

New member of staff: Introducing... Chris Morris

Chris joined the unit from Oxford in September 2009. He is excited to be moving to Devon and is enjoying being part of the unit; and will lead the programme of research.



He has been awarded Masters and Doctoral degrees from the University of Oxford for research about children with cerebral palsy. He led the development of a new family-reported outcome questionnaire for children with foot or ankle problems. He has also been an orthotist for 20 years, and edited the book *Paediatric Orthotics*.

One of his first initiatives at the unit was the *What's the Evidence?* reports which can be found on the unit website, and he hopes the reports will be helpful to families when they are deciding whether to pursue or purchase treatments. Chris has a special interest in the social inclusion of disabled children and plans to develop research on this topic. He also wants to conduct clinical trials to find out what works to improve the health of disabled children, particularly improving function and preventing deformities. Chris believes strongly that involving children and families in the work of the unit is crucial to the success of these projects.

What's the Evidence?

Our new What's the Evidence? series of short reports are now available on our website.



These reports have been written in response to queries from parents and carers about specific therapies. They are designed to provide parents with information about the therapy and the evidence that is available which may help with decision making about which therapies to pursue. So far we have produced reports about **Brainwave and Footsteps**, the **Scotson Technique** and **Tomatis** (a form of listening therapy), and we are working on reports for Selective Dorsal Rhizotomy and Epilepsy Medication. These reports appear to be a hot topic and we have received lots of feedback! Please join in the discussions on our forum...

We will continue to produce these reports in response to your queries so please let us know if there are any treatments or therapies that you would like us to produce a What's the Evidence? report for.



Nappy Services

One of the issues raised during our launch events last summer was the frustration parents felt when dealing with the nappy services provided in Devon. We are currently gathering information about this service with a view to posting advice about the service on our website. If you have information that may be helpful; please get in touch.

Upcoming Meetings

Question Prioritisation Meetings

Tuesday 19th January 12noon – 2.00pm

The Imperial, Exeter

February date to follow

For an update on the process so far see [article on Page 3](#)

Advisory Group

Thursday 11th March 10.30am–12.30pm

PMS, St Luke's Campus, Exeter

Please contact us for more information

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 in reviewing information leaflets about specific studies or for general CRU publicity, sitting on trial steering committees for specific studies, work with us to design studies, assist with disseminating the results of studies, or any other aspect of the work that we are doing that you have an interest in. We will ask for your email address, phone number and postal address and will send you regular updates. If you are interested in becoming a member of the Family Faculty then please let us know.



Advisory Group

We have an advisory group for the CRU that meets every few months.

The advisory group provides advice about various activities that the CRU are involved in and is crucial to the success of our work.

Currently two parents sit on the Advisory Group, but we are very keen to encourage more parents and carers to join us. If you would like more information about what would be involved then please get in touch.



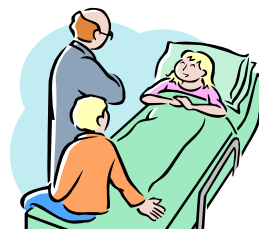
Exciting New Research Project!

Improving communication with children with disabilities on the ward study

Children with disabilities tend to be admitted more frequently to hospital than other children, and many will have difficulties with communication. Parents have identified communication difficulties between staff on children's wards and families as a significant cause of distress to the children and to them.

Researchers at the CRU looked at the scientific literature and found that many health professionals believe that they do not have the necessary experience or training to communicate with children with communication difficulties. We plan to develop a training package focusing on communication skills for health professionals, which could be delivered by parents/carers of children with disabilities.

To help develop this training package, we plan to interview children with disabilities and their parents/carers about a recent stay on one of two children's wards in Devon. The children and their parents/carers will be encouraged to suggest different strategies which could be used by health professionals to help communication. Parents will be interviewed at home and children will be interviewed in school or home. An adult who is familiar with communicating with the child (e.g. speech and language therapist, teacher, parent) will help the researcher interview the child. Health workers of different professions (nurses, doctors, allied health professionals, non-clinical staff) will also be interviewed about their experiences of caring for children with communication difficulties on the ward. The information gathered from these interviews will be used to develop the training package.



From Spring 2010, we would like to interview 20 parents and their children who have recently been discharged from hospital. This is a really exciting project as children and their families will have an opportunity to change the practice of health professionals who care for them in hospital.

