Defeating Dementia in Down Syndrome (DiDS) – A CIDDRG Project

About the Newsletter // Contact Us!
We are resuming this biannual newsletter! This newsletter is written by the Defeating Dementia in Down Syndrome (DiDS) team, which is part of the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG). It is for people with Down syndrome, their families and other caregivers who are interested in our projects, as well as anyone else!
We are looking for people with Down syndrome (and their carers) to join our editorial team. If this interests you, or you’d like to share a story for the ‘Your Stories!’ section or contact us for any other reason, please email our admin Lucy Gillies at ciddrg@medschl.cam.ac.uk!
A Letter from the Research Leader

Looking back on this year, although we all continue to be affected by Covid-19, we remain in good spirits.

Many thanks to all our participants and research team we have achieved much to be proud of. We have carried on with our programme of research to help us to understand how to keep our brains healthy.

We are very excited and fortunate to have been awarded more money from the USA to carry on with this very important research. The funding has allowed us to bring wonderful new people on to our team (welcome!), but we are sad to see some of our previous team leave and move to different pastures.

The future looks bright next year as we will be putting in even more effort and edging closer to finding the answers to help people with Down syndrome and their health.

We may be ready for a clinical trial next year.

I am particularly excited about our plan to reach out to more people around the country to get involved with our work. The benefits to participants who engage in research are well established.

If you know someone with Down’s syndrome who would be interested, then please contact Lucy or one of us as we would like to know you.

Dr Shahid Zaman
DiDS Lead
“Everybody has found the past two years hard with the restrictions needed to control Covid, but I found it particularly hard as I was not able to train at my athletics club (Cambridge and Coleridge). I am a sprinter and compete for GB at international level along with other athletes with Down Syndrome. It also meant a number of competitions I would normally attend were cancelled. I did manage to do some training at home but it does not have the same level of support and encouragement that I get from my coaches and peers.

What I did find though was that I had time to do some other activities, things I would not normally have time for. In particular I enjoyed doing my art and have really enjoyed getting back into this, I also enjoy Gardening, right now I am spending a lot of time leaf clearing! I feel better when I get some fresh air, Walking the Dog, Gardening or running, but sometimes it is nice just to get my sketch pad out and draw.”

Catching up with Jack!

I liked doing the research with April in Cambridge. I told everybody at my day centre, The Assist Trust, and my group, About with Friends. I’m looking forward to the next research project.
Amy’s EEG Study Feedback!
I hope what you found out from doing this research study helps other people in the future (that's one of the main points I'd like to put across)! There's nothing that I didn't enjoy about taking part in the EEG study.. Wearing the special cap that monitors brain activity was one of the highlights! The researchers were friendly and helpful.. I've found that in every study that I've taken part in! Some of the memory games and puzzles required a lot of thinking (but I like a challenge) and I found the whole experience fun and interesting!

Charlotte’s Experience!
I liked meeting April and helping with research, I hope it will help, I found some of the questions hard but I did my best to answer and having the cap on was OK, it did not hurt, the gel washed out OK and left my hair shiny.
**Hellos**

**Shemaya**
Hello everyone, I’m Shemaya. I have taken over from Monika as a research assistant working on the NiAD (soon to be ABC-DS) project. I have already had the pleasure of meeting some of you and look forward to meeting many more of you. In my spare time I enjoy trampolining, reading, and cooking.

Hi there! My name is Valerie and I’m one of the new Research Assistants. I enjoy baking, sport and playing with dogs. I’ll mostly be working on the TRC-DS and H21 studies but you might also see me helping out with NiAD and ABC-DS. I’m looking forward to meeting many of you!

**Valerie**

**Lucy**
Hi! My name is Lucy, and I am the new team Administrator! Here to support you and the team! When I'm not busy working, I take my dog on adventures or I train/compete in sprinting. I am a national sprinter, hoping to try out for the Team GB bobsled / Skeleton team.
Hi everyone! My name is Akila and I am a masters student studying the cerebellum using diffusion imaging. Thank you to everyone who took part in the study, it was a pleasure interacting with you while doing the quizzes and puzzles. I will be starting my PhD in Neurology at UCL in January and I thank everyone from the CIDDRG lab for their input, help and making this an amazing place to work! Good luck to everyone in their future!

