

# NEWSLETTER

## North of Scotland Parkinson's Research Interest Group (NoSPRIG)

Compiled by Andrew Grant

This Newsletter highlights what is involved in participating in **research** and being a volunteer involved in PPI (Patient and Public Involvement) and Lay Grant Reviewing, told through the experiences of two members of NoSPRIG.

### **Adventures in Parkinson's Research**

I have been asked by NoSPRIG to write about my experiences in Parkinson's research. I was diagnosed with Parkinson's in February 2018. Once I had overcome the initial feelings on my diagnosis, I wanted to do something to help fight the condition. As I have a scientific background I immediately thought of research.

I found the link (see below) on the Parkinson UK website called "Get involved in research." On this page you can find out any opportunities to be part of a research project, volunteer to help in research or simply find out more about research happening.

I immediately went to the section "Take part in research" whereby entering your postcode you can see what opportunities are available in your area. Not surprisingly there were no opportunities in Caithness! However, there were opportunities to take part in online surveys to help researchers. On further reading I found five in person opportunities that looked as if they fitted my profile. Filled with enthusiasm I applied to these opportunities. I was rejected immediately by a few for a variety of reasons. However, one based in London, got back to me saying they would like me to do more. After filling in an initial questionnaire, I had a chat over the phone with the researchers to explain what was involved. The main thing was to conduct a specialised MRI periodically over a period of years to monitor changes in the brain. The researchers said that an issue was I lived so far away. I explained it was not an issue as I travelled to London regularly. Everything looking good I thought. Then the unwelcome news that because I had

an artificial hip, I could not take part. Back to the drawing board.

I continued to look for opportunities, and indeed still do. I also joined the Research Support Network. As an aside I would recommend even if you have a passing interest in research you should join as it keeps you up to date with what is happening. An opportunity came up to be a Patient and Public Involvement (PPI) volunteer. A PPI volunteer helps researchers by reviewing plain English summaries in application documents. Also, PPI volunteers are sounding boards to help design research. One particularly interesting workshop was one to look at how a new medication would be delivered. The company involved had a wide range of options. The delivery methods were discussed, and problems identified. What was rewarding was seeing the look of comprehension on the face of one of the researchers when they understood the issues raised.

I have also taken part in a trial that used a smart watch to help control drooling. I found it very interesting and I am waiting for the results to be published.

Another meeting was one to help decide if further research should continue on GDNF. GDNF is the drug featured in this BBC Two programme;-

[BBC Two - The Parkinson's Drug Trial: A Miracle Cure? - GDNF: The Ongoing Controversy.](#)

The meeting was involved but challenging as there were different views held by participants and it was important that the correct decision was made.

In summary my experience of being involved in research has been rewarding and fulfilling. The researchers are inspiring as they are dedicating their career to curing Parkinson's.

[Get involved in research | Parkinson's UK \(parkinsons.org.uk\)](https://parkinsons.org.uk)



### **Volunteering with Parkinson's UK for Patient and Public Involvement (PPI) and Lay Grant Reviewing**

I am a 63-year-old Person with Parkinson's (PwP) who moved up to the NoSPRIG area on retirement from a University post a couple of years ago. Although "retired" I was (still am) fortunate enough to be able to continue to contribute a little to research in my academic field, which, I hasten to add, is in the humanities and has nothing to do with Parkinson's (PD).

Since my PD diagnosis 7.5 years ago I have participated from time to time in research studies as a PwP, but I was motivated to increase my engagement with the work of Parkinson's UK after being fortunate enough to obtain a last-minute ticket for the "Living Well With Parkinson's. Highland Gathering" in Inverness in September 2023. It was a brilliant "day out", with really interesting and informative talks from top experts on the latest research, and opportunities to find out about a wide range of local activities, and to participate in taster sessions, e.g. for various types of exercise, as well as to meet other PwP. I was particularly impressed by how well the day was organised and by the involvement of a fantastic, welcoming and dedicated group of volunteers. This inspired me to wonder whether there was

anything more I might be able to contribute. After a bit of discussion with Liz Nash, we decided that the best thing might be to become a volunteer for PPI and Lay Grant Reviewing. These are two distinct roles, but both have to do with bringing your experience as a PwP to bear on research.

PPI is about helping researchers to formulate their work in ways which take account of the point of view of a PwP. This, I hasten to say, does not mean trying to second-guess the researchers on the science – we don't have the expertise to do that – but for example where a project involves the participation of PwP, helping the researchers to take account of the range of problems and issues that a potential participant might have, whether e.g. with travel and access to the research venue, or helping to ensure that any patient participation information is easy to understand and as free from technical terms and scientific jargon as possible.

Lay Grant Reviewing involves reviewing applications that have been submitted for research funding and giving a lay-person's assessment of how attractively the proposed research has been formulated from the point of view of a PwP.

Before you can officially take on the role as a PPI and LGR volunteer Parkinson's UK arranges for you to participate in a training programme, which you work through at home in your own time. It includes exercises that simulate things you might be asked to do in the role in real life and the Parkinson's UK staff support you by giving you wonderfully constructive feedback on each completed exercise. I found it a lot of fun, and among other things very good mental exercise, but although this isn't emphasised in any way, I think the training also provides a good opportunity to see whether these roles are "for you". I completed the programme for both roles in autumn 2023 and since

then have been offered two or three PPI opportunities for real. I chose one which involved commenting on a draft Patient/Participant Information Sheet, which I found both fascinating and rewarding – I got a real sense of satisfaction from making a contribution, however small, to tackling, and as we all hope, eventually defeating Parkinson's. There is absolutely no pressure to take on any specific task and I had no hesitation in turning down another offer which, though very worthwhile, involved a regular commitment which I felt I wasn't in a position to take on. Lay Grant reviewing takes place seasonally, and I was just too slow off the starting blocks to participate in the autumn round of assessments, but I hope to be able to join in on the next round.

In summary, if you have an interest in Parkinson's research, I'd strongly recommend putting yourself forward as a PPI or LGR volunteer. It can't do any harm to give the training a try, and you may, like me, find it a great opportunity to play an active and rewarding role in Parkinson's research, as well to learn more about the science of Parkinson's and thereby to understand better your own condition and symptoms. If you think one or both of these roles might be for you, contact Liz Nash: ([lnash@parkinsons.org.uk](mailto:lnash@parkinsons.org.uk)).

We hope you found the foregoing informative and helpful.

If you are interested in Parkinson's research, you can listen to our podcast series by clicking on the logo below!

