The story continues….

We have tried in these newsletters to give you a flavour of how research develops and progresses over time. Our early research was all about how age affects people with Down’s syndrome including developing better ways for recognising and diagnosing dementia, using the CAMDEX-DS informant interview and the CAMCOG psychological assessment. This work then led to the neuroimaging and many other studies. In the UK the LonDown research consortium also has an active programme of research and together with the work we do, the UK can be proud of its commitment to researching the link between Down’s syndrome and Alzheimer’s disease.

There are also Centres in continental Europe that are engaged in similar research and Shahid Zaman, the lead investigator for our group, has been key to establishing a Europe wide Down’s syndrome research group with support from the Jerome Lejeune Foundation. There are very important funding opportunities from the EU and we here in the UK have to wait to see whether we can still be part of this when Brexit happens. Working together across Europe is so important as it ensures that we have the best expertise and we can work together when larger studies are required.

At a recent meeting convened by Shahid and held here in Cambridge, representatives from several European countries came to discuss their research, to work on up-dating the CAMDEX and CAMCOG, and on paving the way for a clinical trial. A representative from a pharmaceutical company was present and able to help the group plan for such a trial. In preparation for this we have obtained further funding for Liz Jones so that she can start a period of consultation with many of you about this.

As you will also read in this newsletter Maddie Walpert continues to study the eye now using some more advanced technology. Ruma has submitted a further paper that partially challenges our ideas about how amyloid gets into the brain and ultimately gets deposited as plaques. As mentioned before research is an iterative process with steps forward and sometimes the odd one back!

Thank you all again for taking part and for being such wonderful partners in this on-going endeavour.

Professor Tony Holland
Study updates

The AR-UK study will soon come to an end. This study has focussed on following-up a number of participants who took part in the earlier MRC study asking each of you to have a further PET and MRI scan and to repeat those tests yet again! This study has been run in partnership with the NiAD study (see below) and we have been able to share data across the studies. Elijah and Conchy have spent time developing the best techniques for analysing the complex data that was collected over two time points.

Two papers are in submission one of which is a report of the findings from one person who has taken part in the study on four separate occasions. The commitment of this person to our research has been amazing — thank you. This report plus another paper has confirmed that brain amyloid increases with time and this looks to be associated with thinning of brain tissue in specific regions. When these papers are published we will send you all further details. Thank you to Alzheimer's Research UK (AR-UK) for your wonderful support.

The NiAD study is still forging ahead at full speed. Many of you have taken the time to come to Cambridge to help us investigate the links between Down’s syndrome and Alzheimer’s disease. We also have many new participants who have never taken part in any of our previous research into Down’s syndrome - welcome to you all!

Liz and Monika have been out recruiting new participants around the country and have met many wonderful families. Back in Cambridge, Liz and Monika are busy scanning participants and will have finished the first round of visits by Christmas. Everyone is busy preparing for the second visits of the study and we look forward to welcoming you all back again after Christmas!

In America, a new site in Washington DC has replaced the Arizona site and both Pittsburgh and Madison-Wisconsin have begun seeing previous participants for their second visit.

All the families involved in the study have been amazingly co-operative and the whole team owe everyone a massive thank you – none of this would be possible without you!

Welcome Monika!

We would like to give a warm welcome to Monika who joined us in October as our new research assistant.

Monika completed her degree in Psychology at Edinburgh University followed by her MSc in Cognitive Neuroscience at UCL. She spent a year working for the Transport Research Institute in Edinburgh while also gaining support work experience with three Scottish charities: Scottish Autism, Alzheimer Scotland and Capability Scotland. She has now joined us here in Cambridge as a research assistant working on the Neurodegeneration in Aging Down Syndrome (NiAD) project. Monika is looking forward to meeting all of our participants on their next visit!

NiAD team visit the USA!

Dr Shadid Zaman, Dr Isabel Clare and Monika Grigorova visited Pittsburgh in November to visit our team over in America. Dr Shahid Zaman presented the Cambridge Alzheimer’s Disease in Down Syndrome legacy studies at the NiAD investigator meeting in Bathesda, Maryland. They reported back from their USA trip and informed us that all of the sites are on track and reaching their targets.

