About the Newsletter // Contact Us!
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 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!
A Letter from the Research Leader

We all feel so joyous about coming out of the pandemic and being able to socialise more than we have been allowed to. One of the highlights of this has been our attendance at two important meetings in June 2022, which happened in the same week in sunny California. We presented some of our findings to other scientists and clinicians who are working in Down syndrome research. It was great to be able to mingle with others who are like-minded and interested in helping people with Down syndrome to improve their lives. It certainly beats being on Zoom calls!

We are encouraged that we have ethical permission to start on the main study (ABC-DS) that we are doing here in Cambridge. The doors are open to volunteers – we certainly do need many more. We are also looking forward to starting a project aimed at creating a group of volunteers who are interested in taking part in future clinical trials. It is our ultimate aim to find treatments, so this is a huge step forward.

Finally, it is so good to hear that the Down Syndrome Act has been enacted, as this will make it easier to support people with Down syndrome – power to democracy! Hope you enjoy the rest of this year without the pandemic.

Dr Shahid Zaman
DiDS Lead
Hello! My name is Jo Barker. This is my story of my 100 laps sponsored charity walk. I was inspired by many things and many talents of my life. This is a new and recent venture, during lockdown. I wanted to raise money for charity by walking 100 laps up and down my road, at Ridgway, which is a quarter of a mile up and down. I was inspired by Sir Captain Tom Moore and he is one of my favourite heroes of all time. He is a hero I truly miss.

Let me take you from where it all started. During the pandemic broke out, I decided to take on a challenge by walking 100 laps (1 lap is up the road and back, a quarter of a mile), and the main challenge was to complete 100 laps in one month, November 2020.

It was been 15 years since I was sponsoring many charities, but this was the biggest challenge I’ve ever done. I truly love it even more. Every day, I took a walk with my mother Judy, then we took walking sticks with us and started walking. We walked a half an hour every lunchtime, after I had finished work, and then had lunch together. That didn’t take long since I was typing my own Autobiography book as well. We managed to do at least 4 laps (1 mile) every day, sometimes 6 or even 8 laps. My brother Matthew helped by setting up a Facebook for anyone or anybody, friends and neighbours so they can sponsor any money they wished to raise for me, while they still can. Thank you.

Our neighbours, friends and carers and Kate sponsored me with money, which we are very appreciated. I was, and now sponsoring the charity called Cancer Research UK for many cancers around the world that everyone had over the years. The cancers like this, is hard to live with at the moment. I had aimed to raise the money over £1,000 pounds originally, but raised over £1,547 pounds in total. So I finally reached my target and aim. In fact, I walked 112 laps! After dinnertime together, I did my final lap. When the neighbours and friends came by, seeing me finishing off my final walk, they clapped and cheered me on. I am proud of what I have done.

What a night it was. I am so glad I did this charity walk, because, it meant so much to me. I love being involved in many charities, this is a charity I wanted to raise for, just partly on my own. You’re the inspirational people I ever known, and thank you. Thank you for hearing my story of 100 laps sponsored walk. I love my sponsors like myself and still making a difference. You are the best friends I owe so much in my life.

Your best friend and Yours Truly Joanne Barker.
Your Stories!

John’s research experience

My name is John Barnabas Fletcher. I will be 40 in December. I live with my parents and my dear dog ‘Georgie Girl’. I dance a lot on videos and in March I went with Project 21 to dance in Trafalgar Square. That was great.

Before the Research started I went to my sister’s house to have a zoom meeting with Jessica all about what’s going to happen if Down’s Syndrome people get older with Dementia. I don’t really have it but here’s the story I had with Dad.

My first session we went to Fulbourn in the morning and we met Shemaya and Jessica and Dr. Shahid. I had a medical check-up and then had quizzes with Shemaya and that was fun. Dad was in a different room with Jessica to talk with Jessica about me in recent life.

We took our lunch out on the bench outside. Then in the afternoon we went to Addenbrookes Wolfson Brain Imaging Centre. We parked the car in an enormous car park and walked to the Centre. It was very hot and sunny day. We met Shemaya and walked in and booked and signed in. The nurse asked me to take off my belt and watch and fit-bit and weighed me. First, we had to take the blood samples. I felt that I wouldn’t but it’s only for the research project, so I had to. Then Dad played some puzzle games with me while we waited for the next bit of research. The brain scan is like sliding lying down through the tunnel with the music you can choose. I listened to Alfie Boe but I had to be very still for forty minutes to check my brain scan and the machine was very very noisy and I can’t hear the music I chose.

