

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

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A Letter from the Research Leader

So much has been happening in our group recently. We will sadly see Shemaya leave our group as she goes to her new job. She has been amazing, and I am sure those who may have met her would agree. We wish her the best of luck. We also want to congratulate Jess who has become a mother! We look forward to seeing her re-join the group later this year.

These changes will leave our group smaller than before, but we are in the process of recruiting more people to be part of the research group.

There are also exciting advances being made in treatments to slow down dementia. We are involved in a trial that may slow down or stop the build-up of the protein called amyloid in the brain. We think that by removing amyloid with a vaccine we can slow down the onset of dementia. If you are over 35 years old with Down's syndrome, then you may be eligible for being a part of this trial. Let us know if you are interested.



Dr Shahid Zaman
DiDS Lead

Your Stories! An and Sammy

It was on the 13th November 2022, still in quite a state of disbelief that it was actually real and happening, that Sammy and I travelled to the Sony Music studios in London having been invited take part in Tom Walker's music video for the song The Best is Yet to Come.



What a day it was. The adventure started shortly after I had posted a short reel of Sammy on Instagram using part of The Best is Yet to Come as the audio. When we got a message from Tom's team saying that the video had touched them and that they would love us to come and be part of the music video for the song it was a huge surprise. To be honest my first thoughts were that this was a scam but after a bit of checking and several emails it was confirmed that it was genuine and we were on our way. After an early start leaving home and driving to Cambridge to catch the train to London we arrived at the Sony Music studios where we were made to feel comfortable and very welcome and enjoyed eating plenty of pizza. Until we got there we hadn't known whether or not we would actually get to meet Tom Walker in person but it was the icing on the cake that we did. Not only is he talented but he is really lovely and genuine and we made him feel tall. It was an absolute pleasure to meet him. We also got to meet some really amazing people that day people with incredible stories of survival, perseverance, determination, strength and love.

It was a long day and a tiring day but we are so glad that we got to have such an amazing experience and the honour of being able to share part of our story and play a part in sharing the message of the importance of inclusion and acceptance. Different is okay!

Your Stories! Alison

I have a syndrome called Down's Syndrome and it makes me feel special and famous.

On Tuesday 25th April, I went to Addenbrookes Hospital in Cambridge, as I am taking part in a research program, this will help other people in the future. The research is to find out about Alzheimer's in people with Down's Syndrome. I call that work but I am a volunteer. On Tuesday I had tests on my knee and then on my head to look at my brain.



This is me having my lunch in between tests.

In the evening I went out for dinner, liver and bacon my favourite. I had pudding which was a chocolate and orange flavour ice-cream. I also had a pint of lager.

On Wednesday I had two PET scans. In my arm I had an injection of radioactive material. One scan in the morning and one scan in the afternoon. The scan was noisy and the injection hurt. For lunch I had a prawn mayonnaise sandwich and coke. I liked my goody bag. The drive home was long and I yawned a lot.

Your Stories! Alison continued...

Where I live, we have an art room and every Wednesday morning I go there and use my rug making skills to create the initials of my name. AJW. Alison Jane Wheatley. These will go on my wall when they are finished. I have already made some rugs which I use in my flat.

Here are some pictures of me making my rugs.



Hellos and Goodbyes!

Welcome to Zhiyuan

Hello everyone, my name is Zhiyuan and I am a PhD candidate in the CIDDRG. My research focuses on using Artificial Intelligence technique for early diagnosis and prognosis of Alzheimer's Disease in the Down's Syndrome population. I am looking forward to working with you all! Outside of work, I enjoy spending time with my cats, cooking, and playing basketball.



Goodbye from Jess (for now!)

As some of you already know I will be off on maternity leave soon but won't be gone for too long! I'm looking forward to the exciting few months ahead and will keep everyone updated on how baby is doing. Wishing everyone all the best with the studies over the summer. I will miss seeing everyone coming in for their study visits but look forward to catching up when I return!