Excitingly, researchers have been busy analysing the brain images and blood samples of our participants. This is some of the first data analysis to take place and the researchers were able to present some preliminary findings at the conference.
Recruitment round up

Olivia, one of our participants, answered some questions about her time in Cambridge with us. Here is her interview with Liz:

**What made you want to take part in this research?**

I wanted to take part so that I could help other people. I was a bit scared at first, as I thought I might have Dementia, but Liz and Anna explained everything to me and that made me feel better.

**Did you enjoy your visit to Cambridge?**

I LOVED my visit to Cambridge! I enjoyed the train ride to get there, and staying in the hotel. I went to the hospital, and even though I didn't get to have my scan, I did get to lie in it and see what it was like. I know what to expect next time now.

**What did you like best about Cambridge?**

I went around Cambridge on an Open Top Bus Tour, and I went punting along The Backs, which was brilliant. I loved walking around the city - it's beautiful, and very busy. There was lots to see and do. I enjoyed going to Addenbrooks too - it's a very big and busy hospital.

**Would you recommend taking part to other people with Down's syndrome?**

I think it would be very good for other people with Down's syndrome to take part in this research. You never know, it might help them one day, if they get Dementia. It might help me too, if I get it.

NiAD study participant speaks at the World Down's syndrome congress!

In July this year, Glasgow hosted the World Down Syndrome Congress and we were proud to take part. Our Emeritus professor Tony Holland was a plenary speaker and Liz accompanied one of our NiAD participants Hannah to give a talk about 'Promoting the inclusion of adults with Down's syndrome in research'.

Hannah is one of our participants who lives in, and travels from Glasgow to Cambridge to take part in our scanning study and she is a great advocate for people with DS taking part in this important research.

Liz said ‘Hannah really helped me make the talk come alive! She was not at all nervous and had the audience in the palm of her hand! I can’t thank Hannah and her sister enough for their support of this study in so many ways’.

Here is a photo of them having a well earned refreshment break after the conference!
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 Agnes Hoctor, phone: 01223 465 216, email: ah937@medschl.cam.ac.uk, post: Department of Psychiatry, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH.

Farewell Conchy…

It has been two and a half years since I started work as a Research Associate here at the CIDDRG group at the University of Cambridge. Time passes by very fast and one is not always aware of all the important things in life until the moment one decides to make a big change. And that is the case with me! Now that I am leaving Cambridge, all the special moments that I have lived with, all the participants, their families, and my colleagues come to my mind.

One of the things that I have enjoyed the most is visiting the families taking part in the study in their homes along with my colleague Liz Jones. I loved their hospitality, the chats before starting the evaluation or during the breaks, laughing with the participants with DS while we were doing the different games included in the NP evaluation... People with DS are full of heart and have a great sense of humour. Not only that, they showed me that they are extremely brave and perseverant when they came to visit us in Cambridge to have their scans and blood taken. To all of them, I would like to send a big THANK YOU! Also, to all the NiAD team for their support and all the things that I have learnt from them during my stay in Cambridge, it has been very special to me.

Merry Christmas to all of you!

Maddie’s eye study

Maddie will soon be starting another eye study hoping to find additional markers in the eye and the retina related to Alzheimer’s disease. She would appreciate hearing from anyone with Down’s syndrome who might be interested in taking part in this study, if you or someone you know would like to know more please contact Maddie on mjw208@cam.ac.uk or 01223 465261.

A call for participants

We are always so grateful to our participants who allow us to carry out our work and we are always looking for more people! If you know anyone aged 40-44 with Down’s syndrome who might be interested in taking part in the MRI/PET scanning study, we would be extremely grateful if you could let our NiAD team know by contacting ej268@medschl.cam.ac.uk or mg927@medschl.cam.ac.uk. Tel: 01223 465 268.

Thank you and keep us updated!

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