Another year has nearly passed and with each year we learn more but there is always this feeling that there is so much more still to discover. As our scientific papers and those from other research groups are published so our understanding develops. It seems clear from the brain scanning studies that the two proteins, amyloid and tau, are important in understanding the pathways in the brain that lead to changes in the brain and eventually to the clinical symptoms of dementia due to Alzheimer’s disease. But it isn’t as simple as that. The work of Ruma Raha-Chowdhury suggests that changes in the interface between the nervous system and the rest of the body – the blood brain barrier and the choroid plexus – may also be crucial, as might the inflammatory response in the brain that is part of this disease process.

These various observations from clinical and basic science research identify ‘targets’ for intervention. For example, they raise the questions as to whether or not lowering amyloid, stopping the changes in tau, or modifying the inflammatory changes in the brain would delay or prevent the onset of Alzheimer’s disease? It will only be trials of different agents that will definitively answer such questions, and we are getting closer to such trials. With the onset of trials, that methods for investigating brain changes with age become crucial (the work of April Le using EEG), as do studies of possible markers of Alzheimer’s disease outside of the brain, such as in the retina as studied by Maddie Walpert.

As time passes of course those doing the research come and go and we will shortly say goodbye to Maddie – she has become one of the world experts on the retina in people with Down’s syndrome and Alzheimer’s disease and we are seeing her work now being published, and like all research this will add to the rapidly expanding body of knowledge on the link between Down’s syndrome and Alzheimer’s disease. Maddie is taking up a post with one of our key funders – Alzheimer’s Research-UK and we wish her the best.

As Maddie leaves so others join and we are delighted to have Stephanie Brown who will continue the neuroimaging analysis so ably undertaken until recently by Elijah Mak. Also Chiara Avancini, who has recently been awarded a PhD, will be helping with the EEG studies that April Le is doing and also reanalysing some earlier EEG data collected by Sally Jennings. Welcome to both. As always I wish to emphasise our gratitude to all of you who have helped us and continue to help us by volunteering to be part of the research or by supporting someone with Down’s syndrome to take part. Thank you and best wishes for 2020.

Professor Tony Holland
**NiAD Update**

41 out of our 55 NiAD participants have now been back to Cambridge to complete their Visit 2 and the remaining participants will be invited back very soon! The follow-up has been a big success and we are grateful to all our participants and their families for all their efforts.

We have also recently reached our recruitment goal for the study with Olivia who completed her Visit 1 last month and you can see photos of her in the Clinical Research Facility (CRF) having her blood pressure taken and in the Wolfson Brain Imaging Centre (WBIC) where she is about to have her PET scan. Looking ahead, Visit 3 is scheduled to start in February 2020 and it will be the same as Visit 1 – participants will have two scans, quizzes and puzzles and a blood draw. Our participants should expect us to be in touch soon with more information on when they can come back!

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**Lumbar Punctures**

We are pleased to share that we have completed four lumbar punctures as part of the NiAD study to date. Thank you to everyone who has taken part so far! Dr. Dhruv Panchal and Dr. Zanna Voysey are our two lovely doctors who are helping with these procedures.

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**Participants thoughts and experiences of having the Lumbar Puncture**

John says “I did it for all my mates, any age” and that the procedure “was very easy and quick, won’t feel a thing” and the “the service is very friendly”.

Amy felt a little nervous before her lumbar puncture but was sure she wanted to go ahead. She thought that she had been given enough information and had a fairly good idea of what to expect. Afterwards, Amy didn’t have any headache but her back was a little sore, but by the next day it was better. Amy says she would do the lumbar puncture again for the sake of research and her Mum would support her decision.

**Find out more about what Amy has been up to on the next page…**
Amy has been performing with her drama group, ‘Bedazzled Inclusive Theatre’ at the Edinburgh Fringe Festival. They performed every night for a week debuting their play, “I’m a Non-Typical, Typical” which received excellent reviews. She learned lots of words in preparation for her performance. The cast stayed in a big house just outside of Edinburgh which was great fun and Amy says the whole experience was pretty amazing!

Isabel and Shahid’s trip across the Pond

Isabel and Shahid attended a large meeting in the USA for all the groups who are involved in the Down’s syndrome and dementia project (https://niad-project.org/). The meeting was held at the National Institutes of Health in Bethesda, close to Washington DC. We discussed the progress that the groups in the consortium have made so far. These were impressive and we expect publications to be submitted this year.

The group also discussed plans for more funding for a further five years to allow us continue and to expand our research so that more people with Down’s syndrome can get involved. We have applied to the National Institutes of Health again. If our application is successful, it will be very exciting, as it will improve our understanding of memory problems and their treatment, as people get older.

We have also been funded for two years, as part of another USA-led consortium, to help kick start clinical trials to treat memory problems by targeting brain amyloid using medications. We are still discussing what would be the best treatment to trial, but we will be looking for volunteers in the not too distant future.

Maddie’s Eye Study and a Fond Farewell

I am happy to announce that the last project looking at the eyes and the retina has finished recruitment and testing! Thank you to everyone who came to Addenbrooke’s and took part. The next stage of this work is to analyse the data which we will be doing with our collaborators both in Belfast and California.

We have also been able to publish the results of our first retinal study, which took place here in Cambridge and also in London. The results of this have been published in the journal Alzheimer’s and Dementia: Diagnosis, Assessment and Monitoring, if you would like to receive a digital copy of the paper please email us.

I have really enjoyed working in this area of research for the last seven years and I have been very lucky to do my PhD and post-graduate work in such an interesting topic and to meet such amazing people. I will be leaving this role at Christmas and starting my new job with Alzheimer’s Research UK in the New Year. I am very sad to be leaving, it has been such a great experience but I am also looking forward to new opportunities and challenges.
Welcome Stephanie & Chiara!

I did both my undergraduate studies in Biomedical Sciences (Hons. Physiology) and Ph.D. in Psychiatry at the University of Edinburgh. I then began my postdoctoral experience at the Icahn School of Medicine at Mount Sinai, New York. My specialization is neuroimaging in both psychiatric and neurodevelopmentally affected populations.

I also undertook a visiting scholarship with Massachusetts General Hospital and Harvard Medical school to train in PET imaging analysis. I am looking forward to starting a new avenue of my research in Down's Syndrome and Alzheimer's Disease at University of Cambridge with the DS group.

Dr Chiara Avancini

I have recently completed my PhD at the University of Cambridge. I have an interest in using electrophysiology to study dynamics of cognition. During my PhD, I looked at the effects of anxiety on working memory and attention with a focus on how that impact maths processing.

After completing my PhD, I was a research associate at the Cambridge Consciousness and Cognition Lab working on a project investigating dynamics of brain plasticity during sleep. I will now be working with Professor Tony Holland and Dr Shahid Zaman using electroencephalography to identify early markers of Alzheimer in Down syndrome participants and early markers of psychosis in Prader-Willi syndrome participants.

Dr Stephanie Brown

A call for participants

Our PhD student, April Le, is looking for participants for her EEG (electroencephalography) study. It involves a 2-3 hour visit to Addenbrooke’s Hospital and wearing a special cap that records brain activity. If you are interested and are over 20 years of age, please contact April on 01223 365201 or email her at AL804@medschl.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:
phone: 01223 465 216,
email: dh-admin@medschl.cam.ac.uk,
post: Department of Psychiatry, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH.

Christmas Word Search

Thank you and keep us updated!

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