

# Peninsula Cerebra Research Unit PenCRU Childhood Disability Research Family Fagulty desianed by Matt aged 14 Inside this issue: > APEx-D results (autism dentistry) > Hospital Comms publication PenCRU Newsletter > Cerebral Visual Impairment update December 2017, Issue 26 > PenCRU staff updates **APEx-D** project results The results of our research into the experiences of parents taking their children with autism for dental check-ups has been published! Key findings: •

- The study asked 17 parents of children with autism aged between 4 to 13 years old, living in Somerset or Devon, what it has been like taking their children for high street dental check ups.
- Dental visits were more successful when parents felt confident to advocate for the specific needs of their children; the dental team were flexible in responding to parents' requests; and the whole dental team were involved in providing a positive experience.
- The study highlighted the value of clear communication and the need for a better understanding of when and where to refer a child to specialist

dental services, should it be needed. The academic paper is published in International Journal of Paediatric Dentistry or read our accessible plain language summary. Nicole also made a great video which summarises the research project.



### Family Fun Day



We had a brilliant day out in September at Wildwood Escot. The Annual Family Fun Day is a way to say 'Thank you' to members of the Family Faculty who have been involved in our work, and to keep in touch with some members who we



haven't seen in a while. As usual the amazing Vinny was there to entertain us all, in addition to talks on wolves and otters, and getting lost in the maze!



# CATCh-uS project (ADHD)

The project's Study Steering Committee made up of researchers, clinicians, commissioners and representatives from ADHD support groups met in November to receive an update on the project, and advise on next steps. It was great to have a representative from the Family Faculty there too. All were impressed with what has already been achieved!

The first round of the Mapping Study has now been completed, and a list of ADHD services will be published on the website alongside the new survey in early 2018. Please do take time to complete the 5 minute survey yourselves and share the <u>link</u> with as many others as you can in the New Year.

#### Improving continence project

The <u>NIHR</u> is commissioning research to look at the evidence for interventions to improve continence in children with neurodisability. We have submitted a full application to carry out the study with several clinical specialists in the topic. The Family Faculty working group meetings in June and October were very helpful for planning how we will approach the research if we should be funded. A decision on the funding application is expected in March 2018.

### Cerebral Visual Impairment project

Cathy Williams at Bristol University is leading a programme of research funded by the NIHR into the prevalence and impact of



Cerebral Visual Impairment (CVI). In November Cathy and her colleague Anna Pease came to visit PenCRU and meet with our Family Faculty. They shared preliminary results of the prevalence study, and were advised by the Family Faculty on the next stage of their project. You can find meeting minutes <u>here</u>, and read more about the <u>CVI research project</u> on the website.

# PenCRU staff updates

Helen Hambly left PenCRU in October to take up a new role at Cornwall Council (nearer where she lives). We'd like to thank her for all her hard work on the Hospital Communications project and What's the Evidence? summaries.





In December, our lovely administrator Anna Stimson left PenCRU to take on new

role as a Probation Service Officer; she will be greatly missed! From January, we will be joined by Kath Wilkinson, Associate Research Fellow at PenCLAHRC, who will take over the Hospital Communications project.

Hannah Morris, PenCRU Associate Research Fellow, will

return to PenCRU from maternity leave in February. We look forward to welcoming Hannah back and working with Kath.



## Hospital Communications project publication

A new academic paper has been published in BMJ Paediatrics Open about our work to develop and test training for hospital staff on children's wards to improve communication with disabled children when inpatients. You can access the paper for free, or read the plain language summary. We will be evaluating the training in a small number of hospitals next year. Find out more about the Hospital Communications project on the website.

