Competition Time

Remember our CLANGERS?

Can you spot the 10 differences? Email your answers to us. First correct entry drawn out of the hat on 12th Jan wins a prize!







Contact the team

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PenCRU Newsletter December 2020, Issue 33

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Healthy Parent Carers

Our Healthy Parent Carers programme was developed as a peer-led programme for face-to-face delivery in community settings. However the pandemic and need for social distancing changed that.

Members of our Family Faculty have been very helpful these past few months in the process of adapting the programme to online delivery. Chris secured some short-term funding from The National Lottery Community Coronavirus Support Fund to facilitate this work.

The benefit of taking the programme online is that many parent carers who would otherwise be unable to physically attend a venue can now take part.

Challenges of online delivery include adapting group activities that involve physical activity. Also, how is it best to present online, and how do we build relationships when there is no informal chat in the coffee breaks or in the car park? We've appreciated all the suggestions that our working group members have contributed. It's been fun to meet on Zoom with the domestic backdrop of pets, parcel deliveries and even a friendly robin perching on the screen.

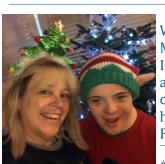
STAFF NEWS











We're very excited to announce that Bel McDonald has joined PenCRU as our new Family Involvement Coordinator. Bel is a parent carer and long-standing and experienced member of our Family Faculty. Many of you will have met her and her son, Fergus, at one of our Family Fun Days.

"I believe that the voices of the Family Faculty

should be firmly in the centre of any research that PenCRU undertakes. I have always felt incredibly lucky that they are on my doorstep and that I can contribute to their research. The research team really do listen to the opinions of the Family Faculty and I know how much they all value your input. They have all shared with me that the meetings are the highlight of their jobs as it helps to bring the research alive for them.

I know that the current Covid-19 pandemic has been really hard for everyone but I am very aware that it has been particularly difficult for a lot of you, being locked down with your children, many of you without the usual access to any support services. Fergus, my 22 year old son, is on the Critically Extremely Vulnerable list so he is currently at home again due to Lockdown 2 and I am juggling working and stopping him setting the kitchen on fire trying to cook bacon sandwiches!

I have really enjoyed catching up with some of you, albeit virtually and am so excited about all the good work we are doing together in modifying the Healthy Parent Carers Programme for delivery online. I am planning to arrange a weekly informal catch up on Zoom from January so do look out for an email about that.

Christmas may well be a bit different for you all this year, but I really do hope you have a lovely time and Santa brings you all the presents you have asked for. Here's hoping that 2021 is better than this year has been!" **Bel**



Telling people about our research

Chris and Gretchen presented at the <u>European Academy for Childhood Disability</u> (EACD) Annual Scientific Meeting in November. Gretchen presented about <u>Healthy Parent Carers</u> demonstrating feasibility of delivering the programme in the community. Chris presented our <u>ICoN project</u> about improving continence for children and young people with neurodisability. He had also done a longer lecture like this for the professionals' <u>conference of ERIC</u> The Children's Bowel & Bladder Charity. Recording a presentation or lecture at home speaking to your fruit bowl which is then played at a conference later is another weird thing we have learned to do in this strange year.



PenCRU team: Bel. Alice. Chris. Annette. Fleur

Making Healthy Parent Carers sustainable

As well as modifying the programme for online delivery, we have secured funding through an Economic and Social Research Council (ESRC) Impact Accelerator Award to pilot two national charities implementing the Healthy Parent Carers programme. We have a Community Working Group with representatives from leading national charities *Contact* and *Council for Disabled Children* and other stakeholders. This enables us to think through implementation at scale, and any necessary modifications. We will be trialling the online programme in the Spring.

Prophylactic antibiotics to prevent admissions for respiratory infections: We have a small Family Faculty working group assisting with this trial, do get in contact if you have relevant experience and would like to join the group.