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# JOIN DEMENTIA RESEARCH NEWSLETTER

## AUTUMN 2016

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Professor Martin Rossor

**Hello and welcome to the Autumn edition of the Join Dementia Research newsletter.**

Over the summer we reached a new milestone, with over 20,000 volunteers now registered with the service and more than 5,000 participating in studies.

As volunteers, you're playing a vital role in progressing research, and we want to provide you with the best service possible, so in this issue we're asking for your feedback on how you think we're doing, and things we could improve.

We've also taken a look at some of our latest studies and two of our helpdesk team

members give us an insight into their working day.

As well as all this, you can read about some new questions we've added which could help increase your likelihood of matching with certain studies.

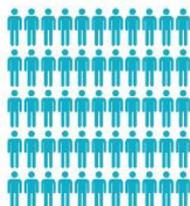
Thank you once again for your involvement with Join Dementia Research.

Best wishes,

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

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### JOIN DEMENTIA RESEARCH IN NUMBERS



**23,723**  
total volunteers



**6,019**  
participants enrolled  
in studies



**81**  
Studies currently open  
to recruitment



**139**  
NHS, University &  
Commercial sites recruiting

## JOIN DEMENTIA RESEARCH SURVEY - TELL US WHAT YOU THINK

Join Dementia Research is here to accelerate the pace of dementia research, but it's nothing without our willing volunteers.

Thanks to those that completed our survey last year. We want to make sure we're providing the best service we can so we'd love to get your views again, as well as hear from our new registrants.

Our survey takes less than 10 minutes to complete and will provide us with lots of useful feedback. The survey can be completed online at: **[tinyurl.com/JoinDementiaResearchSurvey2016](http://tinyurl.com/JoinDementiaResearchSurvey2016)**

If you are unable to complete it online, please call one of the charity helplines where an appointment can be made for you to complete the survey over the phone.



**Alzheimer Scotland:** 0808 808 3 000 (SCOTLAND ONLY)

**Alzheimer's Research UK:** 0300 111 5 111 (UK WIDE)

**Alzheimer's Society:** 0300 222 1122 (ENGLAND, WALES & NORTHERN IRELAND)

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## LATEST JOIN DEMENTIA RESEARCH STUDIES

There are always a variety of new studies being added to Join Dementia Research. Below are just a few of the most recent ones. Log in to your Join Dementia Research account to see if you are eligible to take part in these or any other studies that are currently on the system.

- The **ENGAGE study** is looking to determine whether a new medication called Aducanumab, can slow progression of early Alzheimer's disease, as well as investigating whether it's safe to use in patients.
- The **Preliminary evaluation of Lithium as a GSK-3 inhibitor in MCI study** is looking at a brain enzyme called 'Glycogen-synthase kinase 3' (commonly referred to as 'GSK-3') which may possibly be an effective way to prevent dementia. This study is looking to find the lowest dose of lithium which is effective to 'switch off' the GSK-3 enzyme activity.
- As well as causing memory problems, dementia can make it hard for people to carry out everyday tasks. The **TASKED study** is looking at how factors such as changes to the home environment and the role of carers can help improve the quality of life for people with dementia.
- The **RHAPSODY Project** is an EU research project funded by the Joint Programme for Neurodegenerative Diseases. They are looking for volunteers to test a new 24-hour online source of information and support designed for carers of people with young onset dementia.



## MEET THE HELPDESK HEROES!

Our three charity partners provide an essential service to Join Dementia Research, manning a telephone helpline, to answer any questions about the service and to help people sign up. Thousands of people register through the helpdesks every year and often have a variety of different questions about dementia research and dementia in general.

We spoke to Catherine McKeever, Research Information Officer at Alzheimer's Research UK, and Catherine James, Helpline Supervisor at Alzheimer's Society to find out more about their roles and the important work that they do on behalf of Join Dementia Research.

Here's an excerpt of what they had to say:

### What's your favourite part of your role?

Catherine James: It's great to know that we are giving people hope and potentially making a difference in the future. I'll always remember the lady who said 'I'm so excited, I feel like I've won the lottery' when told there were potential study matches for her husband. Similarly, when we make follow up calls, seeing the changes in study matches when we've updated a person's details, shows how valuable our input is both for volunteers and researchers.

Catherine McKeever: The feeling that you have really helped someone, either by signing them up to Join Dementia Research (especially those with a diagnosis), or by listening to their story and answering their questions. I really enjoy feeling like I've made a difference to someone's day, either because they previously felt there was nothing they could do and are now thankful there is something they can help with, or if they needed an answer to a question, but didn't know where to turn.

To read the full interview with our helpdesk heroes, please visit: [www.bit.ly/helpdeskheroes](http://www.bit.ly/helpdeskheroes)



Catherine McKeever and Catherine James

## GETTING THE MOST OUT OF YOUR ACCOUNT

We are always looking for the best way to make sure we match people to the right studies. We've recently added a couple more questions to the sign-up process that we hope will help match people to certain types of research.

The questions we've added are about APOE4, a gene that has been identified as a potential risk factor in Alzheimer's Disease, and brain proteins called amyloids. We have added a section on our FAQs page to help explain these in more depth: [www.joindementiaresearch.nihr.ac.uk/help](http://www.joindementiaresearch.nihr.ac.uk/help)

Below are the questions as they will appear when you log into your Join Dementia Research account:

Has the volunteer ever been tested for the Alzheimer's risk gene APOE4? 

Yes  No  Don't Know

Has the volunteer ever been tested for presence of Amyloid Plaque in their brain? 

Yes  No  Don't Know

To get the most out of your Join Dementia Research account, please log in to update your records and answer these new questions which will allow us to match you with studies more effectively. Alternatively, you can call one of our helplines on the phone numbers below.

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## DEMENCIA FRIENDS

Join Dementia Research has been teaming up with Dementia Friends to show how you can help change people's perceptions of dementia.

By becoming a Dementia Friend you'll learn more about dementia and the small ways you can help people affected by dementia in your community. It's all about putting understanding into action.

Find out more about becoming a Dementia Friend at [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)



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## GET IN TOUCH

We would love to hear your views on the Join Dementia Research newsletter or your experiences of taking part in research. Please email [comms.jdr@nihr.ac.uk](mailto:comms.jdr@nihr.ac.uk)

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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