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 and to share your opinions on what you’d like to hear about. If you’d like to share a story or contact us for any other reason, please email us at ciddrg@medschl.cam.ac.uk.
A Letter from the Research Leader

We have been going through lots of change recently. We are delighted to have new staff on our team (see below). We are very grateful to Shemaya, Valerie, Maddie and Jess for their hard work, and unfortunately even though we probably won’t be seeing them again, the good news is that Jess will be back soon.

The best thing about being in my position is that I get to work and know wonderful people including the participants and their carers. We are so grateful for all your efforts—you are fabulous!

Progress is being made in our research and our findings will be helping to improve the wellbeing of people with Down syndrome. We are continuing with our important work in the ABC-DS and the TRC-DS consortia trying to work out how we can diagnose conditions earlier and so more accurately to progress to better treatment protocols. For example, we have found that there are blood tests likely to be useful in the clinic in the very near future.

However, we have a small problem, we need more people to take part in this research. Once we have more participants to give their valuable time we can get there quicker. If you are interested in joining us or know someone who might be then please do get in touch. We need volunteers.

Dr Shahid Zaman
DiDS Lead
Hello to three new team members!
Sarah, Ellie and Malwina join the team…

Hi everyone! I’m Sarah and I joined CIDDRG back in July 2023 after graduating with an MSc in Psychiatric Research from King’s College London. My current research is focused on investigating the development of Alzheimer’s disease in people with Down’s syndrome. I currently work on the Trial-Ready Cohort – Down Syndrome (TRC-DS) study, as well as the Horizon 21 study. When I am not on the job, I enjoy thought-provoking challenges and have a deep interest in true crime, as well as exploring my artistic endeavours and indulging my love for seeing new places!

Hi everyone! My name is Ellie and I’m really excited to be joining the DiDS team as a research assistant! I’ll be working on the ABC-DS study focusing on how more people from different communities can join our research, and telling people about the benefits of being part of research and keeping your brain healthy. Before this role, I worked with people with mental health problems and did research about neuromuscular disorders. Outside of work I love hiking, cooking, reading and going to the theatre! I also love watching football and support Newcastle United!
Hi, everyone! My name is Malwina and I joined CIDDRG as a Research Assistant in August 2023. I am coordinating ABC-DS study and look forward to seeing everyone coming in for their study visits. My previous research work focused on treatment for anxiety among autistic adults with intellectual disabilities and specific phobias among children with intellectual disabilities. In my spare time I enjoy music, particularly playing the piano, needlework and embroidery as well as spending time in nature, such as taking walks in the countryside and sailing. I have been also regularly volunteering at summer camps and other activities for children, which helped me pursue my passion for improving welfare of people in my community and making a positive change for others.

And a goodbye from Chris…

• It is sad to say that after over a lovely year of working for CIDDRG and supporting the ABC-DS project I shall be moving on to a new role with Cambridge University Press & Assessment. I’ve thoroughly enjoyed my time here and especially the people that I’ve gotten to know and work with. I’m very proud to have supported such important research!
Team News: What we’ve been up to..

- Our new starters have been doing lots of training and finding out about different studies they will be helping with. They have also moved to Cambridge which is a very pretty city where it is peaceful to watch the people in boats go by!

- Ellie, Sarah, Malwina and Shahid went to a conference in Cambridge to hear about all the different research which is being done in the city and in the rest of the country. We heard a lot about different studies which help us understand and treat dementia!

It was great to see how people participating in research leads to lots of people having better, healthier and happier lives.

- The ABATE study has started recruiting! This exciting study is looking into a new treatment not on the market yet, designed to reduce the level of a protein called Amyloid in the brain and slow the loss of memory. The study will test whether this vaccine slows down memory loss better than a placebo which does not have active ingredient. The study is open to people with Down’s syndrome who are aged 35-50 years old. If you would like to know more about this, you can email Maddy at: Madelaine.Smith9@cpft.nhs.uk
In August, Joni came over all the way from USA to Cambridge, to spend two days talking with our team. The ABC-DS study uses lots of different methods to look for processes inside the body which may help us to see whether someone has Alzheimer’s disease or if they might be more likely to have this problem in the future. This is a big project and there are lots of teams across the world all recruiting and testing participants at their sites. We are close to discovering breakthrough ways to be able to predict if someone with Down’s Syndrome will get dementia, which would mean we can offer treatment quicker which will be more effective. We are looking forward to welcoming participants to our lab again! It was great to share ideas with our wider team and learn more about ABC-DS!
WHY PARTICIPATE IN RESEARCH?

Without our amazing participants agreeing to take part in research, we would not be able to find treatments which help improve people’s lives!

There are lots of different reasons to want to be a part of research, and lots of different types of research. Here are some of our reasons!

To help other people who might get dementia get better care

Because participants might be able to get new treatments that aren’t available to everyone yet

To have a fun day out where travel, food and accommodation are paid for!

So that if anything is wrong it will be caught and treated earlier

To see your brain scan!

Contributing to research and the wider community has been shown to boost happiness and brain health

Because we don’t know if new treatments work for people with Down’s Syndrome without research

Can you think of any more reasons to participate in research? We’d love to hear them!
WHY PARTICIPATE IN RESEARCH?

Which studies could you participate in?

- **‘ABC-DS’ study = The Alzheimer’s Biomarkers Consortium – Down’s Syndrome:** This study uses methods like brain imaging and completing puzzles to look for biomarkers (processes inside the body which may help us to see whether someone has Alzheimer’s)

- **‘TRC-DS’ study = Trial-Ready Cohort – Down Syndrome:** This study is creating a group of people who will be monitored using lots of different methods so that they can be matched up with new clinical trials

- **High-Resolution Brain Imaging and Sleep in Down’s Syndrome study:** This study uses methods like brain imaging and a FitBit to look at the role of sleep in the development of dementia

- **Imaging the Retina in Down’s Syndrome study:** This study uses eye tests to look whether there might be changes in the eye related to the development of dementia

- **Horizon 21:** This study involves using various existing puzzles to better understand and improve the current assessment process catered to people with Down’s Syndrome

- **Regression in People with Down’s Syndrome:** This study is investigating why and how episodes of ‘regression’ happen

And finally, we would love to hear your thoughts, stories, and opinions!

To help us understand why people with Down’s Syndrome or their caregivers do or don’t participate in research, we would love to hear your thoughts and experiences. To contact us about this, participating in any of our research, or any other thoughts or stories you would like to tell, please either email us at ciddrg@medschl.cam.ac.uk or scan this QR code to register your interest!
Study Spotlight: Sleep & Brain Imaging in Down’s Syndrome

Invitation to take part in a study that looks at sleep and aging in people with Down syndrome

We would like to invite people with Down syndrome aged between 25-50 years old and healthy control volunteers to take part in a research study. We are interested in why some people with Down’s syndrome develop Alzheimer’s disease as they get older. We are investigating how Alzheimer’s disease is linked to sleep problems and brain changes in people with Down’s syndrome.

So far, we have had some really enthusiastic participants in the study! We would love to hear from you if you might be interested in taking part or learning more. If you’re interested in getting involved, please contact Dr. Stephanie Brown, email: sb2403@medschl.cam.ac.uk
Finally, a big thank you again to everyone that helps with our studies. We really love working with you and please do pass this on to any friends or family who might be interested! We always need more volunteers and supporters. Please get in touch if you would like to include anything in the next newsletter.