

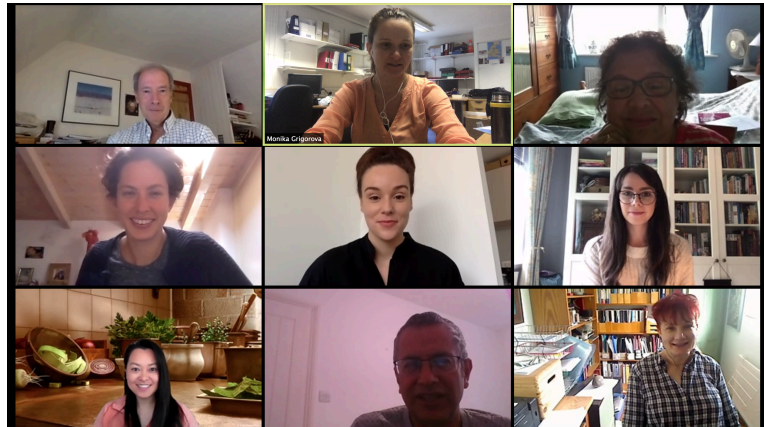


UNIVERSITY OF
CAMBRIDGE

Defeat Dementia in Down Syndrome Research Group

Making progress during difficult times.

This newsletter comes when we have all been living a life that we could never have anticipated. We have been restricted to our homes, limited in who we see and where we see them, and we have not been able to go to work or to take part in our usual activities. COVID has dominated our lives.



However, this has also been a time when our research group has been able to focus on all the data we have collected over the years with all of your help. Bringing together the findings from the many assessments, analysing the different brain scans, the EEGs, the eye scanning data and the blood findings and then integrating these findings to understand how they are all inter-related, is a massive task. Over this period we have, in collaboration with European partners, also refined the diagnostic assessments - the CAMDEX-DS and the CAMCOG - to make them more suited for the 2020s and beyond. This newsletter helps bring you up-to-date with some of these developments.

This newsletter also brings to you the announcement that the University of Cambridge has secured its place in the continuation of this massive research effort for another five years, once again funded by the USA National Institutes of Health. I would like to thank you all for your continued commitment, which has made this possible, and also thank Dr Shahid Zaman for his knowledge and leadership that has enabled us to be part of this major endeavour, and for the commitment of everyone who is part of this programme.

As discussed in the newsletter, clinical trials are part of what is planned for the future. These trials will be testing medications that may delay or prevent the development of Alzheimer's disease in people with Down syndrome. We will be asking for help with these trials and I hope we have the opportunity to talk to many of you and your families about these developments.



Finally I would like to say a personal thank you to Liz Jones. You will see that Liz has retired. She and I worked together in the local clinical service for many years. She has been critical to the work of the research group bringing her knowledge and wisdom to help us recruit to the various projects. We all wish her the best in her retirement but I am sure we will call on her for guidance from time to time. All of us also wish you the best during this time of continuing uncertainty - please keep safe and thank you for your help.

Professor Tony Holland

The National Institutes of Health Award New Grant for Research into Ageing in Down Syndrome

The news we all have been waiting to hear – the NIH, the main funding body of the NiAD project, has officially extended its funding for the study of ageing in Down syndrome for 5 more years!



This means that the NiAD study will be changing – to start with, we will have a new name – ABC-DS (Alzheimer's Biomarkers Consortium of Down Syndrome). The Universities of Cambridge, Wisconsin, Pittsburgh and Washington-St Louis will now be joined by 4 new research sites to form an even larger consortium! The new sites include Columbia University, Harvard University, University of California, Irvine, and the New York State Institute for Basic Research in Developmental Disabilities. There will also be some small changes to the quizzes, puzzles and questionnaires we ask our participants and their families and carers to complete. We are sure you are excited to learn more about this new endeavor and we will keep you updated!

From Research to Treatment

The ultimate aim of all the scans, blood draws, quizzes, puzzles and the many questions we have asked our participants and their families throughout these years, has been to understand the process of ageing and inform treatments for dementia in Down syndrome. We can now say that we are a step closer to this goal. Our research group has joined the TRC-DS project which will recruit a trial ready cohort of participants with the aim of preparing them for a future clinical trial for Alzheimer's disease in Down syndrome.

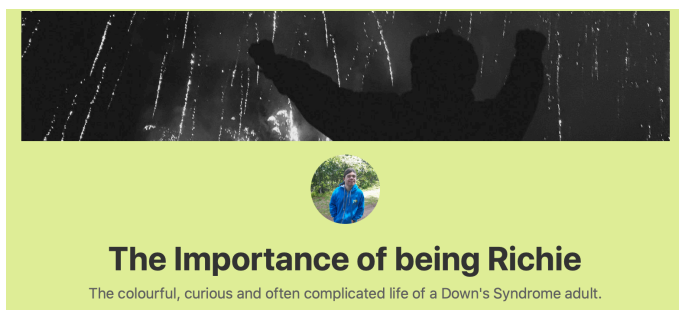
We are also in the process of starting a clinical trial with the pharmaceutical company Syneos Health. This clinical trial will investigate an intervention for the prevention or delay of dementia in Down syndrome.



