Shropshire, Solihull and Bedford.
- Healthy Parent Carers programmes have run for the second time in Enfield and Bedford with new participants learning to focus on their health and wellbeing.
- Facilitator training courses in September and November are almost fully booked, but we're always keen to make contact with potential delivery partners. Contact Alice at a.garrod@exeter.ac.uk for more info about booking.

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

"Try this Course it might just change your life and the way you look at it." Mark, Bedford

"I am quite isolated and have high anxiety, having the course via zoom and meeting other parents going through the same as me was really helpful." Anon, Exmouth

"Training to facilitate this course has not only given me the skills and tools to help others, but has also helped me. Learning about the CLANGERS has helped with my own wellbeing and I look forward to helping others." Heather, Solihull

Family Faculty Fun Day

Saturday 24th September at Paignton Zoo



This invitation is to members of our Family Faculty and our way of saying thank you for supporting and being involved in our work, welcoming recent members and old friends, and simply celebrating our Family Faculty.

Our budget limits numbers to two adults per family and any siblings. We hope to be able to accommodate all our families that would like to go, but please register soon so we know numbers and can confirm your place.

We'll send you more details about when and where we'll be meeting and the activities taking place closer to the date.

If you would like to attend please fill in form below by Wednesday 7th September.

<https://forms.office.com/r/H5Qqqxtwzd>

Thank you to those families who have already signed up. We're looking forward to seeing you all!

SPaCE Study launches

This new study programme sadly doesn't involve any volunteer astronauts before you dash to sign up!



The SPaCE Project

Support for Parent Carers in England

Led by Gretchen Bjornstad, Alice Garrod and Sarah Walker and wider team, with help from a project specific working group of Family Faculty members, the study aims to:

- To examine the prevalence of mental health problems among parent carers of children with special educational needs or disabilities (SEND) in England, before and during the Covid-19 pandemic.
- To explore the current pathways to identification, referral, and treatment for mental health problems for parent carers

The project has had the first working group meeting. We'll keep you posted as things progress and for any ways to get involved. [SPaCE Study](#)

Parrot Study takes flight



The PARROT trial is looking to find out whether 12 months of treatment with an antibiotic called azithromycin reduces how often children with neurological impairment have to stay in hospital with chest infections. The trial is now recruiting participants with neurological conditions

like cerebral palsy or Down syndrome who have recurrent chest infections. Some of our Family Faculty members are on the Parrot project working group advising on the design of the trial.

[University of Exeter news item](#)

[More info about PARROT](#)

Have you signed up to take part in the Reset Study yet?



At the start of the COVID-19 pandemic many services for disabled children paused. When they restarted, services were often provided in a different way, usually online. Many families of disabled children have struggled to cope during the pandemic.

This research will find out what impact the changes in services have had on children's health and wellbeing. We are examining which changes worked well, which changes were not supportive for families and disabled children, and why. We are working with families and professionals from the NHS, social care and education to show how services could be delivered better to provide high quality care to disabled children as the NHS is remodelled.

We will define core principles for health service provision during future emergencies. We need your input via a survey to help decide these core principles

Click below to register your interest in the study and keep up to date with our progress.

[Register interest in Reset Study](#)

Check out our websites

[Healthy Parent Carers](#) website is looking all new and shiny to reflect our progression into appealing to a wider audience of commissioners and parent carers across the country, rather than just research. Click below to take a look.



[PenCRU's website](#) has been transferred to the main university of Exeter platform, so it is now adapted to be viewed better all devices. Thank you to all who sent us photos to use. It brings it life and certainly adds the 'Aaaah factor.'

Finally we wish you all a happy summer break.

We'll keep you posted on Facebook and Twitter with other updates.



Best wishes

Bel, Chris, Alice and Fleur



The screenshot shows the PenCRU website homepage. At the top, there is the University of Exeter logo and the PenCRU & Family Faculty logo with the tagline 'making childhood disability research more relevant, useful and accessible'. A search bar is located in the top right corner. Below the navigation menu, the main heading is 'What is the Peninsula Childhood Disability Research Unit?'. To the right of this heading are buttons for 'What is research?', 'Join our mailing list', and 'News and social media'. The 'News and social media' section includes a link for 'Spring Newsletter 2022' and social media links for Twitter, Facebook, and Instagram. Below the main heading is a large image of a young child with a pink balloon. Underneath the image, there is a paragraph of text describing the unit's mission. At the bottom of the page, there are three columns: 'What's the Evidence?' with a small image, 'Get involved!' with a small image, and a 'Twitter' section showing a tweet from PenCRU (@PenCRU) mentioning a new system for dealing with enquiries.