

ICoN Study



The ICoN study online surveys about toileting and continence support for young people with neurodisability are now drawing to a close. We have had a great response with 950 people taking part and sharing their views and experiences which is really excellent! Responses came from a mixture of parent carers, health professionals, young people and school and care staff from across the United Kingdom. Analysis of all of the information provided in these surveys will now take place. The systematic review has also been completed, and the findings are being written up. The results from both aspects of the study will be looked at together before we can share the study findings in spring 2020. We will be working with professional, parent carer and young person groups in 2020 to share, discuss and interpret the findings. Thank you to all those that took part! You can find more about the study here: <http://sites.exeter.ac.uk/iconstudy/>

STAFF NEWS!

Farewell Beth!

We bid a sorry farewell to Beth in October who has gone to work for CAMHS, we wish her lots of luck!



BABY News!

Katharine has had a gorgeous little boy called Conall! Mum and family are all doing really well.



Contact the team

Email: pencru@exeter.ac.uk
Phone: 01392 722968
Website: www.pencru.org

Find us on Facebook:

www.facebook.com/Pencru



Twitter: twitter.com/Pen_CRU



Address: PenCRU, University of Exeter Medical School, South Cloisters, St Luke's Campus, Exeter, EX1 2LU



PenCRU & Family Faculty
making childhood disability research
more relevant, useful and accessible



MERRY CHRISTMAS



PenCRU & Family Faculty

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- Family Faculty Fun Day
- New PhD Students

PenCRU Newsletter

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Healthy Parent Carers

We are in the final stages of the Healthy Parent Carers project, with all participants being asked to complete their final questionnaires over the next couple of months. We are looking forward to hearing from everyone one last time and then putting the results together! We have also been interviewing participants about their experiences taking part in Healthy Parent Carers and held a one-day taster session of the programme to create a short film, which you can see here! <https://vimeo.com/376771910>

We brought our Family Faculty, our programme facilitators, and representatives from the organisations that have been involved in Healthy Parent Carers together at an event at the end of November to share an update on the project, to hear from some of the parent carers who delivered the Healthy Parent Carers groups for us, and to watch a preview of our film. It was wonderful to see so many of the people who have made this project possible and have supported it along the way!



Family Fun Day



We had another 'Crealy' great day for our annual Family Faculty Day! There were some amazing plate and ball spinning skills performed by the children!

Many thanks to Vinnie for entertaining us and all the families who came to make it a

great day out! Vinnie compared bumps with Katharine..... I wonder who's due first!? Further news on this later on!



New PhD Students

Chris is co-supervising two new PhD students at the University of Exeter. Javiera Salazar Rivera is an Occupational Therapist from Chile whose research is about school-based therapy OT Interventions for children with special educational need or disabilities and particularly OT's role in implementing the Universal Design for Learning.

Fatema Shamsaddin is a Physiotherapist from Saudi Arabia whose research is evaluating changes to the brain, nerves and muscles following task-specific training in children with spastic cerebral palsy.

If you are interested in either of these topics and would like to find out more or support Fatema or Javiera then do email is.



Recent Publications

From CATCh-uS study with Helen and Astrid [Transition between child and adult services for young people with attention-deficit hyperactivity disorder \(ADHD\): findings from a British national surveillance study](#) in The British Journal of Psychiatry



From research Gretchen has been involved in evaluating a school-based antibullying programme: [Introducing KiVa school-based antibullying programme to the UK: a preliminary examination of effectiveness and programme cost](#) in School Psychology International.

From the PaReNt study with our colleagues in Evidence Synthesis Team, SNUG (Supporting Neonatal Users and Graduates), and staff in neonatal care in Cornwall and Exeter [They've walked the walk': a systematic review of quantitative and qualitative evidence for parent-to-parent support for parents of babies in neonatal care](#) in Journal of Neonatal Nursing.

From our Healthy Parent Carers programme the [protocol for the current trial](#) has been published in the journal Pilot and Feasibility Studies

Chris is a co-supervisor for Pegah Firouzeh a PhD student University of Alberta, Canada, and was a co-author on this paper by Pegah and colleagues: [Ankle foot orthoses for young children with cerebral palsy: a scoping review](#) in Disability and Rehabilitation.

There's plain language summary of a paper our Core Health Outcomes in Childhood Epilepsy (CHOICE): [What is most important to measure in research for children with epilepsy?](#) published in the journal Epilepsia, 60(5), 857-871. This is part of the CASTLE project (Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy).

[Clinician perspectives on the use of NICE guidelines for the process of transition in Attention Deficit Hyperactivity Disorder \(ADHD\)](#) in Child Care Health and Development.