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PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

NHS
National Institute for
Health Research



Raising Awareness of Parkinson's Research



Contact us

Contact: Olivier Bazin
Tel: (01865) 738538
Email: o.bazin@nhs.net

PARKINSON'S^{UK} **CHANGE ATTITUDES. FIND A CURE. JOIN US.**

NHS research staff are looking for people with Parkinson's who are willing to share their experiences of the condition and their views on research.

These interviews will be publicised to help raise awareness of Parkinson's and the urgent need for more and better research.

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DeNDRoN - Who we are

DeNDRoN is a NHS research network that aims to improve the amount and quality of UK-based research in Parkinson's, dementias (e.g. Alzheimer's disease), Huntington's disease and Motor Neurone Disease.



DeNDRoN's dedicated multi-disciplinary research team helps to run high-quality, nationally important studies.

Thames Valley DeNDRoN

The Thames Valley DeNDRoN team supports research in Berkshire, Buckinghamshire, Leicestershire, Milton Keynes, Northamptonshire and Oxfordshire.

We would like to invite people with Parkinson's to be interviewed to help raise awareness of the need for Parkinson's research.

We are particularly interested in interviewing people who:

- have recently taken part in a Parkinson's research study and
- are members of a local Parkinson's UK branch or support group

The interview on the following page shows the types of questions we would ask. We would also like to take photos, and if possible, use your names.

We would publicise your interview (once you have seen and approved it) in NHS research news and information materials.

We are also keen to share your views and experiences more widely in local newspapers. This next option can be discussed in more detail and will certainly not occur without your permission.

What would happen next:

If you would like to consider helping, please get in touch through the contact details on the back page. A member of the DeNDRoN team will contact you to carry out an initial interview and take some photos. This can take place in a venue of your choice (e.g. your home).



Research: a participant's perspective

The following interview was carried out with a participant and caregiver, who took part in a study on the long-term effect of rigastigmine (Exelon) capsules and skin patches in Parkinson's dementia. The questions and answers offer a sense of the kind of information we would like to portray.

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

"It's like a day out really. We enjoy the journey & like coming to see {the research team}. We're not worried about asking any questions. We really feel involved in the process. It's not like 'us and them'."

Why did you decide to take part?

"We just hope that something might help because Parkinson's is such a nasty condition. Anything that could make a difference is worth trying."

What do you most enjoy about your visits?

"We get a lot out of coming here. When we have questions, they are answered there and then, or at least, on our next visit. The research team look at the patient as a whole, they don't just think about the drug intervention or the study. We also feel grateful that somebody is taking an interest in us and trying to help us. By 'us', I really mean everybody with Parkinson's, because the condition really knows how to hit you."

What do you least enjoy about your visits?

"Injections for blood samples! I've never liked needles... Also, we start with high hopes, but we have to accept that we won't necessarily get our dream wonder drug. Still, every little helps. And I guess we're used to that uncertainty anyway."

What do you hope to get out of your participation in the study?

"Slightly better quality of life, and helping to provide information the medical community can use to advance treatments. Anything that gives any hope is worth a shot. Helping other people also plays a part."

What would you say to someone in a similar position who's unsure about taking part in research?

"Well, I'm biased of course, but I'd say 'go for it'. We were advised very clearly at the start that we could always decide to withdraw from the study if we wanted. I would personally prefer to have slightly better quality of life for 5-10 years, rather than 10-20 years of mediocre life. We felt there's always a chance (even a small one) of improvement, of it helping a bit. We'd certainly appreciate the offer of taking part in other studies in future."

