

## Our day out at World of Country Life

We had a fantastic day at the World of Country Life, on Saturday 24th September, even the weather was great. Thank you to all the Family Faculty members who attended for an action packed day. We were entertained by Vinny the mime artist, in the morning, while we nibbled delicious croissants and cookies. In the afternoon, there were several fun activities such as goat walking, the bird of prey exhibit and our own private trip on the 'deer train'; we got a chance to get close to the deer and had them feeding out of our hands. Fun was had by all, see over the page for Ann and Robert's experience of the day.

Pictures taken by Ann (10)



Sheri's picture of the PenCRU team hard at work!



By Sophie

By Adam



By Kieran

We look forward to next year, where will we go.....?

## Personal Stories and Experiences

We have taken this as an opportunity to introduce a new feature to our newsletter. If you have a story you would like to share with other families, please get in touch.

Here are Ann and Robert's experience of coming to the Family Faculty fun day at the World of Country life

### Ann's day out

*'The trip out to the World of Country Life was brilliant from start to finish. At the start we were all entertained by a mime artist. My little brother got asked to help with one of the acts. All of the kids were very impressed by the mime artist. Seeing as they were all giggling their heads off.*

*I took some very good pictures of all the things that we went to, including some pictures of the hawks show and the deer train but my favourite things were the models and museum at the start. The PENCRU members were very warm and welcoming. I met Rebecca who I did some work for. I was really glad I got to go.'*

### Robert's day out

*'We went to the World of Country Life on Saturday. We went just for fun with cerebra fun day. I watched a mime artist.*

*We watched the hawk show display. The harrier was on the man's hand. I saw the owl fly through the sky. My sister took some pictures on the deer train. We feed the deer's and llamas.*

*I got a lazer gun. It was fun.'*

## Building a Partnership Training Event

**Due to the success of our last Building a Partnership event we have been asked to host it again. If you would like to come please get in touch, or if you found it useful last time please spread the word!**

**Would you like to know how to find reliable information about your child's condition on the internet?**

**Come and learn how at our Build a Partnership event.**

**Thursday, November 10th 2011; 10.00am–3.00pm**

**WK Norman meeting room, PCMD building, St Luke's Campus, Magdalen Road, Exeter, EX1 2LU**

At this free training event, families affected by childhood disability can bring an issue that is important to them and learn how to formulate it into a research question and then develop skills to confidently and quickly find reliable and credible information that is freely available on the internet.

## Project update

### **Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? (CHUMS)**

NHS outcomes are things that we measure to give us a clear picture of the effect that NHS health care has on patients. These are a few examples of the types of things (or outcomes) that we might measure:

- Functionality
- Well being
- Quality of life

Questionnaires are often used to measure these outcomes. The CHUMS study will identify which of the questionnaires that are being used to measure NHS outcomes in children with neurodisability today, are the most suitable. If you would like to know more about this project or be involved, please contact Becky on [rebecca.taylor@pcmd.ac.uk](mailto:rebecca.taylor@pcmd.ac.uk) or 01392 726002.

### **Improving communication with disabled children when they have to spend time in hospital**

We have completed a systematic review of the literature and submitted this for publication. We have completed interviews with 17 parents and focus groups with health professionals who work on children's wards in Exeter and Barnstaple to gather their views on how to improve communication with children who have communication difficulties. Once we have completed the 'qualitative' analysis of the interviews & focus groups we will use this to develop a training package for health professionals. Parents will be involved in

designing and delivering the training package to professionals. If you would like to know more about this project or be involved, please contact Claire on [claire.lloyd@pcmd.ac.uk](mailto:claire.lloyd@pcmd.ac.uk) or 01392 722901

### **Peer Support Project**

In the last issue we told you about a new project looking at the benefits and costs of providing peer support to parents of disabled children. The project is now well underway. In July we had a very successful first meeting of our stakeholder group. This group, made up of parents from the family faculty, volunteers and staff from Face2Face and representatives from the NHS, Devon County Council and various charitable organisations, will help us to design and manage the project and will be involved in all key decisions. At our first meeting, we drew up a list of the research questions we thought were essential to address in this research project. You can read the summary from this meeting on the website

