

INVOLVE Visit

PenCRU was very pleased to be able to invite two members of the Family Faculty to meet with Zoe Gray, the Director of INVOLVE, on her recent visit to the University of Exeter Medical School. INVOLVE supports active public involvement in NHS, public health and social care research. Zoe was very interested to hear Jane and Karen share their stories of how they have added value to PenCRU research, and what they have gained personally through their participation too.

Baby News!

The team are very happy to report both Hannah and Katharine's new additions have arrived safely. Hannah is now the proud mother to Rupert, while Katherine has a little sister for James: Naomi Ellen who arrived on 2nd April weighing in at 6lb 12oz. All are doing well—congratulations!



Upcoming Meetings

If you are a parent or carer of a disabled child, or have particular experience or expertise in the topic, and are interested in attending a meeting, then please [get in touch](#) for more details.

Meeting	Date	Time
CATCh-uS - ADHD Transition	Wednesday 19th April 2017	10.30am - 12.30pm followed by lunch
Project update, and meet our new staff members	Thursday 27 April 2017	10.30am - 12.30pm followed by lunch

Contact the team

Email: pen cru@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



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New and Continuing Projects

We are excited to be starting three new projects this year.

The [PROMOTE study](#) aims to improve the quality of life of children who have been treated for brain tumours by changing the way families and clinicians discuss priorities in outpatient consultations. It is led by Prof Colin Kennedy at the University of Southampton.

CASTLE stands for [Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy](#). It is a 5 year programme of research led by Prof Deb Pal and Kings College London focusing on the most common type of epilepsy. PenCRU will lead work to identify the best ways to measure health and quality of life outcomes for children with epilepsy.

PenCRU is also part of a team led by Dr Jeremy Parr at Newcastle University that will examine ways to improve eating, drinking and swallowing for children with neurodisability (the FEEDS study).

We're also continuing with our Healthy Parent Carers project: testing a programme to promote health & wellbeing; and also the Hospital Communications study which is piloting a training package for hospital ward staff to improve communication with children in hospital.

Cerebra's Working Wonders Awards 2017

The Awards are designed to celebrate some of the amazing achievements of children with brain conditions along with the tireless support of the professionals who help families discover a better life together. Nominations will close on 30th April 2017, so act fast !

You can find out more and download a nomination form at www.cerebra.org.uk

Staff Updates

It's been all change here at PenCRU H.Q. recently, and we are very pleased to welcome three new members to the team.

Gretchen Bjornstad and Helen Hambly have joined us as Postdoctoral Research Associates, and will be leading on the next stages of the [Healthy Parent Carers](#) and [Hospital Communications](#) projects respectively, as well as looking at 'What's the Evidence?' questions and other research tasks.



Gretchen brings experience of evidence-based interventions for improving the health and well-being of children

and families. She has also worked with children in residential treatment settings and as a family counsellor. In



her spare time, she is most likely to be playing pretend princesses with her 5 year-old daughter!

Helen's research interests include communication in healthcare settings, listening to children's perspectives and support for children with speech, language and communication needs. When Helen's not in the office, she is often found somewhere off the coast rowing a gig.



While Katharine Fitzpatrick, our Family Involvement Co-ordinator, is on maternity leave, her role will be

covered by Silvia Bortoli. Silvia has a first degree in Psychology and a Masters degree in Social Policy and Development, where she focused on health policy and health NGOs. She has previously worked for several policy institutes and think tanks, and in her last job she worked on a project involving breast cancer patients in health service improvement. In her spare time, Silvia plays golf and loves cooking.

BACD annual scientific meeting

Several projects that PenCRU and the Family Faculty have been involved with were presented at this year's British Academy of Childhood Disability meeting.

Rebecca Gumm presented a poster on Hospital Communications; Will Farr and Diane Sellers presented posters on the on feasibility trial for using WiFit as a potential therapy and further work on the Eating and Drinking Ability Classification System for cerebral palsy, respectively; and our own Chris Morris contributed a couple of teaching sessions too!

Recent Publications

Academic papers

Farr W, Green D, Male I, Morris C, Bailey S, Gage H, Speller S, Colville V, Jackson M, Bremner S, et al (2017). **Therapeutic potential and ownership of commercially available consoles in children with cerebral palsy.** British Journal of Occupational Therapy, 80(2), 108-116.

Armstrong M, Morris C, Abraham C, Tarrant M. (2017) **Interventions utilising contact with people with disabilities to improve children's attitudes towards disability: a systematic review and meta-analysis.** Disability and Health Journal. doi.org/10.1016/j.dhjo.2016.10.003.

'What's the Evidence?'

Our latest summary looked at [Snowdrop for Brain Injured Children](#). We were asked if the Snowdrop programme was likely to be more effective than speech and language therapy to help a child with acquired brain injury understand more and to use speech as their main way of communicating.

We're also currently working on one about Functional Electrical Stimulation to improve gait for children with cerebral palsy, and another on interventions for young people with autism to improve social skills and/or reduce social anxiety.

Information & Resources

Paediatric Continence Forum (PCF)

The PCF is a multidisciplinary campaign group whose aim is to raise awareness of bowel and bladder problems in children. They have produced, amongst other things, a NICE accredited Paediatric Continence Commissioning Guide, and a lobbying toolkit for parents who have experienced problems accessing suitable services and support. Nicholas Madden, the Vice-Chair of the PCF and a Paediatric Surgeon/Urologist, has asked if we could share his request with the Family Faculty. Firstly, they would like to hear about your experiences to help them direct their activities towards the most important areas, and secondly they are able to offer assistance if you feel there are specific issues relating to continence care either of individuals, or groups, which need addressing.

Their website is: <http://www.paediatriccontinenceforum.org/> or Nick can be contacted directly by email: nickpmadden@btinternet.com