Working ‘Together’ in partnership

The film ‘Together’ made at our open day held in March 2016 to celebrate World Down’s Syndrome Day highlights the importance of working in partnership for research. First and foremost this is a partnership between people with Down’s syndrome, their families and others who support them, and the research community. The involvement of people with Down’s syndrome and their willingness to engage with our research, have blood tests, lie in brain scanners, undertake memory tests etc. is absolutely essential to the success of our research.

It is also important to emphasise that research is increasingly complex and requires partnership with individuals and groups who have very different expertise. In addition to the expertise of psychologists, psychiatrists and nurses in the assessment and recruitment of people with Down’s syndrome, brain scanning requires the expert knowledge of radiographers to undertake the scans and also experts in radiochemistry to prepare the labelling materials that allow ‘amyloid’ and ‘tau’ (both found in excess in the brain in people with dementia) to be imaged, and physicists, computer scientists and neuroscientists to carry out and interpret the analysis of the scans. These new scans allow us not only to look at the deposition of amyloid and tau in the brain but also to look at the fine details of brain structure and how different parts of the brain are connected and communicate with each other, but these analyses are complex and need very special skills.

The new scanners we have at the Wolfson Brain Imaging Centre were funded by a very large grant from the Medical Research Council (MRC) following an application made by a team of experts here at the Clinical School. We, as a research group, can now capitalise on the availability of these scanners and the highly skilled professionals who work here.

In addition, the funding of research is increasingly acquired from varied sources. We have been very fortunate to obtain funding from Alzheimer’s Research UK for a two year study to follow up people with Down’s syndrome who took part in our recently completed MRC funded project. We are also part of a multi-centre study funded by the National Institute for Health in the USA. This will enable us to follow a group of people with Down’s syndrome for even longer so that we can much better understand the progression of the age-related changes that can affect the brains of people with Down’s syndrome. These two grants dovetail brilliantly and enable us to get the full value from both. The many other organisations who have funded our research in the past are acknowledged on the back page.

Thank you again for your help and support and I hope you find this newsletter interesting. If you have a general enquiry about our research please do get in touch. Many thanks also to those of you who pass this newsletter on to friends, family and colleagues. Please keep doing it and if anyone you know would like to receive it directly please point them to our contact details on the back page.

Tony Holland, Emeritus Professor of Psychiatry
Supporting Rachel

Kerensa Stocker, a Care Manager at Moorecare, writes about her recent experience supporting one of her residents to be involved in our research:

Moorecare is a private care organisation that offers person-centred support for people in both residential and supported living accommodation. We support and provide accommodation to 40 people who have a learning disability in the town of Buxton in Derbyshire.

Rachel lives in supported living and enjoys many activities in the community including horse-riding, trampolining and swimming. Rachel also likes to spend time with her family and enjoys visits to the café with her mum and dad.

In 2013 Rachel took part in the Cambridge research project and was approached to continue this over the next few years. For me as a manager it was important to establish Rachel’s understanding and capacity to consent to re-join the project as the tests required do involve a degree of commitment and possible slight discomfort.

To this end I completed a capacity assessment and also observed Rachel’s interactions with staff from the project who have visited several times. I was surprised at Rachel’s amazing recall of her past involvement in the project and also her ability to understand and reason at why taking part is so valuable.

This process demonstrated clearly that Rachel both had the capacity and enthusiasm to take part. This has been a learning curve for me, as initially I had concerns that the information presented would be too complex for Rachel to understand – and I am happy and humbled to say she proved me totally wrong.

VODG Report

We were delighted to be featured in the latest report published by the Voluntary Organisations Disability Group (VODG). The report was titled: Staying Put: Developing dementia-friendly care and support for people with a learning disability.

The publication explores how support, services and treatments can be developed for people with learning disabilities and dementia. The document is divided into sections looking at the issue from the perspective of policy, research and practice. Our work on the amyloid and tau proteins was featured to demonstrate how researchers are working in this area and highlighted the crucial involvement of people with DS in this work.

The document can be downloaded from the VODG website at www.vodg.org.uk.

News from the Wolfson Brain Imaging Centre

In the course of our research we have worked closely with colleagues at the Wolfson Brain Imaging Centre (WBIC) at Addenbrooke’s. This is home to some of the most advanced scanning equipment available to researchers and we are lucky to have it on our doorstep here in Cambridge. The new PET-MRI scanner is now in place ready to go. For more information visit the WBIC’s website: www.wbic.cam.ac.uk.
Not just Down the road - research travelogue

Recruiting participants for the new study has taken researchers Liz Jones, Dr Conchy Padilla and Luciana Fonseca to some beautiful parts of the UK. They have met wonderful people interested in our research, some of whom are pictured on the front page of this newsletter.