[http://www.pencru.org/files/meetings/notes\\_peer\\_support\\_11\\_07\\_20.pdf](http://www.pencru.org/files/meetings/notes_peer_support_11_07_20.pdf)

We have also made good progress with the literature review to bring together the findings of studies that have already been done about peer support for parents of disabled children. We have searched a large number of electronic resources using some key words about parents, children and support. After we had taken out all of the articles that came up in more than one database, we were left with 3405 articles to sort through! Fortunately, most of these won't be included in the review, because when we looked at the title and summary, we realised they didn't meet our inclusion criteria. Although it is a very time consuming process to go through all of the articles, it does mean that we can be as confident as possible that we haven't missed out any important studies. We hope to finalise the exact studies that will be included in the review very soon. Our next task is to submit the plan for the project to an ethics committee. The purpose of the ethics committee is to ensure that the research being done is of good quality and value, and will not put the participants at any unnecessary risk or distress. They will decide whether we are allowed to do the study and whether there are any aspects of the study that they think should be changed. They will be particularly interested in the part of the project where we hope to interview parents about their experiences of receiving and offering peer support. We hope to have a decision from the ethics committee before Christmas. If you would like to know more about this project or be involved, please contact Val on [val.shilling@pcmd.ac.uk](mailto:val.shilling@pcmd.ac.uk) or 01372 726041.

## What is a working group?

When an issue or query has been prioritised, the first stage in turning this into a research proposal is to set up a working group. This is a group of people who are particularly interested in the topic and who are willing to feedback and share their ideas, experience or expertise. This group could be made up with families, professionals and members of the research team. The group will meet several times to think about how to turn the issue into a research question using the PICO format, to think about the practicalities of a research project, and to develop a protocol. They will consider if this topic can be carried forward for research and explore potential funding.

## Current working groups:

### Virtual reality technology- 1st meeting

An initial meeting with parents and professionals generated a lot of discussion about the types of computer games that we might be interested in, and the improvements that we might look for in children who had played them regularly. We also discussed comparing playing computer games to more traditional types of therapy, i.e. Physiotherapy and Occupational Therapy. The next steps for this project are to carry out more detailed searching of the existing literature and talk to some groups of children about the types of computer games that they enjoy playing. We hope to be able to use this information and continue to work with families and professionals to start to narrow down and develop our ideas. *Next meeting TBC*

### Social inclusion

We are developing a research programme to promote the social inclusion of disabled children. Several meetings have been held with parents and health and social care professionals to outline potential lines of research activity.

We want to promote positive attitudes towards disability. Parents working with us prioritised focusing on promoting positive attitudes of school-aged children and young people towards disabled children. We have secured funding for a PhD student to lead this work, and Megan will be beginning in October 2011, supervised by Dr Mark Tarrant, Chris Morris & Prof Charles Abraham.

We are looking at ways of defining and measuring inclusion of children and families using the principles of equality of opportunity and freedom to choose to be involved in key life situations. The first steps will be to review existing definitions and to interview children, young people and parents to identify the key life situations that all children and families should have the opportunity to participate in, regardless of disability.

We also want to investigate ways to define and measure any perceived stigma experienced by disabled children, parent and siblings. Parents working with us and previous research suggest that there are both positive and negative effects associated with the 'social identity' of being a family with a disabled child. We are also working with social care professionals employed by local authorities in Devon, Plymouth & Torbay who deliver individualised services to promote inclusion of disabled children. Such services are a valuable resource for families, and we are interested in evaluating how they are effective in promoting social inclusion, participation, health and well being.

