Defeat Dementia in Down’s Syndrome Research Group

Celebrating 15 years of research in the field of intellectual disabilities

The research under ‘Defeat Dementia in Down’s Syndrome’ has been part of a broader body of research undertaken by the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG). This group was established in 2002 when the University of Cambridge was awarded a 15 year grant from the Health Foundation to support a range of research in the field of intellectual disabilities. Our research has been led by senior clinicians and academics in psychology, psychiatry and sociology and has also involved collaborating with a diverse range of disciplines such as the law, genetics, and anthropology.

The Health Foundation grant comes to an end early next year and on Friday 29th September 2017 we will be holding a reception and dinner at Clare College, Cambridge to celebrate the achievements of CIDDRG over the last 15 years to which you are all invited. The main reception will start at 4.00pm and will include posters about our research. There will also be refreshments. To enable us to do our research on Down’s syndrome and dementia we have had amazing support from many of you and I hope very much that some of you will be able to come and join us for this celebration (please see the enclosed invitation). We would like to use this special occasion to thank you for all that you have done to help us and to share with you what we have learnt.

As the Health Foundation grant comes to an end there will be some changes. However, research into Down’s syndrome and dementia will continue with the grants and support we have from Alzheimer’s Research-UK (AR-UK) and from being part of the NIH funded multi-centred study led from the USA. We are very pleased that Carol Routledge, the new head of research at AR-UK, will be joining us at our next meeting to plan various Down’s syndrome projects. We will also be linking more closely with Professor John O’Brien’s research group. John is a Professor of Old Age Psychiatry at the University of Cambridge and a world expert on dementia. Elijah Mak from his group will also be working with Conchy Padilla to help with analysing recent brain scans. Shahid Zaman will continue to be the main lead for the Down’s syndrome research.

In our group, congratulations goes to Sally Jennings for completing her PhD! She has had her PhD viva and is now working on writing up the research for publication. Those of you who took part in Sally’s study will have received a summary of her findings. Maddie Walpert has also completed the ‘DARC’ part of her eyes studies. Again a very special thanks to many of you as it was all a rush for various reasons beyond our control and those of you who took part did so at rather short notice. Maddie has further support from AR-UK to continue her work throughout 2018.

Tony Holland
Pittsburgh Pals

On 19th July, our collaborators (Ben, Joni, Leslie, Bill, Brad and Annie) on the NiAD study from Pittsburgh, Pennsylvania, USA paid the NiAD team a visit at Douglas House. Over tea and biscuits, (or cookies as they call them in the US!) we had several productive discussions, from reviewing cognitive testing methods to strategising on data entry.

We then drove to Addenbrooke’s Hospital to show our American visitors around the Clinical Research Facility, the Wolfson Brain Imaging Centre and even the labs where the imaging tracers are made. This meant they were able to see our testing sites and meet with the scanning team.

After a long day, everyone met up for some afternoon tea at the Tamberlaine Hotel. Clive, one of our participants, was also able to join us for cream tea and spent the afternoon chatting to our US friends about the part their country played in World War II. Everyone enjoyed a well-earned cake break before it was time for the US team to head back to London. It was great to meet our American team in person, and we look forward to continuing to work together in the future!

Eye Study Part II - DARC trial

We are pleased to announce that our second eye study has been completed! For those participants who were involved in the first eye study they will know that Maddie has been eagerly awaiting this second study for a long time! We had 16 participants take part in this study, all came to London and spent the day at the Western Eye Hospital having many eye scans. We cannot thank the participants and their parents and carers enough for supporting this study and giving up their time at very short notice.

This study is called DARC, which stands for Detection of Apoptosing Retinal Cells. The purpose of this study was to investigate whether tiny cells at the back of the eye could be seen using a combination of an OCT machine, a camera which can take photos of the retina at the back of the eye, and a special drug which was able to highlight dying cells as part of a regeneration process. The process of these dying cells may be an indication of early stages of Alzheimer’s disease and this is an easy way to image them.

All of our participants underwent at least 5 eye scans during the 6 hours that they spent at the Western Eye Hospital, in addition to an injection and eye drops to dilate the pupils. Part of this study was to investigate any side effects of the drug and we are pleased to announce that there have been no side effects in our Down’s syndrome group.

A Call for Participants

We are so thankful to our participants who allow us to carry out our work. However, we are always looking for more! If you know anyone aged 25-35 years with Down’s syndrome who might be interested in taking part, we would be extremely grateful if you could let our NiAD team know by contacting ej268@medschl.cam.ac.uk or leave a message on 01223 465 211 for a call back.
76 Years Young

Liz and Anna recently took a trip to Ely to visit Frances. Last year Frances was recognised all over the world for reaching her 75th birthday, making her, to our knowledge, the oldest woman with Down’s syndrome in the UK. Wayne, the care manager, said he called the local newspaper to tell them of Frances’ achievement and was extremely surprised to receive thousands of congratulatory messages through social media.