Spotlight & Goodbye – Shemaya

Goodbye from Shemaya

My time on the ABC-DS study will sadly be coming to an end at the end of June. I have loved meeting so many of you and getting to complete the quizzes and puzzles with you – everyone's commitment to helping other people is inspiring. I am now going to work for a charity aiming to end homelessness for young people in London. I am hopeful that this new chapter will help me reach my goal of becoming a clinical psychologist. I will definitely miss all of our participants though!!!



ABC-DS Project Meeting

In April, Shahid and I (Shemaya) went to Washington DC for a meeting with staff members from all of the ABC-DS sites, including those in the USA. There were over sixty people at the meeting! We spoke about how many participants we already have taking part in the study (280 so far) and how we can get more people to take part, especially people who are not white. Different scientists also spoke to us about the research questions that they are answering using information collected from ABC-DS participants (= you!). As you can see above, I also got to spend some time in New York while in the USA.



Current Projects – High Resolution Brain Imaging and Sleep in Down's Syndrome

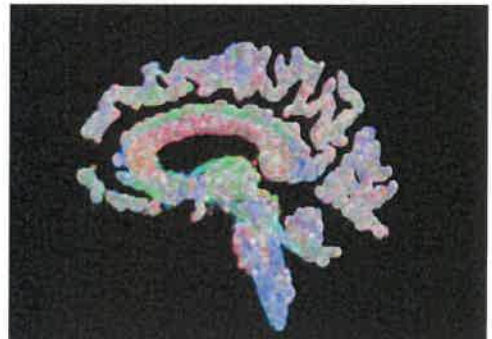
We're really excited to have begun our latest study run by our very own Dr Stephanie Brown exploring the role of sleep and dementia in people with Down's Syndrome.

The role of sleep in the development of dementia is beginning to be seen as an important risk factor for cognitive decline. But, processes by which poor sleep quality may contribute to dementia remain largely unexplored.

The aim of this research is to address the question of whether sleep patterns and sleep proteins in the brain are associated with a variety of brain changes in people with Down's Syndrome, and whether these changes are linked to memory problems.

For the study we'll be using 7 Tesla (7T) MRI scanners which have stronger magnets than other MRI scanners. This means the images of the brain that are taken are much more detailed and clear. With this enhanced type of brain imaging, the ability to identify subtle changes in the brain associated with early dementia onset and their links to sleep quality is significantly improved.

During the research participants will also be given a Fitbit, which they will wear for a period of one week to assess their sleep duration and patterns. A visit to a sleep clinic is also optional for this study. If you're interested in taking part please get in touch with Dr Stephanie Brown - sb2403@medschl.cam.ac.uk



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).

A modified Cued Recall Test for detecting prodromal AD in adults with Down's syndrome

Dr Isabel Clare along with our colleagues in America have published a paper looking at whether a memory test called 'The Modified Cued Recall Test' can be used to assess whether someone with Down's syndrome has dementia. Some of you may be familiar with this test if you have participated in the NiAD and/or ABC-DS studies. They found that the test can be useful in detecting dementia in people with Down's syndrome but that more research is needed to see whether the test can track changes over time. These findings are important as this test could be easily adapted for use in clinical practice and potentially be used as an assessment of drug efficacy in future clinical trials.

Read the full paper here:

<https://doi.org/10.1002/dad2.12361>

Cognitive outcome measures for tracking Alzheimer's disease in Down's syndrome

Shemaya and Isabel, alongside colleagues in the USA, discussed how cognition (or thinking) can be measured in Down's syndrome. Cognition includes how much someone can remember or how well they can stay focussed on one task. In ABC-DS, we measure thinking using our quizzes and puzzles. The results of these quizzes and puzzles are important as people's thinking changes as they develop dementia, and these quizzes and puzzles can track this. In this article, we talk about different quizzes and puzzles and how good they are at tracking dementia and some of the issues that can stop quizzes and puzzles telling us the information that we want to know.

Read the full article here:

<https://doi.org/10.1016/bs.irrdd.2022.05.006>

Enjoy your Summer!



Finally, a big thank you again to everyone that helps with our studies. We really love working with you and please do pass this newsletter on to any friends or family who might be interested! We always need more volunteers and supporters.

NHS 75

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