UNIVERSITY OF CAMBRIDGE

Christmas Newsletter

Down's Syndrome Research Group

Merry Christmas

and a very Happy New Year!

We hope you have had a good year. We have been very busy and many of you have helped us in different ways with one or more studies - for this we would like to say a big thank you! We hope that you enjoyed helping. In this Christmas newsletter we bring you up-to-date with planned and on-going research studies that have the one aim of 'defeating dementia in Down's syndrome'. Each study can be seen as part of a piece of a complex jigsaw. As each piece is put in place and the picture comes together so we learn more about why people with Down's syndrome have this particular risk in later life. Studies are also being undertaken elsewhere in the UK and also in the USA – together we believe that the new knowledge that is gained will lead to treatments that might have a real impact. We have asked some of you to help with more than one study and will be asking others of you to help so that we can compare findings between studies – this brings added value. Thank you for all your support – this research is just not possible without the involvement of people with Down's syndrome, their families and support workers. We hope you find the newsletter informative – if you have any questions do contact us – website addresses, e-mails and telephone numbers are provided on the last page.

Brain activity in Down's syndrome study

Sally has just started her PhD with us. She will look at how the brain activity of people with Down's syndrome changes as they get older. To do this, volunteers would 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 also look at the brain activity of people with Down's syndrome when they hear sounds, see pictures and are relaxing. To do this, volunteers would wear headphones as well as the cap, and also look at pictures on a screen. Sally hopes to be sending out letters soon to invite you to take part.

Eye changes and the risk of dementia study

Maddie has now finished helping Kate with her study and is working on another study until she starts her PhD early next year. Maddie's study will involve looking into the eyes of people with Down's syndrome to see if signs of Alzheimer's disease can be seen. Maddie is joining up with some researchers at University College London and will be using a new type of dye which can highlight different parts of the eyes that show signs of Alzheimer's disease. Maddie will be using special eye equipment, similar to what opticians use, to take photographs of the inside of the eyes so we can understand what is happening in Alzheimer's disease in Down's syndrome. These photographs will also be looked at alongside Liam and Tiina's brain scans, to see if the two images together tell a story and show how Alzheimer's disease progresses. This will be really important in showing whether the eyes can detect Alzheimer's disease earlier in life.

Energy in Down's syndrome study

People who have taken part in Kate's study will know that we are interested in energy made in parts of the cell called **mitochondria**. We think that in some people with Down's syndrome, energy in cells might not be working properly. Scientists know that not having enough cell energy can lead to memory problems in some older people.

Part 1- Scanning study Maddie and I have finished Part 1 of this study. In this part, 28 people were asked to do a special leg scan. We found that on the whole, muscles in people with Down's syndrome took longer to recover from exercising than in other people. This means that mitochondria might not be working quite so fast. This is nothing to worry about, but it might mean that some people with Down's syndrome might get tired more easily. We are going to look into this in more detail in Part 2 of the study.

Part 2- Muscle study We had 18 very kind people donate a tiny piece of their leg muscle. Dr Burak helped us take these samples. Kate will take these pieces of muscle to a special lab in Newcastle and will look closely at the cells to understand what is going on. This will give us very useful information. Doing this together with Tiina and Liam's study lets us learn a lot about how energy and memory in Down's syndrome. It also helps scientists understand what happens in cells in other people who have dementia as they age. Thank you to everyone who took part and to Maddie for being an amazing help!

Dementia in Down's syndrome study

Liam and Tiina are now more than halfway through their study about dementia in Down's syndrome. Over the last two years, they have been to visit lots of people with Down's syndrome and their families. They asked these people some questions about their memory, and then invited them to Cambridge to have some pictures of their brain taken. So far, 34 people have been to Cambridge to have their brain scanned, which is a fantastic number!

But Liam and Tiina are still working hard to find more people who would like to take part. It is very important for scientists to know what happens in the brains of people with Down's syndrome when they get older. Liam and Tiina hope that if they take pictures of enough brains, it will help them to understand why some people with Down's syndrome forget things when they get older. Then this will help scientists to know what kind of medicine could help people with DS in the future.

So, Tiina and Liam are still looking for more people to come and have their brain pictures taken, especially people who are over the age of 40. If you know anyone who would like to take part, please let them know that they can get in touch with Tiina and Liam by using the details below. Also, don't forget that you can keep up to date with how our study is going by visiting www.dementiainds.com! In a few months, it will be time for Liam and Tiina to look at all the information that they have collected and the pictures of brains that they have taken. We will let you know what they have found out in the summer newsletter. But until then, have a wonderful Christmas and a very happy New Year!

CONTACT US

If you want to speak to someone about the :
Brain Activity in Down's syndrome study you can speak to
Sally—srj32@medschl.cam.ac.uk or call (01223) 746147
Defeat Dementia in Down's syndrome study you can speak to
Liam—lrw34@medschl.cam.ac.uk or call (01223) 746 127
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Energy in Down's syndrome study you can speak to
Kate—km511@medschl.cam.ac.uk or call (01223) 746 190
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Many thanks to Jonathan Hurley for letting us use his fantastic photos. Jonathan has an online blog which can be found at **www.jonathanhurleyadvance.blogspot.co.uk** And a special thanks to Heather Kent for appearing in our video and letting us use the photo. We would also like to thank the people and organisations who have helped us, including 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 and those at the Wolfson Brain Imaging Centre.

Dementia in Down's syndrome study www.DementiaInDS.com
Energy in Down's syndrome study www.DementiaInDS.com/energy

act Addenbrooke's Charitable Trust

MRC Medical Research Council

Down's Syndrome Association