It was lovely to meet and have a cup of tea with Frances who is now 76, and we are really hoping she will take part in our new study!

Recruitment Round Up

Taz’s Paintings

tazpaintings.wordpress.com

We asked one of participants Tazia to tell us about her artwork and why she likes to take part in research.

“Art is my main interest and hobby and it became a professional job even though I’m self-employed. It means I buy all the supplies myself. I’ve recently started using glitter pens for an elephant I’m making at the moment with card collages and acrylic in the background. I’m a bit of a mixed media person! I used to use oil pastels and I’ve also done a collage of all my breakfasts!

“Doing tests is an honour. I understand the importance of it because my grandad was diagnosed with Alzheimer’s”.

What It’s Really Like To Be On The News

Russell, one of our participants, was interviewed for BBC News ‘Look East’. Here he describes his experience of being on the news.

How was the experience?
A bit nerve racking, but really interesting because I learnt a lot from it about Alzheimer’s. When people asked me questions I felt more relaxed because all the people doing research are very friendly and polite.

Now a lot of people have been talking about it—I work in the Marks and Spencer shop and my customers come up to me and tell me that they saw me on the news. They want to know about Chariots of Fire and ask ‘What’s Alzheimer’s Disease?’ and I can tell them about it.

What was your favourite part?
When people were asking me questions - I loved being interviewed! When I was younger I loved to interview myself and it’s my dream to be an interviewer. It was a really good experience for me and I felt important - I felt like a star!

What was it like playing yourself instead of someone else?
That’s a good question! Being myself meant I was more natural - with acting they give me fake lines, but with interviews I can actually be more like myself and think like myself.

Do you think you’ll be on TV again in the future?
Yes, I think I might be, well I would like to be! On stage in my drama group, I was a bit nervous, but I prefer TV work because I can be myself. If someone was to interview me I would be up for that, especially if there were some celebrities!
On Your Marks, Get Set, GO!

The Chariots of Fire race (www.chariots-of-fire.co.uk) is a fund-raising event in Cambridge on 17th September 2017. Maddie and a participant, Russell, have been training hard in preparation and it would be great if any of you could come and join Liz and Anna to cheer and support them on the day!

The race will be raising money for the charity Alzheimer’s Research UK (AR-UK) which has supported much of the research that many of you will have taken part in. This charity is a really great cause to be supporting, so any contribution that you can make to support AR-UK through sponsoring Russell and Maddie would be greatly appreciated! Donations can be made at www.justgiving.com/fundraising/james-ramsey3 or by searching ‘Russell Ramsey’ on the Just Giving website.

A Successful First Scan

The NiAD study involves looking for things in the brain called Amyloid plaques and Tau tangles which build up and can be associated with Alzheimer’s Disease. Therefore, we will be scanning each participant’s brain using a combined MRI–PET scanner. As we are new to using this type of scanner the process of getting people scanned has been held up due to technical difficulties whilst making sure that the scanner was ready to use. This is why a few of you who we recruited may not have heard from the NiAD study for a while.

However, we are pleased to say that it seems as though the scanner is working smoothly and we have scanned our first participant! The image quality of the scan appears to be good which is thanks to Clive, the participant, staying so still during the scan. We hope to start having more regular scanning slots and we will be contacting many of you soon to come in to have your own brain scanned.

Goodbyes and Hellos

We are very sad to see one of our researchers Luciana leave after 6 months of being part of the NiAD team. She is returning back to Brazil to complete her PhD and then is jetting off to the USA. Many of you would have met her either during recruitment or testing. She loved meeting everyone and thanks you all for taking part. We wish Luciana the best of luck with everything– we will miss you dearly!

A warm welcome to two other researchers who have joined us this summer. Natalie is from Philadelphia where she is studying medicine at the University of Pennsylvania. Anna has recently started as a research assistant and she will meet lots of you for testing and scans on the new NiAD study.

Congratulations Sally on finishing your PhD!

Thank you!

Just to say thank you again to everyone that takes part in our studies. We absolutely love working with people with Down’s syndrome and truly believe in the importance of the work we achieve together! If you would like more information on anything in this newsletter or to be added to future mailing lists please contact our administrator, Agnes Hctor by phone: 01223 465 216, email: ah937@medschl.cam.ac.uk or post: Department of Psychiatry, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH.