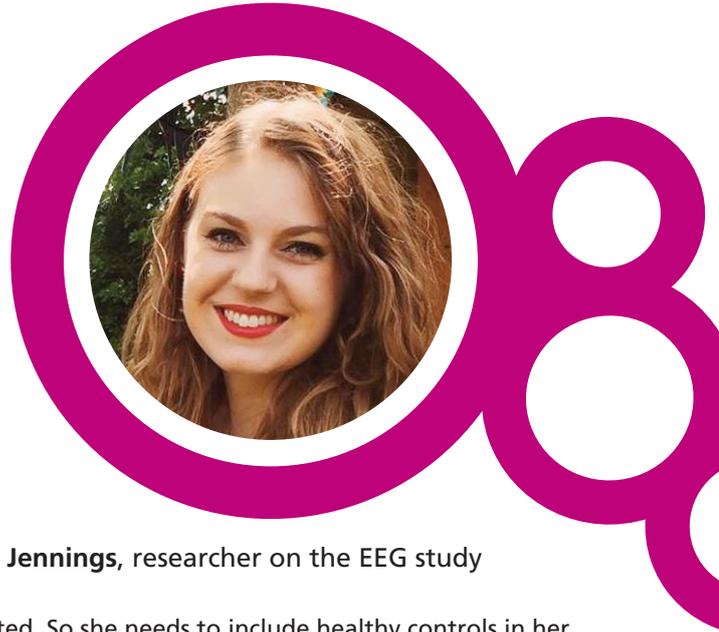


DEMENTIA RESEARCH NEEDS YOUNG, HEALTHY VOLUNTEERS TOO

Join Dementia Research helps with recruiting all kinds of volunteers for research studies, not just people affected by dementia. We spoke to Sally Jennings, a Ph.D. student at the Department of Psychiatry, University of Cambridge about her research on Alzheimer's and Down's Syndrome and Laura Phipps, Science Communications Manager at Alzheimer's Research UK, who took part in Sally's study.

Sally's Ph.D. project is looking at whether an EEG could provide a way to detect Alzheimer's at an earlier stage. An EEG (electroencephalogram) is a test that detects electrical activity in the brain using small, flat metal discs (electrodes) attached to the scalp. Sally is recording the brain activity of people with Down's Syndrome, as people with this genetic condition tend to age faster and have a high risk of developing Alzheimer's disease. She is following a group of people with Down's Syndrome over time. If in the next couple of years any of them begin to show signs of dementia, she will look back at her data to see if their earlier EEG records could have predicted this. Sally also wants to compare the ageing process in the brain between people with Down's Syndrome and people who are not

"The ultimate goal is to spot signs of Alzheimer's earlier, so that when treatments become available, they can be given to patients sooner."



Sally Jennings, researcher on the EEG study

affected. So she needs to include healthy controls in her study. *"The ultimate goal is to spot signs of Alzheimer's earlier, so that when treatments become available, they can be given to patients sooner, which is likely to lead to better outcomes,"* Sally explained.

Sally heard about Join Dementia Research from a colleague and thought it would be a useful way to recruit from a larger pool of volunteers. *"I thought the website looked great so I contacted the Join Dementia Research programme manager to ask if I could include my study. They agreed, so I went ahead. It was really clear how to register. I had to get ethical approval for this minor change to my recruitment strategy, but they explained how to do that. It was all very quick. Within a few weeks I had gone from emailing them, to it all being approved and my study being up on the site".*

Once a study is registered on Join Dementia Research, an email is sent to potential recruits already on the database who meet the study criteria. Sally was looking for healthy volunteers aged 20-60, living within a 25-mile radius of Cambridge. Laura was one of the people who received a study alert via email. She had been one of the team at Alzheimer's Research UK who were heavily involved in developing Join Dementia Research, as she explained, *"I'd spent two years working on the Join Dementia Research project, so I really had to practice what I preach! I enrolled myself on the site, not expecting that there would be studies that needed people like me. There was much excitement in the office when the email about Sally's study came round, because quite a lot of us had signed up".* Several staff members have now taken part.

Once Laura and Sally were 'matched', Sally emailed Laura further information about her research, explaining what taking part would involve. Laura agreed she would be happy to be involved and arranged to go to the lab. Laura described what happened, *"I was there for about three hours altogether. Sally first gave me a more detailed explanation of the study and showed me where all the equipment was set up. I signed a consent form agreeing to how my information would be used, and completed a brief questionnaire about my health. I did a few memory and thinking tests and then Sally gelled the electrodes onto my scalp on different parts of my head. Then I had to do some more tests with the cap on my head. When it was finished, they gave me a towel to get the gel out of my hair before going out again in public! I'm looking forward to hearing about the results. Everyone who took part will be sent a summary when the study's finished."*

Laura Phipps, taking part in the EEG study



From Sally's perspective, Join Dementia Research has made an enormous difference to recruiting people as she described, *"I needed to find people who were the same age and gender as the people with Down's Syndrome in my study. Usually, we recruit through the University, but then you only have access to people in their twenties. Join Dementia Research made it possible to recruit older people too. This has been invaluable as looking at typical ageing is such an important part of understanding dementia. Before I contacted Join Dementia Research, I'd only found 2 healthy controls. Since then I've recruited 37 controls, 31 of whom have come via Join Dementia Research". Sally recommends that other Alzheimer's researchers work with Join Dementia Research, "It's simple to use and makes recruitment much less stressful. My supervisors have been impressed by how quickly things are going. And the volunteers are enthusiastic, which is exactly what you want – they're really interested in what you're doing and how it works out, so they're very motivated to take part."*

For Laura, Join Dementia Research has provided a welcome opportunity to contribute to Alzheimer's research as she explained, *"All our staff are passionate about helping people affected by dementia and there are lots of ways do that – this is another option for us. Taking part in research is so vital. So we want to help that way as well"*.

Join Dementia Research provides the means for people who are interested in volunteering for dementia research to find out about studies in their local area as well as across the UK. Laura concluded, *"It's definitely worth registering in the system, whoever you are, because there are so many different studies. It's not just drug trials – there are many different things you could be asked to do. I know people are very busy and certain studies might not fit, but the great thing about Join Dementia Research is that you can decide on a case-by-case basis. By signing up you're not saying you will definitely take part in research, but just saying that you might be willing to take part if the right study comes along"*.

To find out more, please visit

<https://www.joindementiaresearch.nihr.ac.uk/content/researchers>

Sally successfully used Join Dementia Research to recruit 11 people within the first 4 weeks, and 31 within 12 weeks. These people are now helping to beat dementia.