

## We have launched our new website and changed our name !

### We are now known as PenCRU

(Peninsula Cerebra Research Unit for childhood disability research)

The renaming was necessary to distinguish us as an independent academic research unit, separate from the charity Cerebra. The charity has their own in-house research group which was causing some confusion.

We successfully launched our new website on May 14th and particularly like the pictures of all the lovely children. Have a look and tell us what you

think : <http://sites.pcmd.ac.uk/pencru>



## Renaming Competition winner

Thank you to all of the entries for our renaming competition, there were some great suggestions. Congratulations to Mike Hurley who was the winner and received his £20 gift token. We are now PenCRU!

## Children's Competition

We had a great response to the Children's competition for redesigning our Family Faculty logo. A huge thank you to all those who entered. Congratulations to Matt Tapp, aged 14, isn't his design great? All entries received a prize.



## Recent publications:

### Results from Cranial Osteopathy Trial have been published

Some families may remember that we carried out some research a few years ago looking at whether cranial osteopathy improved the health and quality of life of children with cerebral palsy. In summary, the research found little evidence to suggest that cranial osteopathy is of benefit to children with cerebral palsy. The paper reporting this research has now been published in Archives of Disease in Childhood; to see the online publication follow the link: <http://tinyurl.com/6bvjd3b>

### Involving families in childhood disability research

A letter we wrote to the editor of Developmental Medicine & Child Neurology has been published. This journal is one of the leading childhood disability journals in the world. The letter was about why we think it is crucial to involve families in childhood disability research. If you would like to see the letter please get in touch with us and we will send you a copy .

## Building a Partnership Event

The Building a Partnership (BaP) event on May 11<sup>th</sup> 2011 came about from a suggestion from a parent at a previous BaP event we hosted in October 2010. She explained the frustration of not being able to find reliable information about her child's condition on the internet in a timely manner. We took this as an opportunity to plan a 'shared learning' event offering training to Family Faculty members. The day was a great success. The morning session was hosted by PenPIG (PenCLAHRC Patient Involvement Group) researchers Andy Gibson & Kate Boddy. They explained how to take an issue that was important to the families, using examples that parents suggested, and turn it into a workable research question, using the PICO format. This means thinking about the **P**opulation, **I**ntervention, **C**omparison and **O**utcomes that you are interested in; there is more information about this process on our website.



In the afternoon, the group moved to the IT suite where Sue Abbott, PCMD Academic Support Consultant and Kate Boddy led the session. The focus of this session was on searching the internet for reliable information. This was a 'hands on' session. They gave a demonstration, showing reliable, recommended websites and how to spot a bad one. Families were then given the opportunity to search for information themselves; some found information to help answer the question they had raised in the morning session!

Here are some of the comments made by people who attended:

***'I will be putting it into practice'***      ***'Brilliant'***      ***'It was really interesting'***  
***'I found it all new and very informative and a tool that can be used and individualised for one's own use'***

We have received several requests from families asking if we will be running this training again. We would be very happy to arrange another event. In order to do so we need to have a idea of numbers. If you would be interested please get in touch with Camilla.

## Two exciting new working groups - come and get involved!

### Virtual reality technology

In the last newsletter we asked for your experiences of using Dance Mats and other virtual reality technologies, such as the Nintendo Wii, to improve your child's balance, concentration and gross motor skills. Thank you to those of you who have shared your experiences with us; as a result of the interest that was expressed we are now hoping to further explore a project investigating the use of virtual technology as therapy. We would like to invite anyone who is interested to be a part of a working group which will work together to plan how this piece of research might be carried out.

### Finding and Appraising information on Internet

As part of their series of monthly briefings Cerebra have requested that we produce a guide to assist families with finding and appraising information on the internet. We are looking for parents to help us pull this guide together and make sure that it is something that really will be useful to families looking for information. We have some ideas but need some further input from families. Some of you have already expressed an interest in this piece of work, but if you haven't then please let us know if you have any ideas or would like to be involved.

If you would like to be a part of either of these working groups for these exciting new projects, or have any questions or ideas about these potential pieces of research then please get in touch with Claire or Camilla.

