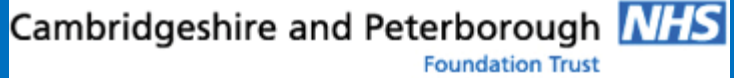


Defeating Dementia in Down's Syndrome (DiDS) Group Newsletter



About the Newsletter // Contact Us!

This newsletter is written by the Defeating Dementia in Down's Syndrome (DiDS) team, which is part of the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG). It is for people with Down's syndrome, their families and other caregivers who are interested in our projects, as well as anyone else!

We are looking for people with Down's syndrome (and their carers) to help us create our newsletters, so that you can tell us what you would like to hear about. 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 us at ciddrg@medschl.cam.ac.uk

IN THIS ISSUE

Editorial Letter	2
Your Stories	3-4
Updates	5
Current Projects	6
Spotlight	7
Recent Articles	8
Colouring Page	9

A Letter from the Research Leader

In this newsletter, we are very grateful to hear the stories from the participants who took part in the research. There are some very inspiring people out there!

We also hear from Dr Stephanie Brown who is leading research looking at sleep in people with Down's syndrome. Sleep is very important for brain health and it can go wrong as we age or if our learning or memory (cognition) starts to fail.

We list some of the publications we have been involved in. Please have a look at these and see how the research we are doing is slowly, but surely getting us closer to a better understanding of dementia and other health problems.

We are entering a very exciting time in our fight against the cognitive problems seen in adults with Down's syndrome. You may have heard on the news that a drug called Lecanemab has shown great promise in a clinical trial. It was able to remove the amyloid protein deposits from the brain and, to a lesser degree, improve cognition. Lecanemab will need to be approved for use in the clinic by the drug regulatory authorities before doctors can recommend it but it seems to be the best one so far. It is likely to be most useful in people with Down's syndrome who might be worried about changes in memory function during adulthood.

Thanks to all the participants. We know from the research done so far that amylo protein deposits in the brain are very likely to be an important cause of memory changes, and by targeting the deposits, we should be able to treat the condition.

In the year 2023 we are planning to start clinical trials that target amyloid deposits. So, we need your help to spread the news and ask for more volunteers to come forward. Please do get in touch if you or anyone you know are interested.

I wish you all a Merry Christmas and a Happy New Year!



Dr Shahid Zaman
DiDS Lead

Your Stories! Sibling duo Tom and Julia

I have been taking part in the research for the last 4 years.

I go to speak with Jess about what I have been doing and I have to do some games and puzzles with her which I really like.

When I go for the brain scans, first I have to take off my belt and put it in a locker and then the staff make sure I don't have any metal on me, . You can't have any metal near the scanner.



Next I go in a small room and sit in a big chair and I have an injection of special dye. It doesn't hurt! After that I have to wait quite a long time for the dye to go round my body, people talk to me while I am waiting so I don't get bored!

When I go into the scanner room I have to lie down on the bed and all the staff go into the room next door to watch through the glass, I have to lie still for a long time but the staff talk to me to make sure I am ok. It's a bit noisy, the scanner makes beeping and banging sounds but its not too bad, sometimes I fall asleep. My sister, Julia goes too but I am braver than her.

I enjoy going. I like telling Jess and the other staff about all the things I do with my family and at work.

- Tom

Your Stories! Julia

When I first heard that the research team was looking for siblings to join the research as 'controls' I jumped at the chance. My brother, Tom, had already signed up to take part in the study and I had already heard everything that had been explained to him regarding the research and I felt compelled to sign up!

I really enjoy doing the cognitive tests, it's amazing how such seemingly simple tasks can become so difficult when in a timed environment!

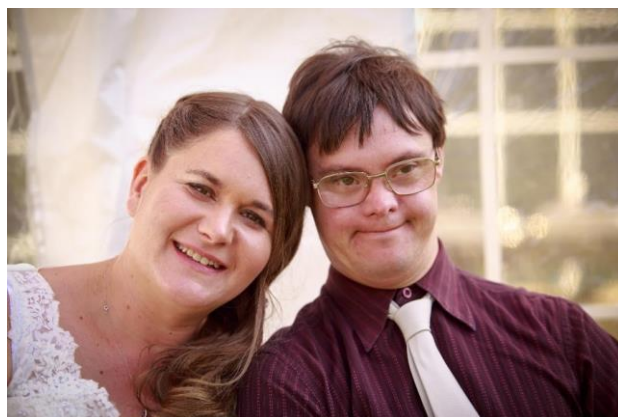
When I have attended the brain scans all of the staff at the Wolfson Brain Imaging Centre are fantastic. They take time to explain the procedure to you and let you know what to expect and there is ample opportunity to ask any questions. The most difficult part is lying still and not speaking for nearly an hour.

We are very fortunate in that we live near Cambridge and therefore attending the appointments is easy and my employer is extremely supportive of my commitment to the research and allows me time off to participate when needed.

Taking part in this research with Tom has given us a unique, shared, experience that not many other siblings have. When either of us has been to our appointments we always talk about how it went and what we did. Tom likes to tease me and say he is braver than me when we have been for the brain scans!

If anyone is considering getting involved as a sibling control, I would thoroughly recommend it and would be happy to chat through my experiences further.

- Julia



New Regression Study!

Welcome to Maddie

Hello everyone! My name is Maddie and I am the new clinical Research Assistant for the group. I am working on the Regression in people with Down's Syndrome and Horizon 21 studies. I'm looking forward to working with you all and hopefully meeting some of you in person. Outside of work, I enjoy walking my dog, yoga, and film nights.



