

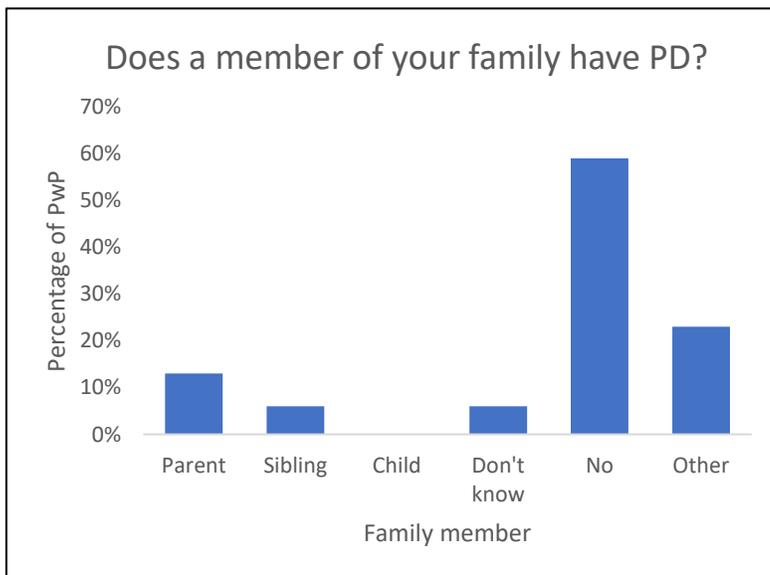
# Rallying to The Challenge 2019 Topline Survey Findings

## Genetics and Parkinson’s disease

220 people completed our 2019 Rallying to the Challenge survey looking at attitudes, understanding, and misunderstanding(!) about the role of genes in the development, progression, and treatment of Parkinson’s disease (PD).

The survey had four sections: the first section included questions on demographics. The second section looked at knowledge about genes and Parkinson’s. The third section looked into the understanding of benefits and risks of genetic testing, and the final section looked into experiences of genetic testing.

86% of participants were people with Parkinson’s (PwP), 60% of the participants were female, 3% of participants were aged 22-40, 13% of participants were aged 41-49, and 84% of participants were aged 50 and over. The nationality breakdown of the participants was as follows: US 24%, UK 46%, Canada 6%, other 24%.



The survey found that 42% of PwPs who answered the survey also had at least one other family member diagnosed with Parkinson’s. 32% of PwP who answered the survey had at least one family member diagnosed with Alzheimer’s/dementia. 27% of PwPs who answered the survey had been offered a genetic test, and 4% had not been offered a test but requested one. 8% of PwP had been offered genetic counselling.

The table below shows a pattern between age at which PwP were diagnosed and being offered a genetic test by a healthcare professional. The percentage of PwP being offered a genetic test

decreases as the age of diagnosis increases: 54% of PwP diagnosed between ages 22-40 had been offered a genetic test and accepted, 30% of PwP diagnosed between 41-50 had been offered a genetic test and accepted, 21% of PwP diagnosed between 51-60, 19% of PwP diagnosed at age 61+. This suggests that Young Onset Parkinson’s disease PwP are more likely to be offered genetic testing than PwP diagnosed at older ages.

Have you ever been offered a genetic test by a healthcare professional?				
Response	Diagnosed between 22-40y(n=13)	Diagnosed between 41-50y(n=50)	Diagnosed between 51-60y (n=67)	Diagnosed at 61+y (n=58)
Yes, and I accepted	54%	30%	21%	19%
Yes, but I declined	0%	4%	1%	2%
No, I was not offered a test	38%	56%	77%	76%
No, but I requested a test	8%	8%	1%	3%
Don’t know	0%	2%	0%	0%

The table below shows a slight decrease in the percentage of PwP being offered genetic counselling as the age of diagnosis increases.

Were you offered genetic counselling?				
Response	Diagnosed between 22-40y (n=13)	Diagnosed between 41-50y (n=50)	Diagnosed at between 51-60y (n=67)	Diagnosed at 61+y (n=58)
Yes	15%	10%	6%	7%
No	70%	82%	90%	84%
Don't know	15%	8%	3%	9%

Many participants commented that they were interested to find out more information on genetics and Parkinson's disease; "keen to find out more info", "would love to know more about it and hope it is offered if it helps us. Also, free testing would be appreciated".

Others also flagged that the interpretation of genetic tests and understanding the results can be difficult; "Generally, a person with PD is not a doctor or scientist and trying to understand the results and what they may mean is difficult", "Most people (not only PwP) don't know how to interpret genetic tests and don't understand the concept of 'risk' and incomplete penetrance".

Some comments also suggested a lack of awareness around genetics; "Genetics has never been mentioned to me", "this shows how little I know about PD", "didn't know we could have a genetic test?".

The below questions are those where 50% or more of survey participants answered 'don't know':

- Qs 11. All Young Onset Parkinson's has a genetic component.
- Qs 12. Genetic forms of Parkinson's have the same symptoms as other forms of Parkinson's.
- Qs 14. Most people with Parkinson's have more than one Parkinson's gene mutation.
- Qs 15. Some genes protect against developing Parkinson's.
- Qs 16. Insurance companies can legally access your genetic information.

As stated earlier, survey respondents came from 21 countries with the majority from the English-speaking countries (UK, USA, Ireland, Canada and Australia). Further studies will investigate and compare responses by gender, nationality, location, age and duration of illness.

Thanks so much to everyone who took part in the survey. Further results will be available later this year on the Parkinson's Movement website: [www.parkinsonsmovement.com/rallying-2019](http://www.parkinsonsmovement.com/rallying-2019)