Over all, the theory is to seek ways in which public attitudes can be modified to reduce stigma and promote social inclusion and well being of families of disabled children. *Next meeting November 2nd, 10.30-12.30*

## You may be interested:

The World Health Organization and World Bank report on disability, it raises many of the issues our families raise and recommends some of the research we are proposing:

[http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html)

### Also:

The latest recommendations from NICE re: "Autism spectrum disorders in children and young people: recognition, referral and diagnosis." This guideline covers the recognition, referral and diagnosis of autism in children and young people from birth up to 19 years, be warned this is a very large document:

<http://www.nice.org.uk/nicemedia/live/13572/56424/56424.pdf>

## Funding news

The way we work is to develop ideas for research, and then seek funding for major projects that we cannot carry out with the resources we have. Over the summer we received a decision on one application we had made for funding over the last year.

### [Evaluating the effectiveness of Lycra-based orthoses](#)

Lycra-based orthoses (splints) are popular with some therapists and families but not available widely as there is limited evidence that they are an effective treatment. We designed a randomised controlled trial that would be the first stage in testing whether Lycra sleeve/glove improves the manual ability of children with hemiplegia. We applied to the National Institute for Health Research's programme *Research for Patient Benefit* and a charity called Action Medical Research for funding to carry out the trial. Unfortunately, although these funders appreciated that this was an important topic for research, neither body prioritised our trial for funding. We have decided not to pursue the trial further at the present time; however the research protocol will be published on our website so that it might be useful for others.

## Projects awaiting funding decisions

### [Children's Outcome Measurement Study](#)

The NHS Outcomes Framework will include patient-reported outcome measures (PROMs) as one way of assessing whether the NHS is working effectively and efficiently for patients. These are carefully designed questionnaires that measure health. The CHUMS research project seeks to identify whether any existing generic (i.e. not condition-specific) PROMs would be appropriate for measuring the effectiveness of NHS care for children with neurodisability.

### [MeASURE: Measurement in autism spectrum disorder.](#)

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); and how well do these reflect and measure issues of importance for patients and carers?" We are part of a large team of researchers around the UK, led by colleagues at the University of Newcastle, which proposes to carry out a systematic review to answer the research question.

### [School-based interventions for Attention-Deficit/Hyperactivity Disorder \(ADHD\)](#)

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 non pharmacological interventions for children with or at risk of ADHD have been shown to be effective when delivered in school settings and how do schools best contribute to their effectiveness?" We are part of a large team being led by colleagues at Peninsula Medical School that proposes to carry out a systematic review to answer the research question.

## Recent publications:

Lloyd C, Logan S, McHugh C, Humphreys G, Parker S, Beswick D, Beswick M, Morris C, Wyatt K. (2011) Sleep positioning for children with cerebral palsy. [Protocol] Cochrane Database of Systematic Reviews Issue 7. CD009257

Morris C, Bowers R, Ross K, Stevens P, Phillips D. (2011) Orthotic management of cerebral palsy: recommendations from a consensus conference. *NeuroRehabilitation*. 28(1):37-46.

Jenkinson C, Dawson J, Morris C. (2011) Aspects of methodology. In Jenkinson C, Peters M, Bromberg M. (Eds) *Quality of Life Measurement in Neurodegenerative and Related Conditions*. Cambridge: CUP

### Coming soon:

#### *Cerebra Monthly Briefings*

Cerebra asked us to write two articles for their October and November monthly briefings. The first article is a compilation of four of our 'What's the Evidence?' reports. The second is a guide entitled 'Finding and Appraising Information and Evidence on the Internet'. We will let you know when these briefings have been published through the news page on our website.

## People we work with

This summer has been a busy one for PenCRU, we had three work experience students who requested to come and work with us. As part of their experience we asked them to write a short article for our newsletter! Here is what they said:

**Nicola Jeffreys** *'In the past I have taken an active interest in PenCRU's Family Faculty, even sharing our experiences by taking part in research into some of the important questions that had been raised by parent carers. We have two daughters, aged 15 and 10 years, who both have additional needs. Our eldest daughter unfortunately has a lot of medical problems and this has led me to decide on a complete career change. So, with a lot of excitement and quite a bit of trepidation I am about to embark on a degree in clinical sciences, which will hopefully result in a career where I can make a positive difference to patient care. This made me think again about PenCRU and the valuable work that they are doing in raising important questions about patient care, so I contacted Camilla and asked if I could do some work experience. They were very happy to put up with me in August for two days and I learned a great deal.*