## Project update

### **Social inclusion:**

The group last met in February 2011. At that meeting the group discussed and agreed working definitions of social inclusion, and endorsed the idea of research seeking to identify key life opportunities that should be available to all young people, regardless of disability, so that inclusion could be measured. The ideas for understanding and improving attitudes towards disabled children were developed into a proposal for a research project that could be carried out by a PhD student. This has received funding so we are currently recruiting for a postgraduate student to carry out this work.

### **Lycra study:**

The preliminary outline proposal "Evaluating a Lycra-based sleeve/glove orthosis to improve the bimanual ability of children with spastic hemiplegia: an exploratory randomised controlled trial" has passed the first stage and we have submitted a full application to the charity Action Medical Research. We will be informed of their decision in August.

### **Patient Reported Outcome Measures study:**

Our outline proposal "Informing the NHS outcomes framework: what outcomes of NHS care should be measured for children with neurodisability" was shortlisted by the NIHR Health Services Research Programme and we have submitted a full proposal. We expect to hear of their decision in August. However in the meantime we have secured a small amount of funding to carry out preparatory work and are currently recruiting a Research Fellow to lead this project.

### **Communication with disabled children as inpatients**

The aim of this study is to improve the care of disabled children when they have to spend time staying in hospital. The focus is on communication between children and staff. In Phase 1, we reviewed published research regarding the broad experience of disabled children when they spend time in hospital. In Phase 2, we interviewed parents of disabled children who had recently spent time in hospital. In Phase 3, we plan to use the issues identified to develop a training package for staff to improve communication between staff and children. We are very pleased to report that Siobhan Sharkey is taking the lead on the analyses of the interviews that Vanessa did with parents, and the focus groups that we carried out with ward staff. Siobhan is an experienced qualitative researcher and will bring a fresh perspective to the work. We'll keep you posted as the analyses progress, the aim is still to develop and pilot the parent-delivered training package for staff.

## Peer to Peer project gets underway

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. We have now started the first part of this project, which is to write a review bringing together the findings of the studies that have been done so far looking at peer support for parents of disabled children. This will help us to understand what is already known about this topic. We have had one meeting so far with some of the volunteer befrienders and the local coordinator from Face2Face in Devon to help us design this part of the project and we are now ready to start the review.

In the next phase of the study we will be moving on to look at the peer support offered by the Face2Face organisation in Devon. We will be gathering information such as how many people use the service, how much money and time is involved and we will be interviewing parents who support and who have been supported to gain an understanding of the impact of peer support for families. We will also be looking for ways to measure the effect of peer support. We will do this by searching for questionnaires that measure things like well-being, coping and stress. We will work with families to see if these questionnaires are appropriate to use, particularly in times of crisis.

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.

## Meetings and events:

### PenCRU meetings:

#### **Advisory Group**

**Date:** Thursday 30th June

**Time:** 10.00 am—12 noon

**Location:** Veysey room 005

#### **Annual Event Planning meeting**

**Date:** Wednesday June 22nd

**Time:** 10.00 am—12 noon

**Location:** Café at Dame Hannah's at Seale Hayne

#### **Reminder:**

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

### Events:

#### **PenCRU and Cerebra South West Family Fun Day**

**Date:** September 24th, 2011

**Time:** 10.00 am

**Location:** Dame Hannah's at Seale Hayne

### Upcoming seminars:

#### **Risk and Resilience Factors related to Family Quality of Life:**

Jan Wallander, Professor of Psychological Sciences, University of California

**Date:** Thursday 23<sup>rd</sup> June 2011

**Time:** 12:00

**Location:** Lecture Theatre, Veysey Building, Exeter

#### **Cerebra 'Carers and their Rights'**

Luke Clements, Professor at Cardiff Law School

**Date:** Tuesday 4th October 2011

**Time:** 9.30am-4.15pm

**Location:** Lecture Theatre, Veysey Building, Exeter, EX2 4SG

**Contact:** [gaynore@cerebra.org.uk](mailto:gaynore@cerebra.org.uk)

#### **Cerebra 'Disabled children, the law & good practice'**

Luke Clements, Professor at Cardiff Law School

**Date:** Thursday 14th July, 2011

**Time:** 9.30-4.15

**Location:** Legends Lounge, Gloucester Rugby Club, Gloucester, GL1 3AX

**Contact:** [gaynore@cerebra.org.uk](mailto:gaynore@cerebra.org.uk)

## Date for the diary Family Fun Day 2011

Thank you so much to all who voted for the venue for the Family Fun day. We are very excited about going to Dame Hannah's at Seale Hayne on **Saturday 24th September, 2011.**

