

# Participant Perspectives

We are very grateful to everyone who has generously given their time and effort to help us with the research so far. Many individuals have told us they found taking part a rewarding experience. Here some of our study participants give us their perspective.

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## Taking Part in Our Research: People with Parkinson's

Paul Beadle, 58, who has Parkinson's and is a member of Parkinson's UK's local Banbury group has already taken part: "I spent half an hour filling in the questionnaire at home. It asked in-depth questions about my health, symptoms, and possible environmental factors that may contribute to Parkinson's developing."

"Then I was invited along to my nearest centre in Banbury. The whole process took about two hours. A painless blood test was taken and then motor skills tests like balancing on one foot, how well I could manipulate my hands, and also a fascinating smell test, because loss of sense of smell can be an early warning sign of Parkinson's. There was also the option to take a brain MRI scan and donate a sample of skin or spinal fluid."

Lucy, is 39, and recently moved to Oxfordshire with her husband and two cats. She was diagnosed with Parkinson's ten months ago. Lucy is taking part in the Discovery Study and has just completed her first visit.



"I decided to take part in the study because I felt I just had to, and an overwhelming responsibility to help. In thirty years' time I don't want to be complaining that there is still no cure for Parkinson's, knowing that I could have taken part and didn't."

"The experience has been fascinating and thorough, and has helped me understand my condition a bit more, as I am still getting used to it. All of the staff were positive and friendly, and having recently moved to the area, taking part provided another means of support."

- Interview was conducted by Sarah Murphy, Dendron research nurse



Cathi Grainger lives in Great Kingshill, Buckinghamshire and was diagnosed with Parkinson's disease in 2012. Cathi is very passionate about finding a cure for Parkinson's, and a few months after her diagnosis became a research participant, along with her husband who is a control subject. Cathi has so far taken part in two of the three sessions and sees how our longitudinal study will help us monitor how Parkinson's develops over time.

Why did you take part in the Monument Discovery Study?

“It was an opportunity for me to ask questions to find out more about this disease and how I could help myself.”

What has been your experience of the study so far?

“The tests were all done in a very relaxed way with my approval to continue sought at each stage, so I didn't feel under any pressure. Between the two study sessions I gave up work and was able to exercise more, spend time with the local support group and attend various classes to improve my wellbeing. I noticed an improvement in several of the tests on the second study which gave me great pleasure, as I felt that I was being proactive for my own good and that what I was doing was working.”

Why are you eager to continue supporting the study?

“I think this study asks all the right questions and takes all the necessary tests to build an enormous database of information for researchers. This disease is wide-ranging in its symptoms with sufferers being diagnosed at different stages and different degrees of degeneration – all of which make it difficult to analyse. The longitudinal nature of the study will continue to add information on the development of the disease and can improve data that is currently available.

The study has also developed, for example, it now uses modern technology – in the first study, the rate of tremor was made as a visual assessment, whereas now it is measured by smartphone to increase accuracy.”

Is there anything you would like to say to encourage other participants?

“I would hope that those involved in the study will make it a priority to continue with it as their information is vital to building up the data needed to find a cure, see how different drugs work and examine their side effects.”

## Taking Part: REM sleep behaviour disorder Participant

Alun from Oxford is taking part in our study to observe people with REM Sleep Disorder who may be at risk of developing Parkinson's. Here he speaks with NIHR Clinical Research Network (Thames Valley and South Midlands) about his experience.



### What was the aim of the study you took part in?

I am part of a research programme at the Oxford Parkinson's Disease Centre (OPDC), called the Parkinson's Monument Discovery Project. It follows individuals over a ten-year period. The aim of the programme is to help predict if people will develop Parkinson's, understand progression and identify potential drugs.

Researchers also hope that this will help develop new treatments to prevent the development of Parkinson's in people who are at high risk of developing it.

### Why did you decide to take part in research?

Although I do not have Parkinson's myself, I have been told I am at greater risk of developing it because I have a condition called REM sleep behaviour disorder (RDB). I was therefore invited to join the study. I have a background in biomedical research myself, so perhaps I have a natural tendency to gravitate to this type of voluntary activity. Even if I did not have this personal link, I would have volunteered, as I am keen to do anything I can to help medical research and contribute to improvements in diagnosis and treatment. I think most people would have this desire if only they knew how to become involved.

### **What did taking part involve?**

When I joined, I was asked if I could attend the clinic for a follow-up visit every 18 months and complete an occasional questionnaire. These are both very straightforward and involve some very enjoyable memory, dexterity and balance tests, as well as having no practical impact on my other commitments. I have provided blood samples too but this, like all other aspects of participation, is purely voluntary.

