

Winter Newsletter

Down's Syndrome Research Group



Research is like a jigsaw in which different pieces come together and eventually you see the full picture. This is particularly so when trying to understand why people with Down's syndrome have specific problems in later life and are at risk for developing dementia (Alzheimer's disease). The challenge of defeating dementia in people with Down's syndrome will only be overcome through research, much of which is only possible with the help of those of you who have Down's syndrome.

In this latest Christmas newsletter we briefly describe the studies you have been helping us with and also some new studies that we would like your help with. Liam and Tiina's brain scanning study has shown us that a chemical called amyloid accumulates in the brain and Kate has shown that the energy source (mitochondria) in the cells of the body are faulty. The new studies we described are exploring some of the very early markers for dementia by using advanced methods for recording the electrical activity of the brain and by looking at changes in the light sensitive layer (retina) in the eye. Thank you very much for your support — if you feel able to help with more than one study this is extremely useful as we can then compare across the different studies.

Please come and hear more about our research at our open day to celebrate World Down's Syndrome Day on 21st March 2015 in Cambridge.

Energy in Down's syndrome study

People who have taken part in this study will know that Kate is interested in **mitochondria**. In some people with Down's syndrome, mitochondria might not be working properly and this causes problems with energy. With your help, Kate has found that some people with Down's syndrome clearly do have energy problems in their cells. These can get worse with age. These energy findings are linked to memory scores, and also to the brain changes that Tiina and Liam have seen on the brain scans. This is a big step in understanding what we know about Down's syndrome in later life. What this suggests is that keeping active is very important to how we age. The good news is that these findings suggest that our risk of dementia could go down if we are active—this might be even more important in those of you with Down's syndrome. Please ask your GP before you take on any exercise but it is a good idea to do regular exercise and to try to eat healthily.



Kate's time with the Down's syndrome research group has finished and she has moved to a new group. She handed in her PhD and is now waiting to be examined. Kate would like to thank everyone who has donated their time and effort to helping with this research and she hopes that the results will help in the future to defeat dementia in Down's syndrome. We are now considering the full implications of her findings.

Kate will still be checking her emails so do email if you have any questions you can reach her on km511@medschl.cam.ac.uk and Alexandra Lautarescu will be continuing her work. You can contact Alexandra on bal34@medschl.cam.ac.uk.

Brain activity in Down's syndrome study (new study)

Sally is looking at how the brain activity of people with Down's syndrome changes as they get older. To do this, Sally will ask volunteers to wear a cap covered with small disks. The disks pick up brain activity and send it to a computer. The computer lets Sally compare the brain activity of younger people, older people and people with memory problems. Sally will be looking at volunteers' brain activity when they are relaxing, watching a silent film and listening to sounds. To do this, volunteers will be asked to wear earphones as well as the cap.

Sally will be sending out letters in January to invite you to take part. Sally is looking forward to getting started!



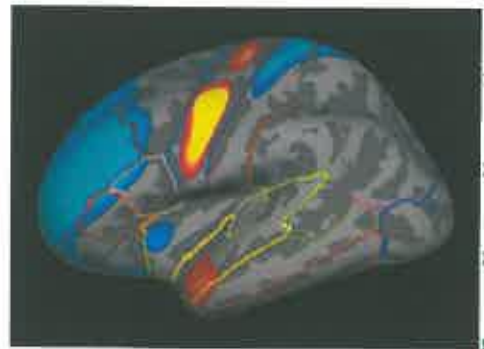
Dementia in Down's syndrome study

The dementia in Down's syndrome project is still going full steam ahead! Tiina and Liam have now scanned the brains of 43 people with Down's syndrome. This is brilliant, but they still need to see a few more people so that they can be certain they will get good results. If you know anyone who has Down's syndrome and is over the age of 40, please feel free to pass Liam and Tiina's details to them or ask them to get in touch via www.dementiainDS.com.

In the mean time, they have started to analyse the pictures to see what can be found out about the brains of people with Down's syndrome. The brains of people with Down's syndrome are clearly a bit different to the brains of people who do not have Down's syndrome, and they have also found out that Alzheimer's disease in older people with Down's syndrome might be slightly different to Alzheimer's disease in people without Down's syndrome. Now they need to find out what this means, and how it might change the way that doctors and scientists look for treatments to stop people with Down's syndrome getting dementia.

Early next year, Maddie will be asking some people who have already had brain scans if they would like to come back to Cambridge to have these brain scans again, exactly like before. This will help the research team to find out how the brains of people with Down's syndrome change as they get older.

This picture shows the areas in the brain that are different between people who have Down's syndrome and those without Down's syndrome.



Eye changes in Down's syndrome study (new study)

Maddie has now started her PhD project and is working with researchers in London using a technique called 'optical coherence tomography' (OCT) to take high quality images of the eyes, focusing on the retina. Maddie will then measure different components of the eyes to see what



changes happen in the eyes as you get older. We think that this might help us to find some of the early signs of Alzheimer's disease in Down's syndrome, which would also help us to treat these problems early on. Maddie will start her study in January 2015 and will be asking people to have an eye test using the machine in the picture to the left. This test is very similar to the test you have when you need new glasses.

THANK YOU

Many thanks to all of you who have already taken part in 1 or more of our studies, we really appreciate your time and effort helping us with this research. It is especially valuable if you are able to help us with different studies — this work is only possible with your help.

We would also like to thank everyone who has helped us complete this research including families and many people who have provided support, the DSA, Hft The Robert Owen Community, SEPT NHS Trust, Homerton University NHS Trust, Mersey Care, Jenny Gurney at the Fynvola Foundation, Dorothy Pritchard from Warrington Mencap, The Quemby family from Down's syndrome OK, Dr Ursula Quinn, the staff at the Wellcome Trust Clinical Research Facility, the staff at the Wolfson Brain Imaging Centre and those at the Herchel Smith Building. We would also like to thank the MRC, Baily Thomas Charitable Trust, the Health Foundation, Alzheimer's Research UK and Addenbrookes Charitable Trust for financial support.

**JOIN US FOR WORLD DOWN'S SYNDROME DAY ON 21st MARCH 2015, HERE-
AT DOUGLAS HOUSE, CAMBRIDGE, CB2 8AH**

CONTACT US

If you are interested in having more information about any of the studies or if you would like to get involved please give us a call or an email, we would love to hear from you.

For information about the open day, or to RSVP, please contact Suzie Tall on (01223) 746007 or by email on st520@medschl.cam.ac.uk

Dementia in Down's syndrome study

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Eye changes in Down's syndrome study

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Energy in Down's syndrome study

Although Kate has now left this research group you can still email her at km511@medschl.cam.ac.uk or Alexandra at bal34@medschl.cam.ac.uk

You can also look at our website for more information

www.dementiainds.com

