Welcome to the 5th participant and carer newsletter from the London Down syndrome Consortium!

This year, we have been busy finishing follow up assessments for our adults aged 36 and over. Thanks to your help, we are learning lots more about people with Down syndrome and what happens as people get older.

See inside to hear more about what we have found!

In this issue:

- An update on our research progress
- Read about our new findings
- World Down Syndrome Day 2017 and 2018
- A move for some of the LonDownS team
In total we have seen over 450 adults which is one of the biggest samples of this type ever collected!

We have been looking at all our data to see how people’s abilities change over the lifetime across the whole group. We know that some people develop memory problems as they get older. Some other researchers have found that planning abilities might change before memory, and so one of the important things we have been looking at is trying to work out which ability changes first. Using all the data we have collected, we think it is indeed memory that changes first, and attention changes can also happen early. With all the data we have from the adults aged 36 and over who we have seen twice, we will be able to see if the same patterns happen for individuals.

We have also been looking at how different health conditions become more common over the lifespan. Similar to what other people have found, adults are more likely to develop thyroid problems as they get older. We have started to put some of this health information together with our test data to see if there is any relationship between different health conditions and people’s abilities. Our results show that people with autism and people with epilepsy can find things more difficult than people who do not have these conditions.

Finally we are analysing brain activity data from people who came to London to see us. We are interested to see if there is any link between brain activity and people’s abilities, and also how brain activity might change over time. Stay tuned to hear what we find!

Changes in the brain as people with Down syndrome get older

Down syndrome is caused by an extra copy of chromosome 21. This means that people with Down syndrome have three copies of the genes on this chromosome rather than the typical two copies (which means they have about 230 extra genes in total) - genes give different instructions to the cells in our bodies. Scientists think that a lot of the health conditions that are more common in people with Down syndrome, including some of the memory problems people can develop as they get older, are because of all these extra genes. One gene that we think is particularly important for causing these memory problems is known as APP, which stands for amyloid precursor protein.

The APP gene is thought to cause these memory problems by producing clumps of protein called amyloid in the brain. Some of our recent research shows that as well as APP, other genes on chromosome 21 might increase the production of these amyloid clumps. We have also found that activity of a group of enzymes (molecules that break down proteins), called cathepsins, might be lower in people with Down syndrome. We think these cathepsin enzymes might break down amyloid to turn it into different forms that are less likely to form clumps. This process might not work properly in people who have Down syndrome if they have lower levels of the enzyme, and this might contribute to amyloid clumps forming and the memory problems some people show as they get older.

We are next going to test this idea, and hopefully find the genes on chromosome 21 that decrease the activity of these enzymes. We also want to see what effects this altered enzyme activity might have on other parts of the body – for example the immune system. We hope that by finding out what causes some people who have Down syndrome to develop clumps of amyloid and memory problems we can develop new drugs to prevent this.
On Tuesday 21st March 2017, LonDownS celebrated World Down Syndrome Day 2017 with an activity day for participants, carers, family & friends.

Thank you to everyone who came and helped to make the day entertaining, fun and educational. It was lovely to see you all again and to meet some new faces. We hope that you enjoyed it as much as we did!

During the day we had activities including making PlayDoh neurons, making a memory tree, looking at cells through microscopes and making brain hats. On the left, below, is Justin, one of our PhD students, showing us how to use the microscope to look at cells (and modelling a brain hat!).

Save the Date: Saturday 24th March 2018!

LonDownS will be hosting an event in central London for World Down Syndrome Day in 2018. Would you like to join us?

Email us at downs syndrome@ucl.ac.uk before 1st December 2017 to register your interest—we will send further details in the New Year!
Congratulations to LonDownS Principal Investigator André Strydom!

Congratulations to LonDownS Co-Founder André Strydom on his new role at King’s College London!

The LonDownS adult research team will be splitting their time between UCL and King’s College while we complete the work you have helped with. However we will also be continuing to develop new Down syndrome research projects from our new home, so watch this space for future work to be involved in!

You can still reach the LonDownS team at our UCL email address below but please note our new telephone number:

020 7848 5701

Visit the LonDownS website to learn more about our research and see all of our previous newsletters!

www.ucl.ac.uk/londowns

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