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April

Doing a PhD has its usual challenges and this was especially true during the pandemic. Fortunately, I had great colleagues and friends who helped me stay in good spirits. Eventually I was able to meet many of you in person through the EEG study. I appreciate that research participants helped us by bringing focus and persistence to the puzzles and quizzes. I hope you got some nice photos in the EEG cap! What I enjoyed most were the laughter, jokes and stories as we got to know each other during the studies. We have now collected most of the EEG data (a few remaining sessions in Jan 2022). I will be analysing it from the northeast of the United States, in Maine – where there is a lot of snow, moose and lobsters. Massive thanks to the research participants, parents, support workers and colleagues who made this work possible!

Hugs from Maine, April.

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Akila
…are not forever! Updates

Monika

In 2018 I moved to Cambridge to start my journey with the CIDDRG group and NiAD. In the 2 years and 10 months that followed I met some amazing and inspiring participants, families, colleagues and researchers. I am deeply grateful for the opportunity to learn/grow and for all the support I received in my work and my professional development in general. I want to say “Thank you!” to all our participants and their families who returned again and again to Cambridge for all the quizzes, puzzles and scans! Time flies and now I am training to become a clinical psychologist in London. Nevertheless, the NiAD study has been such a big part of my life, I will be sure to check in to ask how its continuation (the ABC-DS study) is going!

At the end of 2019 I joined the CIDDRG to look at how brain electrical activity changes could be a marker of dementia. This was my 1st time working on Down syndrome and I was very fortunate to collaborate with April. The lockdowns stopped me from meeting our volunteers but luckily I could work on previously collected data. I am very grateful to the participants that have taken part in our studies over the years and I am happy to say that we are in the process of publishing some of this data! I have now moved to the University of Granada (Spain) where I study the electrical brain correlates of consciousness. However, I am still collaborating with the CIDDRG and closely following their amazing research! ¡Hasta luego!

Chiara
**Current Projects**

**Using Artificial Intelligence to Predict Dementia**
Dr. Stephanie Brown, Research Associate with the CIDDRG group, is investigating how we can use artificial intelligence to predict memory problems in DS and other dementia-related changes.

**Horizon 21**
Horizon 21 is a team of 10 research groups across Europe, including CIDDRG! We aim to prevent or delay Alzheimer’s disease (AD) in people with DS. CIDDRG’s main contribution is finding and validating AD threshold scores for CAMDEX-DS, a cognitive test for identifying dementia in people with DS.

**Eye Changes in DS**
Jess is continuing Maddie’s work on the eye study. She is particularly interested in looking at the retina at the back of the eye. We can do this with a special camera, like the ones at the opticians. We hope that this will help us learn more about how people’s eyes change as they get older. Jess is currently getting approvals to start this study and we will let you know how she gets on.
Recent Findings from the Group!

The team has recently published 2 papers about ‘regression’. What regression means is sudden loss of living skills, language and motor skills. It may be caused by a stressful life event or health issue. It affects between 1 in 10 and 1 in 20 people with Down syndrome. Regression mainly affects adolescents and young adults and is often confused with dementia. However, unlike dementia, about half of those who experience regression recover to some degree.

Acute Regression in Down Syndrome

The findings from this small study on NiAD participants suggest that regression increases the risk of Alzheimer’s disease. This may be important for helping people with Down syndrome and their caregivers plan for the future. But first we need to repeat the study with more participants, since 5 participants is too few to be certain that this is true for all people with Down syndrome and regression.

You can read the study here: https://doi.org/10.3390/brainsci11081109

A Systematic Review of Early Regression in Adolescents and Adults with DS

We looked at 13 different studies about unexplained regression (loss of skills) in young adults with Down syndrome. We found that the most common symptoms were poor sleep, language loss and changes in personality and behaviour. Regression was often linked with a change in living situation. Few people fully get their skills back and no treatment exists so we need to study regression more.

You can read the study here: https://doi.org/10.3390/brainsci11091197
Thank You & Happy Holidays!

Help this winter robin get some cheery colour!

Once again, a heartfelt thank you to everyone that helps with our studies. We absolutely love working with people with Down Syndrome and truly believe in the importance of the work we achieve together! Have a lovely holiday season and see you in the new year!