

## What is it like to take part in research? Glenn's Story

*Glenn Madely tells us what it is like for him working with Professor Tony Holland, at the University of Cambridge, on research to understand links between Down's syndrome and Alzheimer's disease.*



In October 2013 I was told that some people at Cambridge University were doing some research in dementia and they were looking for volunteers to take part. I have Down's syndrome and dementia and I want to help other people who are like me.

Tiina came to my house to meet me and tell me all about the research tests and scans; I had a DVD to show my dad. I talked to my friends and they said "go for it".

Tiina and Liam came to my house (January 2014) and asked me some questions, I did very well and I signed a form to say I wanted to carry on. I feel this will help other people with dementia.

I have been to Cambridge three times, once (May 2014) to have some tests and two different scans of my brain. I met Gloria who works at Addenbrooke's hospital, she put on my CD while I lay in the scan, and I fell asleep. I was given a photograph of my brain which I have put in my Life Story Book. My certificate is on my wall.

In March 2015 I made a second trip to Cambridge and went to Douglas House on World Down Syndrome Day.

I talked to lots of people and told them what it is like to do the tests and have the scans. I also had an eye scan and looked at pictures of behind my eyes – it was just like

going to the optician. I met Tony Holland. I had a great day and then I went to my hotel, had a beer and watched England win their Rugby game.

In 2015 I met Alexandra and did the leg exercises and puzzles. This study looked at how well the energy in my body was being made. I had to sit in a very high chair and lift up my leg, I felt a bit wobbly but I was not scared.

I have another certificate. I liked taking part in this work as I think it is important for people with Down's Syndrome and who get dementia. My dad said he is proud of me.

I have been a volunteer for the Alzheimer's Society since January 2013 and I collect donations in a bucket. I am also a Dementia Friend. I liked meeting Tiina, Liam and Gloria. I liked visiting Cambridge.

The only part I did not like and said no to, was the study about brain activity because 'head gear' looked strange and I did not want to put it on my head.

I have shown my Life Story Book to lots of groups and I have helped to write about my experiences for our newsletter. I wear my Dementia Friends badge. I did a presentation on my work to my local NHS AGM. I always tell them about the research and I show them my brain scan. I let them have a leaflet which tells them about the research and how to get in contact.

I have learnt that some people like me get dementia when we are younger and some people are working to change that. I am proud to be part of that change. Research is important to make things better in the future.

Professor Tony Holland and his team at the University of Cambridge Department of Psychiatry have been trying to understand the links between Down's syndrome and Alzheimer's disease. You can find further information about the variety of research taking place at his Defeating Dementia in Down's Syndrome website [www.psychiatry.cam.ac.uk/ciddrg/research/dementia-in-downs-syndrome-dids/](http://www.psychiatry.cam.ac.uk/ciddrg/research/dementia-in-downs-syndrome-dids/)

The long term objective of Professor Holland's research is to understand why people with Down's syndrome are at risk from Alzheimer's disease so that safe treatments can be developed. His hope is that the research of his team will inform a clinical trial, so that scientists can find a drug to prevent this type of dementia from developing in people with Down's syndrome, and in the general population.

*Here at the Down's Syndrome Association we try to provide information about research projects that have gone through our vetting process. It is very important to us that research is of direct and practical benefit to people with Down's syndrome and their families and of the highest standard. We only list research on our website which is of postgraduate level and beyond and has ethical approval. For more information about our current and completed research projects, please visit our website:*

[www.downs-syndrome.org.uk/about/research-campaigns/](http://www.downs-syndrome.org.uk/about/research-campaigns/)