

PenCRU and Family Faculty team



We want to support the active involvement in research of groups and individuals who are often excluded from research; and make our work relevant and accessible to those it concerns.

'My experiences are adding to the puzzle ...every piece is important and necessary to make up the complete picture.'
A Family Faculty parent

'The fact that research is closely linked to the Family Faculty is very encouraging as this fits so well with the aims of Cerebra... Parents have given time to the Family Faculty despite busy lives. This involvement has allowed them to use expertise and skills gained elsewhere... They provide an important contribution which has been valued.'
Cerebra Trustee

'It has been a great opportunity to collaborate with parents from the Family Faculty and turn real life experiences into research.'
PenCRU PhD researcher

'It is fantastic to work in a place where families of disabled children are given a positive voice.'
PenCRU Family Involvement Coordinator

How can you get involved?

"Not only do I feel I'm being of some use to others in my situation, but I also get useful up to date information as well. I feel like the insight I have is of some use to somebody and if I can help anyone by my experiences I am very glad to." - A Family Faculty parent

We have a designated member of staff who supports the involvement of families in the unit (our Family Involvement Coordinator) who would love to hear from you!

To join our mailing list ('Family Faculty') please contact us using one of the options below, or complete the slip enclosed with this leaflet.

Contact us

Through the website:
www.pencru.org

By Email:
pencru@exeter.ac.uk

By Telephone:
01392 722901
01392 722968

By Post:
Peninsula Cerebra Research Unit
University of Exeter Medical School
Veysey Building, Salmon Pool Lane
Exeter, Devon , EX2 4SG



PenCRU
Childhood Disability Research

Families are Experts
Get involved: Join our Family Faculty



Please note that the research carried out and the views expressed by PenCRU are those of the Peninsula Cerebra Research Unit and do not represent the views of the Cerebra charity, or any other parties mentioned.

Who are we, and what do we do?



We are a research unit within the University of Exeter Medical School. We are funded by the charity Cerebra and conduct research about services and treatments for disabled children and young people.

We do research *with* families from our Family Faculty, not *on* them.

This means that we are not looking to run tests or experiments on our Family Faculty members. Instead we work with families to find out about their life experiences, and use these to help guide and direct the focus of our projects. Families advise on the best ways to prepare and present our findings so that our research is accessible.

What is research and why do we need it?

- Research is finding out information.
- The idea of a treatment may seem good, but research is needed in order to provide evidence that it really does make a difference.
- Research is also important to show that something is not effective.
- Other research might focus on the way services are organised, are they efficient or could improvements be made?
- Research may also explore people's experience of conditions to help others understand more about them.

'I enjoy the training & seminars & learning new things & opinions which are listened to.'
A Family Faculty parent

Examples of our research

We have produced research into areas such as:

- Promoting children's positive attitudes towards disability.
- Improving communication in hospital between paediatric ward staff and disabled children.

These are just a couple of our recent projects, please see our website for more!

www.pencru.org



We also publish 'What's the Evidence?' summaries

These are mini reviews of existing research to answer questions we have been asked about evidence of treatments and interventions for children and young people.

Examples of questions we have looked at:

- How effective is speech therapy for verbal dyspraxia in children with a learning disability?
- Is massage beneficial for children with cerebral palsy?

'I think PenCRU evidence summaries are a good place to start with families looking for strategies to help their children and will direct them towards your website in clinic'

A consultant paediatric neurologist



What do our Family Faculty members do?



'I really like being able to be involved in the bits that interest me. I love the fact I can dip in and dip out depending on how my life is at a particular time!' A Family Faculty parent

How can you be involved?

- Receive emails updating you on our work.
- Attend meetings with families, researchers and professionals, where families can advise researchers.
- No previous experience of research is required to attend our meetings and we try to make meetings relaxed and fun!
- Meetings include a free lunch, cover reasonable travel expenses/childcare costs, and provide an acknowledgement for your time.
- Attend our Annual Fun Day—a free day out for families to say thank you for their interest in our unit.
- Suggest ideas for, and be a part of, Building a Partnership workshops—free events where we share research skills that are of interest to families.
- Present at, and attend, conferences.

'Thank you for the amazing outings, they're really fun and thanks for your research.'
A Family Faculty parent

'It's great to see other families in the same situation as we are and to see how they deal with day to day dramas.'

A Family Faculty parent

