



PenCRU Annual Family Fun Day at Dartmoor Zoo



We had a fantastic day on Saturday 25th September at beautiful Dartmoor Zoo. The Annual Fun Day was to say thank you to members of the Family Faculty who have got involved in our work and research activities, and to get to know each other better. The weather was amazing and Vinny, the mime artist was there to entertain us with his usual flare. We had a great time exploring the zoo and meeting all the animals, including our own 'close encounters' session with snakes, cockroaches and others (yikes!). Everyone had a great day and we look forward to another similar special event next year.



Building a Partnership - we need your ideas!

We would love to hear your ideas about what you would like the next 'Building a Partnership' event to be. This is an opportunity for you to get some hands on experience and learn about research, and also for us to learn from families.

So far we have hosted sessions on two topics.

- Constructing research questions
- Searching the internet for reliable information
- Introduction to research

These sessions were designed by families and delivered by researchers. If you have something that you would like to know about research processes, methods

Funding news

PenCRU are coordinating a new project with the British Academy of Childhood Disability and the James Lind Alliance. The '[Childhood Disability Research Priority Setting Partnership](#)' aims to identify a Top 10 of the most important issues for childhood disability research to address. The process involves identifying unanswered questions about the effectiveness of interventions, treatments and therapies for children and young people affected by neurodisability from patient and clinical perspectives. Then, to prioritise those issues that patients and clinicians agree are the most important. Several parents have helped to design the website and two are on the Steering Group.

INVOLVE conference 2012

PenCRU will be presenting at the INVOLVE conference this year which is being held in Nottingham in November. Julia and Antonia from the Family Faculty are presenting with us, and Bel and Rachel are also participating in the conference. We are presenting on how we involve families in the work we do... we will let you know how we get on.

INVOLVE is a part of the NHS that support public involvement in NHS, public health and social care research; to learn more follow the link:

<http://www.invo.org.uk/resource-centre/conference/involve2012> .

PenCRU are now on Twitter and Facebook!



Why not say you like us on Facebook at www.facebook.com/pencru



You can also follow us @Pen_CRU http://twitter.com/Pen_CRU

PenCRU website

We have recently updated our website and added several new pages. You can read about all our current projects and download a poster describing how members of our Family Faculty are involved in each project

www.pencru.org/research_projects.php

We also have a new guide about what to expect when you get involved in a research project with us at:

www.pencru.org/research_involved.php

Recent meetings

CHUMS – at this meeting we discussed the progress of the systematic review, the qualitative research with young people and parents, and the results of the first round of the Delphi survey for health care professionals.

Peer support – parents joined us to discuss how we write our research summaries. We used these ideas to think about the summary of the literature review for the peer support study.

Read the [notes from our meetings](#).

Upcoming meetings:

Listed below are the upcoming meetings, if you would like to come along then please get in touch.

Meeting	Date	Time	Location
Social inclusion	Tuesday 23 rd October	10.30-1pm, includes lunch	Veysey, room 006
Computer games	Thursday 8 th November	11-1pm, includes lunch	Veysey room 115
Sleep positioning Systematic Review	Thursday 22 nd November	11-1pm, includes lunch	Veysey room 005
Hospital Communication	Thursday 29 th November	12-2, includes lunch	WK Norman, St Lukes
Building a Partnership training	Friday 30 th November	10-2, includes lunch	TBC
PenCRU Advisory Group	Thursday 6 th December	10.30 -12.30, includes lunch	Veysey room 006

Where we have been...

The team recently went to London for the [Cerebra Annual Conference](#). We displayed our posters describing how families are involved in PenCRU projects. Chris presented on health outcomes and the CHUMS project, and Siobhan presented on our Hospital Communication project. There were excellent presentations from other centres focused on the theme of wellbeing.

New Staff:

Hello, I'm Anna and I have joined PenCRU as a Research Administrator working on Mondays, Tuesdays and Thursdays. After studying History at university in Leicester, and then a period of time working in research in London, I moved back to Devon, where I was brought up, about five years ago. As Mum to three primary-aged children who love nothing more than getting wet and sandy on the beach playing with my Dad's guide dog I can say that I am very happy to be here! I can be contacted on anna.stimson@pcmd.ac.uk



New temporary staff:

Hi, I'm Karen and I started at PenCRU in September. My educational background is in psychology and research; I have an undergraduate degree in psychology and completed a Masters in research methods last year. Since I have previously worked with children in a variety of settings I am delighted to be involved with the unit.



I am working with Astrid on the CHUMS project which is investigating patient-reported outcome measures (PROMS) that can be used to evaluate NHS care for children and young people with neurodisabilities.

karen.allen@pcmd.ac.uk.

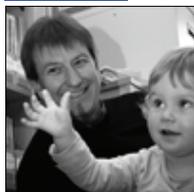
Contact the team:

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Stuart



Chris



Camilla



Claire



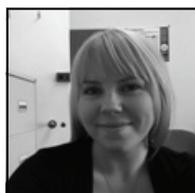
Val



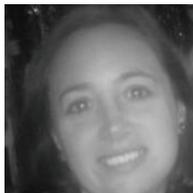
Astrid



Sarah



Megan



Anna



Karen