More about the study

Many families over the years have contacted the Down's Syndrome Association (DSA) because a young person or young adult with Down's syndrome has had an episode during which they've lost skills and had changes in their behaviour. Such episodes are often referred to as 'regression'. The impact of 'regression' can be very serious but very little is known. Why does it happen? To how many people? How best can it be treated and/or managed?

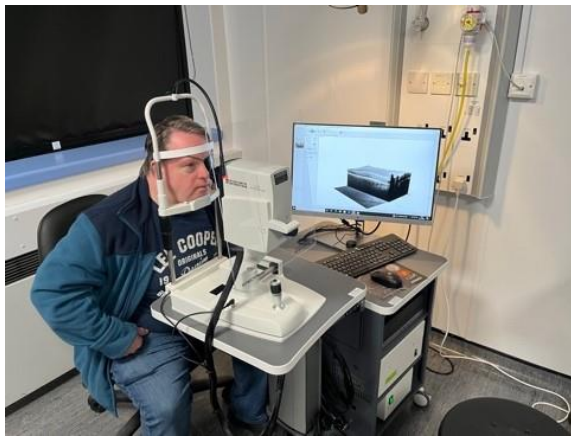
The DSA has funded us to try to find out more about 'regression'. Our study involves the person with Down's syndrome and someone who knows them very well (like a family member) as a Study Partner. We will use different methods including neuropsychological assessments, an analysis of blood, and, if the person with Down's syndrome consents, other investigations. We will also ask the Study Partner to complete some questionnaires about the person.

At the moment, the study is being set up. But when we've done that, we will be asking you to contact us if you know someone with Down's syndrome who had a period of suspected regression lasting at least two weeks when they were aged 11-35 years.

Current Projects – Imaging the retina in Down's Syndrome study

The follow up to our previous eye study is now underway.

We'd like to say a huge thank you to everyone who has taken part already and to the team at the Cambridge Clinical Vision Laboratory (CCVL) who have been helping us collect this data. Here's Richard showing you what it's like to have your eyes scanned!



We will be wrapping up the first section of this study in January 2023, but will look to extend it with some more measures soon. If you would like some more information about the study, please get in touch with Jess.

When Richard isn't helping with our research in Cambridge, he is part of the 'It's My Life' group based in Rushden. They have a new pantomime coming up in March 2023 called 'Dame Stitches in a Muddle' and Richard will be starring, along with his girlfriend Sarah, as Tweedle Dee and Tweedle Dum. His previous role as a pirate in last year's pantomime certainly helped with wearing the eye patch during the eye scans!



Spotlight – Dr Stephanie Brown

I have worked with the ABC-DS team as a Researcher for 3 years and have recently been awarded a Fellowship from Alzheimer's Research UK to continue the important research into why people with Down's syndrome might be more likely to develop Alzheimer's disease.



Specifically, I am interested in looking at how sleep might be involved in brain changes that could lead to dementia. Whether you have sleep problems or not, please do get in touch if you would like to get involved!

Recently I published an academic research paper that used artificial intelligence (AI) tools to see what they could tell us about how the brain ages in Down's syndrome. We saw that brain networks visualised from an MRI scan could predict the levels of amyloid in the brain, without the need for using PET-MR, which uses a radio tracer injection. Further, brain networks can also predict how good you are at doing puzzles and memory tests!

This Autumn, I have given some talks to both members of the public and scientific audiences. As part of the Alzheimer's Research UK Lab Notes series, I spoke about my current research, and how sleep quality may affect the development of dementia in Down's syndrome. I also presented my research at the Down's syndrome seminar series at University College London, and our lab shared our recent findings with a collaborating lab group lead by Professor John O'Brien.

Recent Publications

The information that we collect about you is used in Cambridge research papers, but also in papers led by researchers across the world (if you consent to this).

Exploring electrophysiological markers of auditory predictive processes and pathological ageing in adults with Down's syndrome

Chiara, who used to work in our group, recently looked at the differences in attention processes between individuals with Down's syndrome and typically developing controls. She found that people with Down's syndrome found it more difficult than the controls to stop themselves focussing their attention on unexpected noises that were not relevant to the task at hand. She also found that individuals with Down's syndrome might recover from distraction more slowly than their typically developing peers. If you took part in any of our electroencephalography (EEG studies) with April or Sally, your data was probably used in this paper!

Read the full paper here:

<https://doi.org/10.1111/ejn.15762>

Amyloid- β and tau deposition influences cognitive and functional decline in Down syndrome

Monika Grigorova, whom many of you may remember from the NiAD study, along with other members of CIDDRG published a paper in *Neurobiology of Aging*. Using data collected in the NiAD study, this paper shows how certain chemicals in the brain, namely amyloid- β and tau, work together to influence cognitive and functional decline in people with Down's syndrome as they get older. They found that tau is a very good predictor of cognitive and functional change, over and above the effect of amyloid- β . These findings are important when investigating what type of drugs might treat Alzheimer's disease in the future and will likely inform the design of future clinical trials.

Read the full paper here:

<https://doi.org/10.1016/j.neurobiolaging.2022.07.003>

Enjoy your Winter holidays!

Colour in
this very
happy
snowman!



Follow us
on Twitter!
[@CIDDRG](#)
[@abc_ds_](#)

Once again, a heartfelt thank you to everyone that helps with our studies. We absolutely love working with people with Down's syndrome and truly believe in the importance of the work we achieve together!