Next day we went to the hospital to do another blood draw and another forty minutes brain scan and I asked the nurse to give me to photo of my brain scan and now you can see it.
Recently I was asked to star in a short video called ‘A day in the life of a participant’ I really enjoyed doing the film and had to act out all of the parts of the research like the puzzles and the scans. It was a good, fun day!

You can watch the video on youtube (https://youtu.be/HlAGMIs11Co ) and on the Cambridge Intellectual and Developmental Disabilities (CIDDRG) website, on the “Want to take part in our research?” page of our research section. Feel free to show it to your friends, especially those who might be interested in doing our research!
Chris

Hi everyone, my name’s Chris and I’m the new Administrator for the Group. I’m looking forward to meeting you all and supporting you in whatever way I can. Outside of work I’m an ordained Buddhist and voluntarily do some teaching at the Cambridge Buddhist Centre. I also enjoy film, reading and recently started learning German.

Updates

Hello! Some you may remember me from a few years back when I worked on the NiAD study as a research assistant and had the pleasure of meeting so many of you and your families. I can’t believe that 4 years has passed since then, but I have now successively graduated from University of Cambridge after finishing my Medicine degree which means I am officially a doctor! I am sure that my experience in NiAD helped me secure a place on the course and I so grateful to all of you - working with all of you inspired me further to work in Medicine. I am also seriously considering working in Psychiatry which has been influenced by observing the clinical work of wonderful team in Douglas House. I will be starting officially in August in London and I am excited about the next adventure - maybe I’ll even see some of you again along the journey!
Current Projects – ABC-DS

Many of you have taken part in our NiAD study and know that we worked with researchers in the USA on this project. We have recently started working with even more people in the USA and have created the Alzheimer’s Biomarkers Consortium – Down Syndrome (ABC-DS). Eight universities work together in this research group.

This research group has recently started a new study called ABC-DS, which will follow on from our NiAD study. The tasks in ABC-DS are very similar to those in NiAD, including brain scans, quizzes and puzzles, and blood draws. We look forward to welcoming people who have already taken part in NiAD and our other previous studies to be a part of this research.

We are also looking for new participants, so if you have any friends with Down syndrome who you think would be interested in getting involved, tell them to get in touch with us!

Later on this year, we might also be looking for participants who may be interested in taking part in clinical trials in the future. Additionally, we are developing a study looking at regression, which is a condition that can co-occur with Down syndrome that we talked about in our last newsletter. If these studies sound interesting to you, get in contact with us for more information.
DiDS trip to California

Some members of our team recently went to a meeting in Long beach, California, where people from all of the different universities involved in ABC-DS came together to discuss the project.

While we were there, we also went to the Trisomy 21 Research Society international conference, where researchers from all over the world came together to discuss and hear about all of the latest research into Down syndrome.

There were researchers there working on Alzheimer’s disease, sleep apnoea, and congenital heart conditions, as people with Down syndrome are more likely to have these conditions than other people.

There were researchers there who use human participants with Down syndrome in their work, but there were also researchers there who try to learn more about Down syndrome using animals such as mice, rats, fish, and even fruit flies (!), which they alter so that they have three copies of many of the same genes as people with Down syndrome.
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).

**Impact of the COVID-19 pandemic on daily life, mood, and behavior of adults with Down syndrome**

Using Cambridge NiAD data, this research, led by researchers at a university in the USA, found that the COVID-19 pandemic had widespread effects on adults with Down syndrome. The changes these individuals faced included changes in where they lived and in their employment, with 89% who had been employed stopping working during the pandemic. Some people became more irritable, anxious, and unhappy compared to before the pandemic.

Read the full paper here: https://www.sciencedirect.com/science/article/pii/S1936657422000115?via%3Dihub

**Markers of early changes in cognition across cohorts of adults with Down syndrome at risk of Alzheimer’s disease**

Using Cambridge Horizon 21 data, this analysis, led by researchers at King's College London, looked at which quizzes and puzzles are best able to detect early thinking problems related to Alzheimer’s disease. They found that tests looking at memory, language, attention, orientation, movement planning, and awareness of time and place were most helpful in predicting these early problems.

Read the full paper here: https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/dad.212184
We hope that you have a lovely summer!

Colour in these palm trees to create a sunny Californian beach!

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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!