If you would like any more information about the project, please contact

Vanessa Edwards on 01392 262978 or Vanessa.edwards@pms.ac.uk



Get chatting on the forum!

It is very easy to join; and it is a great place to talk to other families about issues and events that are important to YOU. Have a look at the website for more information.

Where have you seen us lately?

We have been linking in with lots of charities and contributing to forums to try and encourage more parents to join in our discussions. You may have seen us on Hemihelp, Cerebra, Scope, and DISCplus



We are always keen to hear about other places to advertise. If you can think of any publications that parents regularly receive please let us know...

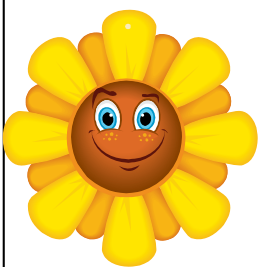
Question Prioritisation process

We have started a new process to give parents the opportunity to work with us to decide which parent initiated research questions we should develop.

We had our first meeting in December and started to think about the sorts of issues that might be important to pursue. Some issues that seemed to be important were:

1. Benefits of social participation and inclusion
2. Evaluation of an early intervention befriending service
3. Organisation of services for children with complex needs

We are meeting again in January and would really welcome some more parents to help us develop these and other ideas.



2010 Annual Event

We are planning to hold an event in the summer for families to come along and hear more about the work that we have been doing, opportunities to get involved,

and take part in lots of fun activities!

We would love to hear from you if there is anything you would like us to arrange for this day...

Would you like to hear from a Doctor or researcher about a piece of local or national research?

Would you like to have training about research?

Do you have any suggestions for suitable venues?

Would the summer holidays or a weekend be better for you?

We will keep you updated about this event...look out on our website for more information

Try our word search!

n r l f f p i o e m e i b e t
o e e i l a t i l i f t t r n
i s k s a g n h a t e m h h m
t s y g e o t p e o t y e e r
a e e t v a n a t r a e e o e
c s l r e a r d o c a l e e s
i l e s v n h c a c p p r f o
n n w c a i h i h t m u y o m
u u e s n e c e r e b r a r f
m m s i a e w e b s i t e u t
m h p l h s d o s e s c e m i
o l t t e d l i h c h t e a n
c h a i v o a g v a c t i f u
t t e o m n t e e e t g n d a
c o r r t t e c o a e o r t n

Can you find these words...communication, evidence, research, services, cerebra, website, therapy, health, forum, child, unit

Future Research...

Social Inclusion measure

What is 'social inclusion' and what does it mean to children and families? The term social inclusion is widely used by policymakers and enshrined in the UN Conventions on the Rights of the Child and Persons with Disabilities. In the UK, the National Service Framework for Children asserts that health and social care should promote social inclusion of disabled children. However, whilst we might have a sense of what inclusion alludes to, it is not well defined and therefore difficult to assess.



We are developing a programme of research related to the theme of social inclusion and participation. We want to work with disabled children and their families to find out more about what social inclusion and participation means for children at different ages. Using this information we can develop a way to measure children's involvement in life, and then assess factors which facilitate or restrict children's opportunities.

Do you think this is important and is this something that interests you? If it is, then please contact us to get involved or write a comment on the online forum to start a discussion.

Lycra Trial

In recent years there has been increasing interest in using Lycra-like elasticated fabrics to make orthoses (splints). Garments can be made either for the whole body, or trunk, or leggings or sleeves with gloves.

Although there have been a few small research studies the results have been mixed; so, further research is needed to find out if these garments improve children's function.



We are particularly interested in evaluating the sleeves and gloves for children with hemiplegia. The sleeves are made-to-measure by a manufacturer in Cornwall. We are working with them to seek funding for a clinical trial. However, we also need parents and children to help us design the trial. This is because we want to ensure we measure outcomes that families think are important, the trial is attractive to children and families, and all the processes and procedures are acceptable.

Please contact us if you are interested in being part of the team for this project.

Contact the Team

Website: www.pcmd.ac.uk/cerebra

Phone: 01392 262901

Email: claire.lloyd@pms.ac.uk

Address: Cerebra Research Unit, Peninsula Medical School, St Luke's Campus, Exeter, EX1 2LU



Chris



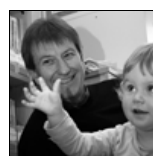
Claire



Camilla



Katrina



Stuart



Hannah