

Competition Time

We're hopeful that we can have a Family Faculty Fun Day on **Saturday 25th September 2021**. Thank you to those of you in our Family Faculty who answered the survey. The majority of those who replied are keen to come.

Here's a photo from our 2019 Fun Day. Can you remember the name of the beret-wearing plate spinner? First correct answer pulled out of the hat wins a £10 shopping voucher.

Email your answers to pencru@exeter.ac.uk. Closing date 23rd July.



Contact the team

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PenCRU team's second meeting this year 'in person'. L to R: Fleur, Stuart, Chris, Bel, Annette, Alice

PenCRU Newsletter
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PenCRU & Family Faculty

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Healthy Parent Carers

After a marathon effort we're celebrating the successful adaptation of the Healthy Parent Carers Programme to an online Zoom version. Thank you to all the Family Faculty members who wrestled with us to turn activities such as balancing armloads of balloons into effective online versions.

The programme is currently being trialled by the charities Contact and Council for Disabled Children. Bel and Mary have trained up several new facilitators to deliver the programme as well as how to navigate all things Zoom related. There are currently sessions running in London and Yorkshire and we are receiving good feedback from them so far.

It's great to hear the benefits of the programme now progressing beyond the south west. We have also had interest from SEND commissioners in other parts of the country who attended a session where Family Faculty member Kate Evans-Jones presented her personal story of how practising the CLANGERS has helped her in her life as a parent carer. You can hear Kate's story on the website. <https://healthyparentcarers.org/news>

Staff News



We are delighted to welcome Ravi Poorun as a new researcher working with the PenCRU team. Ravi is a trainee paediatrician in Exeter where he combines his clinical training with his research interests related to sleep.

His research seeks to understand the link between neonatal sleep and its long term effects on children with neurodisability. His aim is to find ways to support and optimise sleep in the neonatal unit.

We can hear the parents and staff cheering already - but not too loudly- we don't want to

wake the babies!

He will be consulting with the Family Faculty to help direct his research on sleep for children with neurodisability, so look out for him at our meetings. Ravi's catchphrase is "I love sleep".



Recent Publications

Online community engagement in response to COVID-19 pandemic. [Health Expectations, 2021:02:728-730](#)

Parent-delivered interventions used at home to improve eating, drinking and swallowing in children with neurodisability: the FEEDS mixed-methods study. [Health Technol Assess, 25\(22\), 1-208.](#)

Children with neurodisability and feeding difficulties: a UK survey of parent-delivered interventions [BMJ Paediatrics Open, 2021:5:e001095](#)

Implementation of training to improve communication with disabled children on the ward: A feasibility study. [Health Expect. 2021; 00: 1– 10](#)

Protocol for the Toxin Study: Understanding clinical and patient reported response of children and young people with cerebral palsy to intramuscular lower limb Botulinum neurotoxin-A injections..[BMJ Open, 11\(4\), e049542](#)

Research News

Hospital Communications study

Kath Wilkinson has led a new publication from the hospital communications study. The 50 minute training aims to improve communication with disabled children, especially those with communication difficulties, and their families when they have to stay in hospital. The package was developed with parent carers and clinicians and tested in Exeter at Bramble ward. It comprises a manual of instructions on how to deliver, a video of parent carers talking about real experiences, and discussion points. This latest project tested the feasibility of implementing our training package for staff on paediatric wards in other hospitals. Plot spoiler alert - it went well and could be used widely. You can read Kath's research paper in [Health Expectations 2021:00:1-10](#)



Prophylactic antibiotics to prevent admissions for respiratory infections: PARROT



This project is a collaborative initiative led by Paul McNamara and a team in Liverpool. The clinical trial had to stop before it had started because of the pandemic as many staff were redeployed. It is now

beginning to get up and running again and we have a small Family Faculty working group assisting with this trial. [Do get in contact](#) if you have relevant experience and would like to join the group. <https://parrot-trial.org.uk/>

We're pleased to let you know of a new publication from the [Focus on Early Eating Drinking & Swallowing \(FEEDS\) study](#) led by colleagues at the University of Newcastle. This paper describes surveys which identified a range of interventions trialled by parent carers, such as food and drink modification, body positioning and modification of mealtime environments. Health professionals thought the interventions were generally effective but parents' views were less consistent. Both health professionals and parents rated better general health and nutrition as the most important outcomes. [BMJ Paediatrics Open 2021:5:e001095](#)