



National Institute for Health Research

**Join Dementia Research newsletter**  
Winter 2019

As we enter 2019, I want to thank you for all your support last year. By registering your interest in dementia studies, people like you helped to make 2018 an eventful and encouraging year for dementia research.



2018 was a year that saw Join Dementia Research celebrate its third birthday, pass the major milestone of over 11,000 people placed in studies, and saw NICE release new guidelines recommending that everyone with dementia be told about opportunities to take part in research.

For World Alzheimer’s Month in September many of you helped raise awareness of Join Dementia Research, and we would appreciate your help continuing to spread the word as we head into the new year. When you catch up with friends and family, why not tell them about research opportunities? The more people who get involved, the greater the chance we have to improve dementia care and treatments – and one day find a cure.

Best wishes for the year to come, and thank you again for your support. Together we can make a difference to the lives of everyone affected by dementia.

**Professor Martin Rossor**  
**NIHR National Director for Dementia Research**

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## A very special diary

When his father died **Alan Richardson** made an amazing discovery - the birth of the NHS written as an entry in his father's diary. Last year that diary became a piece of history when it was shown to guests at a service celebrating 70 years of the NHS. As a Join Dementia Research and Alzheimer's Society champion, Alan has been inspired to pass on knowledge of his own.



Gerald Richardson in his St John's Ambulance uniform.



On the day Gerald Richardson retired, his colleagues decorated his ambulance with walking sticks.



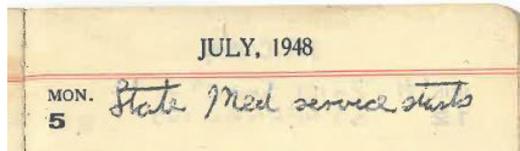
Alan Richardson at the NHS70 celebrations at Westminster Abbey in July 2018.

“ My father Gerald never kept a diary, except for once. When he died in 2003 I discovered the only diary he had ever written, from 1948.

At the start he had written “hopefully this will be a special year” – and it was. Not only did he start working with the NHS, it was also the year he met and married my mother.

He worked for the NHS ambulance service from the very first day, on 5 July 1948.

That historic moment is recorded in his diary: “State med service starts.”



It was amazing for me to go to the service at Westminster Abbey celebrating 70 years of the NHS on 5 July 2018. I had to pinch myself really.

I decided to take the diary with me. At the service I got talking to people, and everyone I met wanted to see the diary and hear its story. There was a mini queue behind me outside the Abbey after the service.

It just felt like having my dad there with me – a way of remembering everything he did.

”





## MPs spread the word about Join Dementia Research

Lawmakers including Minister of State for Care, Caroline Dinenage MP, are fighting back against dementia by spreading awareness of Join Dementia Research.

MPs and peers attended an event in Parliament in November 2018 to support more people getting involved in dementia research.

The event was organised by the Lewy Body Society, which funds research studies through its grants programme, to highlight to MPs the importance of timely and accurate diagnosis.



We were delighted to have so many MPs and peers express their support for Join Dementia Research.

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## Making our service better

Thank you to everyone who completed our survey back in the summer. An amazing 5,153 of you responded. It was great to see so much positive feedback, but you have also helped us identify ways we can make Join Dementia Research better.

Here are a just few highlights from what you said:



Just over 70% of you said it was simple to register. This is a good start but we want to do even better, so we'll be looking at ways we can improve the registration process.



We're delighted that 75% of you said you would recommend Join Dementia Research to a friend, colleague or family member. Not enough people know about this opportunity to get involved in research, so one of the best ways you can help make a difference is to tell someone about the service.



Nearly 40% of you said that you have not yet matched to a study. Please don't be disheartened if you haven't matched with any research yet. New studies are being added to Join Dementia Research all the time. When a suitable study does come along, researchers will be able to see that you have already registered your interest.

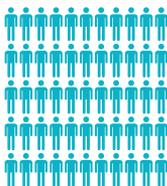
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*If you'd like to read the full version of the stories featured in this newsletter, please request a copy from any of the charity helplines overleaf.*





## Join Dementia Research in numbers



**38,651**

volunteers  
registered



**93**

studies are currently  
open to recruitment



**11,082**

participants have enrolled  
in studies to date



**246**

studies have  
recruited volunteers

*Statistics accurate as of 31 December 2018*

## Get in touch

To update your information on Join Dementia Research, please call one of the charity partner 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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