*One of the aspects about the work PenCRU carries out that surprised me was the length of time it takes for the whole process to be completed. From the initial identification of a research question, through securing funding, conducting research, writing the reports and eventual publication can take from two to three years. The sorts of areas that PenCRU is currently researching include topics such as social inclusion, peer to peer support and the treatment of communication impaired children in hospital. From a parent carer perspective these are exactly the sorts of areas that I want PenCRU to be investigating because there is a strong chance the outcome will make a significant difference to our family experience. At the same time, from a purely professional approach, such research topics are entirely focused on improving patient care; something I feel so strongly about that it has led me to want to work in this field. I am very grateful to everybody at PenCRU for letting me get a glimpse of the important research they are carrying out and giving me an insight into what a difficult and time consuming task their work is. This is a real opportunity for parent carers to have a voice as well as the chance of being involved in research that could have real and practical benefits for our children.'*

**Chloe Tremlett-Williams** *'My name is Chloe; I am 14 and go to Isca College of Media Arts. I came to PenCRU for my work experience week, I originally heard about the Peninsula Cerebra Research Unit through my parents and when deciding where to go for work experience I thought I would try here as it is relevant to me, as I have a 8 year old brother who has Cerebral Palsy. I am glad I came here, because although it is too far ahead for me to really think about what job I would like to have, this has certainly showed me an area to consider. I think I would like to go into medicine, whether in research or something else I don't know yet. Being here has also given me the chance to learn more about things I am interested in such as Cerebral Palsy; I was able to do a small amount of research into massage as a treatment for children with Cerebral Palsy and Cerebral Palsy itself. Giving me a greater understanding of what affects my brother.*

*During the week I did many new things, I went to a lecture; I helped out with a Peer Support Project meeting, which involved looking after 4 year old Cooper, whose mum was taking part in the meeting. I also had the opportunity to take part in a public focus group run by PenCLARHC, which involved generating ideas around healthcare for possible new research studies. The only less interesting thing here was the filing I did and making up the envelopes sent out for the Annual Family Fun day, which I had hundreds to do. Never again will I underestimate the work gone into sending a mass mailing!'*

**Jay Wittram** *'I thoroughly enjoyed the four days experience at PenCRU. The skills learned were invaluable and will be very useful going into the third year of university. The researching experience, especially, will certainly help me in my end of year project, which is a large percentage of my overall degree. The staff at PenCRU made me feel very welcome and were very helpful, so a huge thanks for them for putting up with me.'*

## Meetings and events:

### PenCRU meetings:

#### **CHUMS co-investigator meeting**

**Date:** Friday 4th November

**Time:** 9.00 am—3.00pm

**Location:** Reed Hall, Streatam campus

#### **Social inclusion working group**

**Date:** Wednesday 2nd November

**Time:** 10.30-12.30

**Location:** TBC

#### **PenCRU Advisory Group**

**Date:** Thursday 1st December

**Time:** 10.00 am—12 noon

**Location:** Veysey room 005

#### **Reminder:**

**We are able to pay for travel expenses and child care costs.**

### Events:

#### **PenCRU Building a Partnership training event**

*'finding reliable information about your child's condition on the internet'*

**Date:** Thursday 10th November

**Time:** 10.00 am—3 pm

**Location:** WK Norman/IT Suite, St. Lukes Campus

## Where we've been:

PenCRU and were invited to have a stall at the Mayfield school fete this July. Camilla and Claire went and had an amazing day. We really enjoyed meeting all the families and watching the children chase our PenCRU balloons around the field! If you have an event coming up let us know, we would love to come.



You may have come across Camilla who has been travelling around Devon attending various Parent Carers Voice meetings and Devon County Council conversation events.