### **Did you benefit from taking part personally?**

Although the particular study in which I am participating is not designed to offer personal benefits, many very useful insights into Parkinson's have already been gained, even though the study is still in its early stages. Online updates allow me to read about the latest study news and I find this extremely interesting.

### **What would you say to people thinking about taking part in research?**

I would definitely encourage anyone to ask about taking part in research when they see their GP or consultant. If you see information about a study that sounds interesting, you can contact the research coordinators to seek further detail. If you can, do join in. Some research might help you directly, albeit after a delay for the study information to be analysed. Even if you don't benefit yourself, participation offers an unusual way of contributing to the wider community and provides a very real sense of satisfaction. In short, I'd say 'Just get in touch and go for it!'

## Taking Part: Perspective of a Relative Participant



Michael Doherty lives in Belfast, Northern Ireland. Michael's brother Sean was diagnosed with Parkinson's in 2009. Michael travelled all the way from Northern Ireland to have his first of three appointments in the Monument Discovery study at Milton Keynes Hospital.

How has your life changed since your brother's diagnosis?

"It hasn't changed at all. I was very pleased to see my brother in such good form during my recent visit. This could be attributed to his attitude. He plays golf 3 times a week and keeps himself very mentally active. He has lots of friends who are very supportive. Sean has accepted his diagnosis and is keen to live life to the full. He is very supportive of the study, realising its importance and potential to advance our understanding of the condition. He has also been very impressed with the care and advice he has received from his NHS treatment team."

Why did you decide to take part in the study?

"I wanted to take part to support the efforts my brother is making. I would like to help the medical community in their efforts to diagnose the condition earlier. I'm happy to help in any way so the condition can be alleviated, stopped or even prevented."

As a regular blood donor I strongly believe that we should help others as much as we can. Participating in the study may help researchers find out how conditions like this can be prevented in the first place."

## Taking Part: Perspectives from ‘Healthy Controls’

Many research studies invite people known as ‘healthy controls’ to take part so results can be compared with those of people living with the condition being studied.

Hubert Allen and Fraser Old are members of ‘Friends of DeNDRoN’, a NHS panel of patients, carers and members of the public interested in improving research into Parkinson’s, dementias, and other neurological conditions. Friends of DeNDRoN offer their help and advice in a variety of ways to support local research activity and make studies more relevant to patients and carers.

Hubert and Fraser are both taking part in the Discovery study. They offer here some views on participation.

What is your interest in Parkinson’s?

Hubert: “I cared for my wife who had dementia for more than 10 years. We desperately need a better understanding of the brain through research. It strikes me how little we know about the brain, when it’s arguably the most important organ of all.”

How has your experience of the research study been so far?

Fraser: “The doctor I saw was very approachable – he explained the background in detail. I then spent a pleasant hour with a research nurse completing assessments and doing manual dexterity tests. The whole experience was very smooth and interesting. I was even lucky enough to find a parking space!”

Why did you decide to take part in the Monument Discovery study?

Fraser: “My interest in Parkinson’s is general. I understand that some researchers are moving towards a view that many neurological conditions are sub-sets of the same family. We do have a friend who lost a husband to Parkinson’s. My main consideration was the time commitment, which in the case of the study was perfectly acceptable.”

Hubert: “I am now in my 80s. I don’t feel there is much I can do, but taking part in this study gives me the satisfaction of being of some help.”



Dr Kieran Breen (left), Director of Research and Innovation at Parkinson’s UK, explains why the Discovery study team is recruiting male controls:

“We have recruited enough men over forty with Parkinson’s for the research, but now need to cross match with this particularly hard to reach group of men who may not normally consider volunteering in this way.”



## Taking Part: Lumbar Puncture and Skin Biopsy

Here one of the study's doctors speaks to a participant about their experience of a Lumbar Puncture and Skin Biopsy.

Thank you very much for taking part in our research. Would you like to tell us in a few words why you have decided to have the lumbar puncture and the skin biopsy?

With the lumbar puncture, we were asked if we could do it and I couldn't see a reason why we shouldn't. This and the skin biopsy didn't present any threat at all.

And what was your experience with the lumbar puncture? Was it uncomfortable or unpleasant?

Not at all. The doctor explained what he was going to do. It all happened, there was no pain, no discomfort afterwards. We didn't have headaches, neither me nor my wife. It was very, very painless.

Did you have any pain in the back after the lumbar puncture?

No, none whatsoever.

And how long did it take?

The whole thing, about three quarters of an hour.

And then, did you go home straight after?

We stayed on the ward for about an hour and then we were clear to go. Really, that was a non-event.

And with the skin biopsy, how did that proceed?

Even less disruptive. Quite painless.

Because you had a local anaesthetic, obviously.

Yes. I had a stitch too. I went to our local practice nurse, about two weeks later, she removed it and that was it. No problems at all.