

Upcoming PenCRU Family Faculty meetings:

Listed below are the currently scheduled meetings, please check our website for future dates. **If you would like to come along to any of these then please get in touch.** If you cannot attend a meeting but would still like to contribute, please do let us know.

Meeting	Date	Time
Designing a new dynamic specialised seating system	Wednesday 20th April	10.30—1.00, followed by lunch
Building a Partnership – Skills for involving and for being involved	Monday 23rd May	10.30—12.30, followed by lunch
PICSI - Prevalence and Impact of Cerebral Sight Impairment	Tuesday 7th June	10.30—1.00, followed by lunch

Coming soon... Cerebra has published a new **Problem-Solving Toolkit** to support disabled people and carers who are encountering difficulties with the statutory agencies in relation to the provision of health, social care and education support services. We are hoping to run a practical session for parent carers on how to make the best use of this fabulous resource in the next couple of months with Cerebra and the team who produced it. You can access the toolkit and send feedback online <http://w3.cerebra.org.uk/help-and-information/guides-for-parents/problem-solving-toolkit>

Contact the team

Email: pencru@exeter.ac.uk

Phone: 01392 722968

Website: www.pencru.org

Address: PenCRU, University of Exeter Medical School, Room 101, South Cloisters, St Luke's Campus, Exeter, EX1 2LU



PenCRU Newsletter

April 2016, Issue 21

New Study into Cerebral Visual Impairment (CVI)

We are pleased to announce that we are starting work on a new project into Cerebral Visual Impairment (CVI). Children with CVI can have difficulties perceiving the world around them. For example, they may find it difficult to avoid bumping into people, or changing eye position effectively to keep focused on a task. However, the child may appear to have good eyesight so their problems can be misinterpreted. This new research project, being led by Cathy Williams at Bristol University, aims to explore the prevalence and impact of CVI. The project is funded by the National Institute for Health Research. We would like to give a big THANK YOU to members of our Family Faculty who provided feedback on the funding application for this research. The next meeting for this project will be held on 7th June; please contact us if you are interested in attending or would like to stay informed.

CATCh-uS Update

This project is looking at the transition for young people with ADHD from children's services into adult services. We have asked clinicians to report any young person requiring continuing care to us, and are hoping to collect data about 400 cases in total. At present we have details of 79 relevant cases but will continue collecting information for another 6 months.

Another part of the study involves interviews with clinicians, young people and their parents about their experiences. If your child is receiving medication for ADHD you may be approached about the study yourself at a future clinic appointment.

In preparation for the interviews, the team will be visiting Southbrook School to hold workshops with two different groups to help us learn about doing interviews with young people with additional needs. We are very excited about this new involvement exercise and expect to learn a lot from these young people. We will also be welcoming a new researcher, Anna Price, to the CATCh-uS team in late April.

www.pencru.org

Staff news

PenCRU has been running on a skeleton crew for a few months, however, reinforcements are on the way. Hannah Morris (no relation to Chris!) will be joining us in May as a researcher 3 days/week. Katharine Fitzpatrick, our Family Involvement Coordinator, returns from maternity leave at the end of June, probably 3 days/week. In Katharine's absence we have benefited from support from Kath Maguire in the [PenCLAHRC Public Involvement Team](#) and we hope that Kath and Kristin Liabo, the new lead of that team, will continue to work closely with us.



Recent publications

Children with neurodisability often have invasive medical procedures like blood tests or tube feeding. Our latest *What's the Evidence?* summary explores the evidence for what helps reduce distress and improve cooperation with these procedures in hospital: www.pencru.org/evidence/invasivemedicalprocedures

Other academic papers have been published from Megan's PhD work and the CHUMS study in *Disability and Rehabilitation* and *Developmental Medicine and Child Neurology* respectively, while our review of the evidence examining whether sleep positioning systems are effective for children with cerebral palsy was published in The Cochrane Library. Read the plain language summaries for these papers and all our publications here: www.pencru.org/projectsmeetings/plain_language_summaries

Survey for families with experience of cerebral palsy

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) aims to assist in maintaining and improving standards of care for adults and children for the benefit of the public. They have recently launched a Chronic Neurodisability study, focusing on cerebral palsy. There are surveys open for people with cerebral palsy under 25 years old, and parent carers of children/young people with cerebral palsy.

Questionnaire for young people - www.ncepod.org.uk/questCNpatient.php
Questionnaire for parent carers - www.ncepod.org.uk/questCNparent.php

We encourage families in our Family Faculty with experience of cerebral palsy to take part in this important survey, and to tell other families too. In this way we can all contribute to improving health services for children and young people.

Research Priority Setting

PenCRU previously led a project with the James Lind Alliance to prioritise research questions across childhood neurodisability. This was successful in bringing the attention of the National Institute for Health Research to topics that families said are important. For an update on the impact of this work see here: www.jla.nihr.ac.uk/news-and-publications/news/2015/what-happens-after-a-ppp-has-identified-its-priorities

We are now supporting research priority setting projects focusing specifically on autism, for details see www.autistica.org.uk/research/top10

We have recently been invited to be part of a group that will focus on research priorities for scoliosis (spinal deformity). Scoliosis is common in children with some neurodisability conditions. We will post more information as this project develops. www.bsrp.co.uk/about-us/latest-news/post/3-have-your-voice-heard

Update on Healthy Parent Carers pilot study

Our Healthy Parent Carers project aims to improve parent carers' health and wellbeing by promoting empowerment, confidence, and resilience. We devised a programme to promote engagement with behaviours associated with health and wellbeing using the concepts in CLANGERS - Connect, Learn, be Active, Notice, Give, Eat well, Relax, Sleep. The programme sought to develop knowledge, skills and strategies to implement changes and overcome barriers to these behaviours specifically in the context of parent carers' lives. We believe it's best delivered as a group-based programme to enable peer support and sharing of experiences.

Lots of parents in our Family Faculty contributed to developing the programme. We advertised opportunities to participate in the programme as a one-day event or six weekly sessions and found seven parent carers to participate in the six sessions. The sessions were delivered by Bel and Mary from Face2Face. We are now reflecting and analysing what we've learned from this (a lot!), and will organise a meeting to discuss next steps with the Family Faculty in due course.



More information about the project is on our website www.pencru.org/projectsmeetings/researchprojects/hpcproject/hpcdevelopment/