



JOIN DEMENTIA RESEARCH NEWSLETTER

AUTUMN 2017



The Join Dementia Research service has been up and running for over two years now and in that time we have gone from strength to strength and reached a number of milestones together. I am delighted to say that we have now reached 30,000 registered volunteers, all of whom are looking to take part in research and help beat dementia. Thank you to every single one of you, it is hugely appreciated.

Professor Martin Rossor, National Director for Dementia Research at the National Institute for Health Research

July is always a busy time for us at Alzheimer's Society as dementia researchers and experts from around the world gather for the Alzheimer's Association International Conference (AAIC) to share results and expertise. Join Dementia Research, the NIHR and the partner charities were in the thick of it this year as the conference came to the ExCel centre in London.



The AAIC conference is always a great place to hear about the progress that's being made in dementia research. One of the most significant pieces of news that came out of this year's conference was the findings on dementia prevention. The researchers discovered that modifying nine lifestyle factors could potentially reduce the number of dementia cases by a third. These factors included stopping smoking, treating hearing loss and preventing high blood pressure. The next stages will be to understand how these factors affect each of us on an individual level, and how to get the message across to people that a change in your lifestyle could reduce your risk of dementia.

The results of studies such as these would not be possible if it wasn't for volunteers giving up their precious time to advance our knowledge. Alzheimer's Society has been a passionate supporter of Join Dementia Research from the very beginning, and I'd like to take this opportunity to thank you all for uniting with us against dementia.

Dr James Pickett
Head of Research, Alzheimer's Society



GETTING INVOLVED IN RESEARCH - YOUR STORIES

West Oxfordshire grandmother speaks of her research hopes



Joan Cansfield, 76, was diagnosed with mild cognitive impairment in April 2014. The grandmother-of-two has been taking part in the RADAR trial, looking at whether an existing drug used to treat high blood pressure could slow down damage to the brain during dementia.

Joan said: "My experience has been very pleasant. The researchers are supportive and you need to know that someone is battling for you. Before taking part I was terrified. I'm still scared, but I don't have the same sort of negative thinking about it."

Research assistant reveals the challenges and rewards of recruiting for dementia studies

Daniel Kelleher, 25, a research assistant with Humber NHS Foundation Trust, is one of a team of researchers who visits the homes of people living with dementia to see if they would be willing to participate in research.

Daniel said: "You do form a bond with that person. You look forward to seeing them again and hope that they look forward to seeing you! Quite often, we've enrolled people on multiple studies because they've enjoyed taking part in their first one so much."



"Alzheimer's is like going down a spiral staircase. But if enough people take part in research, we will beat it."



Janet and her husband Andy were determined to get involved with research studies following her diagnosis of young-onset Alzheimer's disease. Daughters Hannah and Rachel first suggested the idea of taking part in clinical research after trying to see what treatments might be out there for her to try.

Andy describes the experience: "We felt so welcome every time, and really looked forward to our visits. It was like a day out. The research centre felt like a home-from-home".

If you'd like to read the full stories, you can request a copy to be sent to you from any of the charity helplines overleaf.

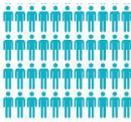


30,000 JOIN DEMENTIA RESEARCH VOLUNTEERS - THANK YOU!

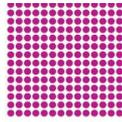
Join Dementia Research has hit a key milestone with over 30,000 people now signed up to the service since launching in 2015.

The tens of thousands of volunteers who have already registered are a mix of people who have been diagnosed with dementia, carers of people with dementia and healthy members of the public who all want to help push dementia research forward.

We would like to extend a huge thank you to everyone who has registered with Join Dementia Research so far and ask everyone to please keep spreading the word about the service and the benefits of taking part in dementia research. You can help us to reach the next 30,000!



30,145
total volunteers



56,956
screenings



7,888
participants that have enrolled
in studies to date



26%
of volunteers have
participated in a study



165
Studies have recruited



108
Studies currently open
to recruitment



852
trained researchers
using the service



176
NHS, University & commercial sites
have used the system

Statistics accurate as of 28 September 2017

'SMALL CHANGES CAN OFTEN MAKE QUITE A LOT OF DIFFERENCE'



Alan Richardson is a Dementia Friend and Join Dementia Research Champion. Alan is urging people to get involved with dementia research in order to help find ways of improving the lives of people living with dementia.

Alan has been a Dementia Friend for over three years now, and a Join Dementia Research Champion for most of that time too. After caring for his late mother, who had dementia, he wanted to get involved with an organisation that would allow him to share the things he had learnt with other people who were in the same situation as him.

To read the full story you can request a copy from any of the charity helplines overleaf or alternatively, you can visit www.bit.ly/alan-richardson



VOLUNTEER EXPERIENCE SURVEY

What has been your experience of registering with Join Dementia Research?

Do you have any suggestions for how we could improve the service?

If so, we would love to arrange a telephone interview with you so we can find out about any changes that you think we should make.

If you would be interested in taking part in the Volunteer Experience Survey, please phone us on 0203 328 6728 by Friday 24th November 2017. We will then arrange a suitable and convenient time to call you back for the telephone interview. You will not be charged for this call.

Participation in the survey is voluntary, your responses will be anonymous and you can decide to end the call at any time.



GET IN TOUCH

To update your information on Join Dementia Research, please call one of the helplines:

Alzheimer Scotland: 0808 808 3000

Alzheimer's Research UK: 0300 111 5 111

Alzheimer's Society: 0300 222 1122

Calls to Alzheimer Scotland are free, calls to other Helplines cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.

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Our mailing address is:

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To unsubscribe from receiving this newsletter, please ring one of our helplines above or email us at comms.jdr@nihr.ac.uk

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