Our research is made possible through developing strong respectful relationships with our participants. In our initial meetings we are able to explain the research that we do in greater detail and get to know the person and their family better.

We usually meet participants at home with their families and have also visited people in care homes and assisted living and met their support teams. We are still recruiting more people with Down’s syndrome to take part in this study, if you or anyone you know might be interested please ask them to contact Dr Conchy Padilla using the details on the back page.

Conference round up

We recently attended Alzheimer’s Research UK’s annual meeting in Aberdeen. PhD students James Henderson and Deniz Ghaffari presented posters about their current work on Down’s syndrome and how the extra chromosome 21 increases the risk of Alzheimer’s disease.

Deniz and James’ posters were very well received and received a lot of attention from other scientists. We also learnt a lot from the talks that were given by other researchers and are already using this information to guide our next experiments. James is studying a protein found in brain cells that has been shown to help the immune system to clear debris in the brain but may also help keep brain cells alive if they are damaged or stressed. Deniz is studying how the levels of iron in the brain affect the immune system and how these levels may be different in people with Down’s syndrome and Alzheimer’s disease. A lot of work we saw here supported our findings which means we may be on the right track. We hope to return next year and present the data we will gather this year!

The Edinburgh University Neurology Society recently hosted its 5th Annual National Undergraduate Conference: Neuroscience to Neurology 2017. The conference welcomed delegates from around the country for an exciting and informative day of translational neuroscience. It was an engaging and interactive event where delegates were afforded the opportunity to both present their work and to hear from experts on topics ranging from neuroethics to video games as stroke therapy to the Down’s-Alzheimer’s link. Professor Tony Holland travelled to Edinburgh to share our cutting-edge research with the next generation of researchers.

Welcome Luciana!

We warmly welcome Luciana Fonseca, a neuropsychologist from Brazil. Luciana has joined our team for seven months as a visiting researcher and is helping us with the “Neurodegeneration in Ageing Down’s Syndrome” (NiAD) study. Luciana brings a wealth of experience with her as her PhD study in Brazil is investigating the neuropsychological features of cognitive decline and dementia in 98 adults with Down’s syndrome. Luciana has enjoyed some trips around the UK meeting people with Down’s syndrome, their families and carers while recruiting people into the NiAD study.

Welcome Luciana!
Thank you for your support!

None of this important and innovative research would be possible without the dedication and enthusiasm of the people with Down’s syndrome who take part in these studies. It is very clear to us that there is only one way that we as researchers and you the public can find the answers we need, that is through working together.

Contact us

If you would like more information on anything in this newsletter, copies of our recent publications or to be added to future mailing lists please contact our administrator:

Phone: 01223 465216
Email: ah937@medschl.cam.ac.uk
Post: Agnes Hector,
Department of Psychiatry,
Douglas House,
18b Trumpington Road,
Cambridge, CB2 8AH

If you would like to speak to someone about the new study please contact the research team on:

Phone: 01223 465211
Email: cfp31@medschl.cam.ac.uk

New publications

We have been involved in three recent journal articles, if you would like to be sent a copy of any of these articles do let us know:


Celebrating Down’s syndrome

Last year we celebrated World Down’s Syndrome day and Down’s Syndrome Awareness week. We hope that many of you will have been involved in events and awareness raising activities this year. We did not hold an open day this year, this is because we are so busy out on the road meeting new participants and preparing for the start of our new strands of research.

Last year we made a film, entitled Together, showing why we are doing this work, and how our participants, their families and supporters are helping us. The filming took place at our Open Day on World Down’s syndrome day, March 2016. The film can be viewed online at https://youtu.be/pB7iqWUXQlM

Fundraising with Chariots of Fire

We were delighted to hear that Alzheimer’s Research UK has been selected as the charity partner for this year’s Chariots of Fire race. The relay race will be staged on Sunday 17th September in central Cambridge and teams are now being invited to enter.

Money raised by Alzheimer’s Research UK will be put towards our brain imaging work. We are planning on entering a team and if anyone would like to join us do let us know!

For more information please see www.chariots-of-fire.co.uk