Stepping back and reflecting

In these newsletters we do our best to bring you up to date with what is happening with our research. They are also for us an important moment to reflect on the problems we may have had and the successes. You will see from the individual reports that we continue with the National Institute of Health (NiAD) study and also with the Alzheimer’s Research-UK funded research. These two projects overlap and this has made it possible to use some of the financial resources to focus on very detailed analysis of the data and using the most cutting edge approaches. Elijah Mak also working with Professor John O’Brien, Professor of Old Age Psychiatry, has been able to further explore the relationship between the ‘amyloid’ and ‘tau’ changes in the brain (hallmarks of Alzheimer’s disease) and loss of brain tissue.

Monika, Liz and Jess have continued with the next NiAD follow-up visit. Jess is working with Shahid as part of the European Network to improve the CAMDEX and CAMCOG assessments for dementia that we first prepared many years ago but are now rather out of date.

Stephanie has accepted a Research Associate post with us to take over the work of Elijah. She brings with her very significant expertise in neuroimaging analysis and we are grateful to AR-UK allowing us to extend the grant that they awarded us. Maddie has submitted her first paper on the eyes studies that she undertook for her PhD. She is now extending this work and also working on a review on the decline that is sometimes observed in people with DS early in adult life. This work has been funded by the Down’s Syndrome Association. They receive many queries about this and it is hoped that we can start a research project to investigate this problem using rather similar techniques as we have done for studying Alzheimer’s disease.

Thank you to our participants for their continued support and to their families and many others who have helped. As our knowledge advances hopefully we will have answers and ultimately new treatments.

Professor Tony Holland
Study updates

Twenty-four NiAD participants have already completed their second visit to Cambridge. Thank you to all of you who took the time to travel and once again completed all the quizzes, puzzles and questionnaires with Monika and Liz! For those who have not heard from us yet - we will email you or call you closer to the time when your second visit is due. We look forward to seeing each one of you again.

It is exciting that some of our participants have decided to take part in the optional Lumbar Puncture procedure. This additional test allows scientists to find out more about the kind of substances that are present in the brain as people get older or develop dementia.

New things are developing both in Cambridge and in the USA - all the NiAD study sites are working together on an application to extend the study, which will hopefully recruit even more participants and will last until 2026! We are also looking into the future possibility of clinical trials and will be looking for people to take part in them too.

Here in Cambridge, Ruma and Elijah have been working hard analysing all the blood samples and brain scans that we have obtained from all our participants. In June Ruma presented her findings at the Trisomy 21 Research Society Conference in Barcelona. Elijah presented the NiAD data at the Alzheimer’s Association International Conference in Los Angeles in July. In this study, we found a strong relationship between the levels of amyloid and severity of tau deposition in people with Down’s syndrome. These findings are consistent with the prevailing consensus in Alzheimer’s disease, and suggest that anti-amyloid therapies may have therapeutic potential in Down’s syndrome. We are now in the process of submitting the manuscript. You can see a list of recent published papers at the back of the newsletter.

Maddie is over half way through her current project, using new imaging machines to look at the eye and to look for the amyloid protein in the retina. She still needs some more participants with Down’s syndrome, and also control participants – especially those in their 40s! This is a one-off research study which takes 1 to 2 hours at Addenbrooke’s Hospital. There are a few exclusion criteria including; diabetes, cataracts and eye surgery, please get in touch with Maddie on mjw208@cam.ac.uk if you are interested and she can go through these with you and what’s involved if you would like to take part. Thanks to everyone who has taken part so far.

Welcome Jess!

We would like to give a warm welcome to Jess who joined the NiAD project this April. Jess studied a BSc in Sociology and a MSc in Psychology at Kingston University. She joined the CIDDRG in November 2017 working on Prader-Willi syndrome (PWS), more specifically assessing the use of vagus nerve stimulation as treatment. Now working for NiAD, Jess will help us with all aspects of the project and you will meet her on your next visit to Cambridge!
On their last visit to Cambridge Annie brought along a delicious selection of cakes and biscuits she had made to celebrate World Down’s Syndrome Day and to raise funds for the Down’s Syndrome Association. The individual packages sported statements challenging some common misconceptions about people with Down’s syndrome.

Sammy’s Mum has developed her business ‘Annie’s Kitchen’ because she was inspired by her daughter Sammy’s food intolerances to gluten and dairy. Having enjoyed experimenting and perfecting baking cakes and biscuits for Sammy, Annie decided to take it a step further and has made a successful small business from home.

Take part in a new study!

April Le is a PhD student in our group and she is interested to understand how the electrical activity of the brain of people with Down’s syndrome changes as they get older. When we think the brain cells need to “talk” to one another, they do this by sending electrical signals to their many neighbours. The EEG (electroencephalography) machine is able to measure the electrical activity and we can now do this in our renovated testing room using new equipment for testing (see the special cap April is wearing!).

April is looking for research participants to help us with this study. We will ask participants to wear a special cap that records brain activity while listening to sounds from a computer and watching a movie; we will also ask accompanying carers or family members some questions about your memory. This study involves a 2 to 3 hour visit to Addenbrooke’s Hospital. If you are interested in this study and are over 20 years of age, please contact April on al804@cam.ac.uk so she can tell you more about this study. If you have participated in a similar study with our group in the past, please do consider coming back again since the data will be just as informative!
Thank you and keep us updated!

Thank you again to everyone that takes part in our studies. We love working with people with Down’s syndrome and truly believe in the importance of the work we achieve together. Thank you also to our collaborators and partner organisations. If you would like more information on anything in this newsletter or to be added to our mailing list please contact our administrator.

Also do let us know if you have changed address or would like to be removed from our list. If you are unwell and prefer not to be contacted about our research at the moment please also let us know.

Contact us by phone: 01223 465 216
email: dh-admin@medschl.cam.ac.uk post: Department of Psychiatry, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH.

A fond farewell to Agnes!

Our lovely Agnes is leaving the department after almost 3 years with us. She has been our star administrator helping book many of you into your hotels and organising flights, train tickets and all the arrangements for your Cambridge visits. She will really miss working with all our amazing participants and their families. We know that the participants and researchers will really miss her too but wish her good luck in her new endeavours. Thank you for everything!

New publications


Thank you and keep us updated!