## Join our Family Faculty!

We are always keen to hear from parents and carers who would like to be part of our Family Faculty.



Membership of the Family Faculty does not commit you to anything, but will mean that you are kept informed about the work that we are doing and will be offered the opportunity to get involved at a level that suits you. There are many different ways of getting involved:

- [Join the Family Faculty](#)
- [Take part in the advisory group](#)
- [Suggest topics for research that are important to you](#)
- [Be part of working groups for specific studies](#)
- [Review information leaflets about specific studies](#)
- [Help us in telling people about the results of studies](#)
- [Come with us to conferences](#)
- [Feedback to us on PenCRU publicity materials and the website](#)
- [Tell other families about the work that we do](#)

In the future, we would also like to involve children in the work of the PenCRU. This will help us understand what things they think are important. If you have any ideas about how to involve children we would love to hear.

Currently, around 140 families are members of the Family Faculty but we would like the group to grow even bigger; the more people that are involved the better!

If you are already involved with us and know of others who may be interested, please tell them about us and the work we do. If you would like to join, please get in touch.

**Email:** [pencru@pcmd.ac.uk](mailto:pencru@pcmd.ac.uk)

**Telephone:** 01392 72 2968/2901



Hello, my name is Angela Dawe. I have taken over the role of Regional Officer for the South West. I have lived in the Plymouth area for the last 30 years so know the area quite well. I have a BSc (Hons) in Social Policy and a Diploma in Social Work. I have been a practising Social Worker for the last 7 years, working for several Local Authorities within the South West. I hope to use the knowledge and skills I gained as a Social Worker to support families who contact Cerebra. I feel that Cerebra is a unique charity that reflects my own values and I am looking forward to making a positive contribution to people's lives.

I am married and have two children who are starting out on the difficult road of adulthood, so I still provide a lot of support to them both. I enjoy walking my dog, exercising, watching my oldest son play in his band and my youngest play Rugby. I am also involved with a charity called the 'Not Forgotten Association' which supports serving, veterans and families of our Armed services. I look forward to offering my support. I can be contacted on 07827 848610 or email: [AngelaD@cerebra.org.uk](mailto:AngelaD@cerebra.org.uk)

Megan MacMillan joins us for her PhD, we will let her introduce herself.....

I am a Psychology graduate starting my PhD at PCMD on 'promoting positive attitudes towards childhood disabilities'. I will be working with my supervisors Dr Mark Tarrant, Chris Morris and Professor Charles Abraham. This research is being conducted as PenCRU Family Faculty stated one of the main problems they encountered about having a child who was disabled was from other people's negative attitudes. This project aims to discover what causes negative attitudes in non-disabled children/young people towards their disabled peers; this will be through the use of surveys in mainstream schools around Devon, Torbay and Plymouth. The outcome is to finally create an intervention, to be implemented in schools, which will aim to modify negative attitudes into positive ones. Hopefully this research will benefit disabled children/young people in their school environment and create a more accepting society benefiting people with disabilities in the future. I will keep you up to date with progress made with this project. Email:

[megan.macmillan@pcmd.ac.uk](mailto:megan.macmillan@pcmd.ac.uk)

## Staff update:

We are thrilled to introduce Rebecca Taylor who joined the team in August and is leading on the CHUMS project, many of you would have met her at the Family Fun day, please join us in offering her a warm welcome to the PenCRU team.

## Contact the team:

**Email:** [pencru@pcmd.ac.uk](mailto:pencru@pcmd.ac.uk)

**Phone:** 01392 722968/2901

**Website:** [www.pencru.org](http://www.pencru.org)

**Address:** Peninsula Cerebra Research Unit, Peninsula Medical School, Veysey Building, Salmon Pool Lane, Exeter, EX2 4SG

Stuart



Chris



Camilla



Claire



Val



Becky



designed by Matt aged 14



PenCRU  
Childhood Disability Research

**Peninsula CLAHRC**  
the NIHR CLAHRC of the South West Peninsula



**PENINSULA**  
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