To plan the day we are going to Seale Hayne on **Wednesday 22nd June 2011 at 10.00 am.**

If you would like to come and help us plan the day that would be fantastic or if you have any suggestions about the day then please get in touch. This is your day!



## 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 taking part for instance: becoming a member of the Advisory Group or committees for specific studies, working with us to design studies, reviewing information leaflets about specific studies or PenCRU publicity documents, assisting with disseminating the results of studies, helping organise events or any other aspect of the work that we are doing that interests you.

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.

Currently, around 120 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 would like to join, please get in touch. email: [PenCRU@pms.ac.uk](mailto:PenCRU@pms.ac.uk) or telephone 01392 72 2968/2901



## NEW FEATURE: Personal Stories and Experiences

Zoe's mum Denise contacted us recently when she read an article about our new peer support project in the Cerebra magazine, 'Newsbeat'. Denise was keen to share her experience so far with other families. Zoe has a diagnosis of Aspergers, Dyspraxia and severe OCD and has recently qualified as a PADI Open Water Diver.

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.

### Denise's Story:

*'I am the parent of a 14 year old girl who was diagnosed with Aspergers and Dsypraxia when she was eight, then Severe OCD when she was thirteen. Face2Face have been a great support to us since her diagnosis and eighteen months ago I trained to be a Befriender. I now support other families. It has been*

*a long road for us, challenging, sometimes humorous and with some great achievements. About two years ago Zoe decided she would like to scuba dive as she loves all animals and marine life. Despite many challenges, she has just qualified as a PADI Open Water Diver. Eighteen months ago Zoe was unable to attend school as her OCD was controlling her life, to the point of not being able to leave the house. After accepting medication in early 2010, she was able to return to school and has been in full time Education for the last four terms, having just taken some GCSEs early in Year 9. I am a very proud Mum, as her main symptoms are stress and anxiety. There will always be challenges ahead, but it's good to celebrate the achievements. It's also good to share with other families that things can change in time, sometimes for the better. Maybe with support, we find coping mechanisms, and look at things with more humour. It is always good when things are tough to have someone who is kind, supportive and who listens.'*



### Where we've been:

#### British Academy of Childhood Disability (BACD)

Chris attended the BACD Annual Meeting held at Derby in March. The theme of the presentations this year was Autism Spectrum Disorder. Chris is also involved in the BACD Strategic Research Group. You can read more about this group and our work here: [www.bacdis.org.uk/research](http://www.bacdis.org.uk/research)

#### European Academy of Childhood Disability (EACD)

Chris also took part in the annual meeting of the EACD at Rome in June. There was discussion about developing evidence-based treatment recommendations for children with cerebral palsy to inform health services in European countries. There were presentations on research related to Cerebral Palsy, Autism Spectrum Disorder, and ADHD. Over 160 posters presented a wide range of childhood disability research.

Chris' trip to Rome was funded by Mac Keith Press, publishers of the leading childhood disability journal and a series of books related to childhood disability. To find out more about Mac Keith Press and their publications here [www.mackeith.co.uk](http://www.mackeith.co.uk).

These meetings are an important opportunity for us to network with the relatively small number of colleagues carrying out research to improve the health of disabled children.

