

## INVOLVE Conference 2010

In November two parents and the members of the research team gave a presentation at the INVOLVE Conference in Nottingham explaining how local families and the Cerebra Research Unit are working together. INVOLVE is a Government funded national organisation promoting public involvement in NHS, public health and social care research.



This is what Kim had to say of her experience:

**“Last November I attended the Involve Conference, with the team from Cerebra Research Unit, I was able to help with the presentation that they gave on the work that Cerebra does, and share some of my experience with a small group of people involved with research, and I was able to attend other talks and learn more about research.**

The whole experience was a positive one, it was nice to be able to contribute and have a say about a subject that is so close to my heart, to feel a part of something that in the long run, will hopefully make a difference too others, as more research is done.

The team put me very much at ease I felt valued and listened too, and we became closer as a group, which will help us, as we all work together over the coming weeks/months, putting together questions for research.

On reflection I was pleased to have been involved, feeling that my many years of bringing up my daughter, who has cerebral palsy and, and the experience I have gained might be put to good use and help make life better for families in the future.”

Kim Antonio (Parent, on the research advisory team)

## Peer Support Study

In April we will be starting a new study to look at the benefits and costs of providing peer support to parents of disabled children. Many of you will have heard of the Face2Face network of trained parent volunteer *Befrienders* who provide emotional support and advice to parents of disabled children. We have worked with members of the Face2Face organisation to develop the idea for this project, which has been prioritised for funding by the Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC).

The project will run for two and a half years and will start with a review of the existing literature on providing peer support to parents of disabled children and carers in other settings. In the second phase of the project we will be talking to people who are involved with Face2Face in Devon; parents receiving and giving peer support. This will help us to understand how peer support works and what impact families feel it has. **This project is what we call a ‘pilot study’. We will use what we learn from this small study to develop a larger project to investigate the effectiveness of peer support in different organisations and locations.**

## Family Fun Day 2011

We so enjoyed the family fun day last year that we thought we would do it again. We would love to hear from you.

- Do you have a suggestion on where we should go?
- When should we have it?
- Would you like to get involved in helping plan the day?
- Would you like a key speaker on a topic relevant to you?
- Do you have any suggestions on how the day should run?



Let us know what you think; this is your day!

## Eating and Drinking Ability Classification System for children with cerebral palsy (EDACS) Meeting January 2011

**“We wanted to say thank you to the staff and parents of the Cerebra Research Unit for the warm and enthusiastic welcome we recently received on an extremely cold day in January. We were really impressed by the Unit, and excited by the very active group of parents who are participating in and influencing the direction of research.**

We travelled to Exeter because Chris Morris is a member of our Research Project Team. A small group of expert parents and professionals from Devon and Cornwall met to discuss the latest draft of the Eating and Drinking Ability Classification System (EDACS) for children and young people with cerebral palsy. Members of the group gave us plenty of really helpful feedback. Everyone was invited to vote for the five most important changes they thought needed to be made to the next draft of the Eating and Drinking Ability Classification System. We will be taking the new improved version to our next meeting in Manchester at the beginning of March.

If you would like to know more about the project please contact Diane Sellers or Sarah Ford at Chailey Heritage Clinical Services, Beggars Wood Road, North Chailey, Nr Lewes East Sussex BN8 4JN tel: 01825724720 [diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)

Follow this link to our website:

<http://www.sussexcommunity.nhs.uk/index.cfm?request=c2008582>

## 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 Cerebra Research Unit 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 Cerebra Research Unit. This will help us understand what things they think are important. Currently, around 106 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 [cerebraresearchunit@pms.ac.uk](mailto:cerebraresearchunit@pms.ac.uk) or telephone 01392 72 2968/2901

## Building a Partnership Event

After the success of the last **‘Building a Partnership’** event in October we thought we would have another one.

Wednesday May 11th, 2011 is the date of the next event. We discussed at the last **advisory meeting having a ‘shared learning’ event** on developing research questions and searching the internet for reliable information. We would love to have some more family input on planning this event, if you would like to get involved let us know.



This will be a great opportunity to learn together and it will be great to have lots of families there.

