



## PenCRU annual Family Fun Day at Dartmoor Zoo



We are really excited about this upcoming event. Don't forget to book your place for the PenCRU annual Family Fun Day at Dartmoor Zoo; there are still places available. We are going on **Saturday 29th September** from 10 am to 4pm.

Please be aware that there are some steep paths, but PenCRU staff and student volunteers will be on hand to help. To learn more about the zoo and the access see the following link: [www.dartmoorzoo.org/your-visit/disabled-access.html](http://www.dartmoorzoo.org/your-visit/disabled-access.html)



### Would you like to come to the INVOLVE conference 2012?

We have two places to offer Family Faculty members to attend the INVOLVE conference in Nottingham on 13-14th November 2012, we are able to cover the cost of transport, accommodation and conference fees.

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 will be presenting at the conference and we will travel and attend as a team. If you are interested in coming please get in touch with Camilla, places will be allocated on a first come basis.

## Funding news

### MeASURe:

#### Measurement in autism spectrum disorder.

We are part of a team led by colleagues at the University of Newcastle who were successful in securing funding for this project. The first Parent Advisory Meeting took place in Exeter on July 6th.



This project was designed in response to a competitive commissioned call for research by the National Institute for Health Technology Assessment programme. The brief asked for research to address the question "what is the validity of tools and outcome measures used in measuring and monitoring autism spectrum disorder (ASD) in children aged 6 years and under; and how well do these reflect and measure issues of importance for patients and carers?"

## Building a Partnership event

### Introduction to research training

On June 21st we held our first 'Introduction to Research' training, which members of the Family Faculty helped us design. It was a great day and the parents who attended found it very informative, here's what they had to say:

- *'it was so good...very interesting, informative and fun!'*
- *'very informative and friendly'*
- *'presenters were a good team, knowledgeable, open, entertaining, funny and informative. A first class presentation!'*

We hope that we will run this training again in the Autumn so if you are interested to attend then please let us know so we can find a day and time that suits parents. Or if you have a suggestion for training we could offer, please let us know.

## Cerebra annual visit

We really enjoyed hosting Cerebra's visit this year. Chris Jones (CEO), Tracy Elliot (Head of Research), Kelly Gadd (Head of Parent Support) and Mark (Trustee) all came along to find out more about what we do. Cerebra fund a number of academic chairs of which Stuart Logan here at Exeter Medical School is one, see their website for more details [www.cerebra.org.uk](http://www.cerebra.org.uk)

We prepared 12 posters about the work we do. We would like to thank parents Julia and Kirsty for their help reviewing/editing the posters so they were clear. It was a great day and the families who came along enjoyed the opportunity to meet and talk to some of the Cerebra team.



## Project update and Working group update

We are currently reviewing and updating our website and in the next month we will provide updates of our projects as well as copies of the posters we created about the various projects for Cerebra's annual visit, so watch this space!

### Where we've been

It has been a very busy spring/summer. We have been out and about here are some of the places we have been...you may recognise our stand



#### Torbay Disability Awareness day

We had great fun at the Torbay Disability Awareness day and really enjoyed meeting many new faces.

#### Devon County Council conversation events

We always enjoy these events which are very informative for parents

#### Mayfield Garden Party

As always a lovely day; our balloons were very popular and it was dry!

### Meetings we have had

There have been quite few meetings recently, for more details please see the detailed notes on our website.

#### ADHD school interventions

This workshop was led by Tamsin Ford and was attended by two parents and some of the team

#### PenCRU Advisory Group

As always this is a really useful meeting for us to get ideas and feedback and make decisions about how the unit is run.

#### CHUMS focus group lead by CDC

Amanda Allard of the CDC led this focus which will be one of several around the UK.

#### MeASURE Parent Advisory Group

We have had a great response to this project and the first meeting was very successful.

#### Second Peer Stakeholder meeting

This was a great meeting with several parents attending.

### Meetings and events:

We have no meetings scheduled over the summer holidays, however we have several coming up in the autumn; for up to date information on meetings dates please see our website: [www.pencru.org](http://www.pencru.org)



**Do you have a query about a treatment or therapy?**

or

**Do you want to know what evidence is out there?**

or

**Do you have a suggestion for research?**

## Who we work with

We work with many different people within the medical school and we would like to introduce you to Obi who works with several members of the PenCRU team.

Dr Obioha Ukoumunne

Obioha has worked as statistician for 18 years. In recent years, his research collaborations have been in the areas of language and literacy development, children's sleep and behavioural problems, ADHD, and obesity.

He is currently collaborating with Stuart Read and Chris Morris on a study examining differences in general and social self-efficacy between adults with and without cerebral palsy. He is also collaborating with Val Shilling and Chris Morris on a systematic review of peer support interventions for parents of disabled children.

Email: [obioha.ukoumunne@pcmd.ac.uk](mailto:obioha.ukoumunne@pcmd.ac.uk)



## Work experience student:

Hello my name is Jack (15) and I was a work experience student at PenCRU for a week. I originally came to PenCRU because it seemed like a place where I could get additional IT skills, but I feel that there are better places to get that now. I have found my work experience week here very informative. I have been doing research on the different instruments used to assess the quality of life for different groups of people; also I researched the effect of a console such as a Wii on rehabilitation from things such as strokes or on disabilities such as cerebral palsy. The week has been a useful experience and I have taken many useful skills away from it. Thank you very much for allowing me to be here for this week. I have always wanted to work in IT, and I felt I needed some experience in the subject. I now know what I would like to do in the field of IT which will greatly help when I go looking for a job.

### Contact the team:

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Phone: 01392 722968/2901

Website: [www.penclu.org](http://www.penclu.org)

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Stuart



Chris



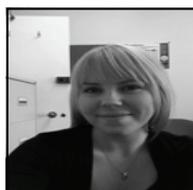
Camilla



Claire



Val



Peninsula Cerebra Research Unit  
PenCRU Childhood Disability Research