## People we work with

We work with many different people within the university and further a field and we thought you may be interested to know who some of them. For this issue we would like to introduce you to a couple of them:

### Dr Siobhan Sharkey

Dr Siobhan Sharkey joined the Peninsula Medical School, University of Exeter, in April as a PenCLAHRC Research Fellow. Her first degree and PhD were in Social Anthropology. In the past she has worked as an oral historian and in mental health, and has worked for the past 16 years as a lecturer and researcher. Siobhan specialises in the use of qualitative methodologies in collaborative health research, with a particular interest in patient and service user perspectives and vulnerable people. Her most recent research and publications explore experiences of young people who self-harm, online support and the use of ethnographic perspectives in investigating health care practice. She is currently working on a range of projects for PenCLAHRC, including our PenCRU research study on Improving communication with children in hospital, investigating perspectives and experiences of parents, children and professionals.

Email: [siobhan.sharkey@pms.ac.uk](mailto:siobhan.sharkey@pms.ac.uk)

### Peter Aighton

Hi, my name is Pete and I work as a project facilitator on several of the Child Health projects. I'd liken being a project facilitator to being a cross between Google and a human yellow pages. My job often involves trying to find answers and solutions to problems that might delay projects and acting behind the scenes to make sure things run smoothly. I deal with some of the less glamorous aspects of projects such as finance and human resources allowing the experts to focus on delivering their research. I didn't grow up wanting to work in project management but each day throws up interesting and unique challenges which I really enjoy solving and if I don't know the answer hopefully I know someone who will.



Email: [peter.aighton@pcmd.ac.uk](mailto:peter.aighton@pcmd.ac.uk)

## Do you have a disabled child who attends mainstream school?

We have noticed that parents whose children attend mainstream school are under-represented in our Family Faculty.

It is important that the potentially very different views and experiences of parents and carers who have children in mainstream education are represented in our decision making.

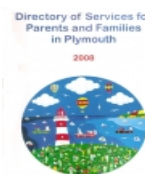
Please do get in touch if you have a disabled child who attends mainstream school, we'd love to hear from you.

The service provides one point of contact for children and families to get the information they need, whether it is about education, health or social care. The local information co-ordinators will help you get information about the services and support available to you in looking after your child. You can get in touch with them to ask any questions by phone or email, see their newsletter : <http://www.devon.gov.uk/cwan-discplusnewslettersummer2011.pdf>

Eastern Devon:	Sue Phillips	01392 385932	sue.a.phillips@devon.gov.uk
Southern Devon:	Cathy Hill	01803 763505	cathy.hill@devon.gov.uk
Northern Devon:	Amanda Smithson	07989 256184	amanda.smithson@devon.gov.uk

Plymouth Parent Partnership provides family information services for Plymouth, their website gives information and links to services to help you as a parent or carer:  
<http://www.plymouthparentpartnership.org.uk>

Email: [parentdirectory@plymouth.gov.uk](mailto:parentdirectory@plymouth.gov.uk)



Family Information Services for Torbay produce an information and resource directory for parents and carers of disabled children:

<http://www.torbay.gov.uk/FIS>

FISenquiries@torbay.gov.uk

Tel: 0800 3285974



## Continance services

Continance services for disabled children is a very important issue for lots of families; nevertheless it is not one that we can readily turn into a research project. We believe that the issues are better addressed by organisations that campaign for high quality services on behalf of disabled children and their families. We have produced a final summary of our meetings which we hope will be helpful to parents and professionals and includes useful links to information and Every Disabled Child Matters campaigns for parents who would like to campaign on this issue.

<http://sites.pcmd.ac.uk/penclu/news.php?id=219>

## Staff update

It is all about change at PenCRU; as well as a new name and a new website we have also had a few staff changes!

We welcomed back Claire from maternity leave in March, she now works for the unit as an Associate Researcher for 2.5 days a week.

We are very lucky to have been able to keep Val who was covering Claire's maternity leave. She is now leading a project on peer to peer support 3 days a week.

Camilla's role has also changed and she now works on the unit 4 days a week as Family Involvement Coordinator.

## Contact the Team

**Website:** <http://sites.pcmd.ac.uk/penclu>

**Email:** [PenCRU@pms.ac.uk](mailto:PenCRU@pms.ac.uk) **Phone:** 01392 722968/2901

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

**Stuart**



**Chris**



**Val**



**Claire**



**Camilla**





PenCRU  
Childhood Disability Research

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



**PENINSULA**  
COLLEGE OF MEDICINE & DENTISTRY  
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