## Project update

### Social inclusion:

This group has met several times over the year, and held wide-ranging discussions about people's experiences and services provided to promote inclusion. We are developing a research proposal to measure **children's inclusion using the principles of equality of opportunity and freedom to choose to be involved**. The next stage is to think about the key opportunities that all children should have the opportunity to be involved in. These opportunities can be formulated into a questionnaire.

We have also discussed influencing the attitudes of people towards disabled children and their families. The group has indicated a preference to influence children in the first instance, perhaps through schools or community groups. Our colleague Mark Tarrant has developed this idea as a PhD proposal for which we are seeking funding. A PhD student would systematically examine psychological processes which underpin attitudes towards disability in young people, and build on this knowledge to develop and test an intervention by which such attitudes can be modified in a positive direction.

### Hospital communication:

The study to develop a training package for health professionals focusing on improving communication with disabled children in hospital is entering its final stages. We have now completed the interviews with health professionals from the Royal Devon and Exeter Hospital and the North Devon District Hospital in Barnstaple, and asked about their experiences of caring for and communicating with disabled children in hospital. We will look at their views, in combination with the views of families whose children had recently been in hospital, and identify themes that could be used to develop the training package.

### 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 of triage and we have now been invited to apply with a full application to Action Medical Research.

### Patient Reported Outcome Measures:

**Our preliminary outline proposal "Informing the NHS outcomes framework: what outcomes of NHS care should be measured for children with neurodisability" has been shortlisted by the NIHR Health Services Research Programme and we have been invited to submit a full proposal.**

### Dance Mat Therapy

Do you have any experience of using Dance Mats or other virtual reality technology to help with your **child's balance, concentration and gross motor skills**? We are investigating virtual reality technology as a potential topic for future research and would like to hear about your experiences.

### Have you seen our annual report?

We have published our annual report, take a look at it on our website at: <http://tinyurl.com/6x4aunv>

### Jargon buster

Thank you to all those who gave feedback on our **'jargon buster' of research terms, look out for the final version** when the website is re-launched.

## Competition!

Would you like to win a £20 Amazon token? We need your help, we would like to rename our unit as people sometimes confuse us with Cerebra the charity, and are not instantly aware that we do research to improve the health & wellbeing of disabled children. Entries should try and encompass children/child, disability, research. Put your idea on a postcard or email with your name and contact details by March 25th.

### Children's Competition

### Prize £20 Amazon voucher



We would also like a new logo for our Family Faculty and we need some help! Send your design to us by March 25th with your name, age and contact details to:

Cerebra Research Unit, Freepost RRGL-TUHE-AHYT, Veysey Building, Salmon Pool Lane, Exeter, EX2 4SG



## DISCplus is Devon's family information service for children with additional needs



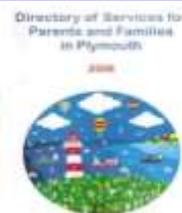
The service provides one point of contact for children and families to get the information they need, whether it is about education, health or social care. The local information co-ordinators will help you get information about the services and support available to you in looking after your child. You can get in touch with them to ask any questions by phone or email.

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](mailto:FISenquiries@torbay.gov.uk)

Tel: 0800 3285974



### Upcoming meetings

**Advisory Group:** June 30th, 2011

**Social inclusion:** TBC

**BaP:** May 11th, 2011

We are able to meet the cost of travelling expenses, and also child care as long as a receipt is provided.

### We are having a facelift or rather our website is!

Hannah Parsons, who is our website designer and the Cerebra Research Unit Team are working hard at the moment to redesign our website. Look out for our email with a development site link for your opinion in the next month, if there is anything you feel we should consider including please let us know.



Many thanks to the parents who have sent gorgeous pictures of their children to include on the website. It is not too late to send us yours if you would like to.

### Staff update

We are looking forward to welcoming Claire back from maternity leave on March 14th. Claire will be returning part time, working 2.5 days a week. Camilla is now working for the unit four days a week.

### Contact the Team

**Website:** [www.pcmd.ac.uk/cerebra](http://www.pcmd.ac.uk/cerebra) **Email:** [cerebrareserchunit@pms.ac.uk](mailto:cerebrareserchunit@pms.ac.uk) **Phone:** 01392 722968/2901

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

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