“The Importance of Being Richie” – Living Through Lockdown One Blog Post at a Time

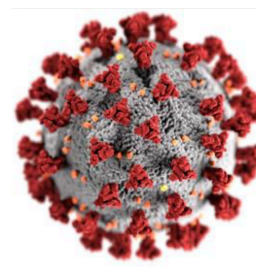
Richard and his sister Fiona are both participants in the NiAD study. During one of their visits to Cambridge a great idea was born! About a year later, the slowing down of life during the COVID-19 lockdown meant that Fiona was able to make it reality: she created a blog which gives its readers a glimpse into the weekly life and adventures of a person with Down syndrome. Richard and Fiona have managed to keep quite busy during lockdown, from attending Zoom bingo to planting sunflowers and designing a Darth Vader mask! You can learn all about it on their blog. Their mother also contributes with notes from Richard’s early years when he was born in Ireland in the 70s. It is an exciting project and we wish them to keep up the good work!

To browse the blog, use the following link: <https://richiemm.wordpress.com> . Enjoy!



COVID-19 – We Want to Hear Your Story

For many of us the last few months have required life changes, created new worries, and required learning new daily habits or ways to work and socialize. We want to hear the COVID-19 story of all our participants. Together with our colleagues from the US sites of NiAD we have put together a questionnaire which we will soon be sending out via email or post to all our participants and their families.



This survey will allow us to see the real impact of the last few months’ events and restrictions on people with Down syndrome and link what we learn from it to our NiAD dataset. In the long term this survey would give us valuable insight into the effects of such daily life changes on people’s health and wellbeing.

Welcoming You Back Safely – 'In-Person Visits'

We are thrilled to announce that after a long few months our facilities are beginning to reopen and we are inviting people to Cambridge for their study visits. To ensure the safety of all our participants and their families and/or carers, we will be increasing our safety measures so things may look and feel a little different to previous visits.

If you decide to visit Cambridge, here a few things to keep in mind:

Socially Distanced Visits

We've made some alterations to the layout of our facilities, introducing one-way systems and removing waiting areas to help our research staff and participants stay socially distanced. Where possible, lunch breaks will be taken outside (weather permitting of course!) or in areas with good ventilation.



Face Coverings & Hand Sanitising

In line with Government guidance, masks will need to be worn by research staff and participants, unless you have a good reason not to, and there will be regular sanitation of hands. All masks and hand sanitisers will be provided by us so you don't need to worry about bringing your own.



Cleaning & Safety Measures

As you'd expect, we'll be carrying out extra cleaning and sanitising to keep all our facilities and study materials as safe as possible.



Welcoming You Back Safely – 'Virtual Visits'

If you decide you'd rather hold off on a visit to Cambridge at the moment, this is not a problem! You will still be enrolled in the study, and we will plan an 'in-person visit' for whenever you feel comfortable.



In the meantime, we will arrange a 'virtual visit' if possible. This will involve parents and/or carers of participants completing questionnaires via video call or telephone. This way we can continue to collect data from participants who are unable to visit Cambridge.



Whichever option you choose, either an 'in-person' or 'virtual' visit, we are excited to have you back and look forward to catching up with everyone's lockdown stories!

Call for participants!

I'm Jodie Rawles, a PhD student working alongside the NiAD team at the Department of Psychiatry. I'm investigating how people with learning disabilities are supported to make decisions about contraception. If you are a family member or support worker for someone with Down Syndrome or another learning disability and are based in England or Wales, I would like to invite you to take part in an anonymous online survey. The survey takes between 15 and 45 minutes to complete.



If you would like to take part or find out more about the survey, please enter this link into your internet browser:

https://cambridge.eu.qualtrics.com/jfe/form/SV_6MAD0F13Lqy2xut

Or you can email me at contraceptivedecisionsstudy@gmail.com

A New Publication!



Clinical and biomarker changes of Alzheimer's disease in adults with Down syndrome: a cross-sectional study

A new study has been published in The Lancet in collaboration with neurologist Dr Juan Fortea and his team at the Sant Pau Memory Unit in Barcelona. The study reports that cognitive and biochemical changes in Alzheimer's disease are seen over 20 years before the onset of clinical symptoms in people with Down syndrome. In this period that precedes symptoms, brain imaging biomarkers change following a predictable sequence. These findings are essential for preventing or moderating the progression of Alzheimer's disease in people with Down syndrome and will likely inform the design of future clinical trials.

A link to the study can be found here: [https://doi.org/10.1016/S0140-6736\(20\)30689-9](https://doi.org/10.1016/S0140-6736(20)30689-9)

A Very Fond Farewell and Retirement Well-Wishes for Liz!

What a joy and a privilege it's been ending my career as a Learning Disabilities Nurse as part of the Cambridge Down Syndrome Research Group. A highlight for me has been travelling around the country to recruit participants meeting fabulous people with DS and their lovely families and carers. Getting to know their life stories and following progress when meeting up again during Cambridge visits. Also working with so many academic colleagues along the way, making lifelong friendships across the world.



Retirement plans for the end of March 2020 came undone when I broke my ankle falling down some stairs, (I hasten to add, no alcohol involved!) in early January. Followed by lockdown my retirement so far has been uneventful. I continue to keep in touch with the research team as a 'volunteer' and still have access to my work email ej268@medschl.cam.ac.uk

It is now September and I'm mobile again and just about to buy a small motorhome, so watch out! You may be seeing me again if I'm in your neck of the woods!