

Questionnaire on Parkinson's Disease and Genetics

Section 1: Background information. This section asks some background information about yourself.

1. What is your age in years?

For each question below, please mark one box only

2. Are you:

- Female
 Male

3. Are you:

- Married / de facto relationship
 Separated / Divorced / Widowed
 Single / Never married

4. What best describes the highest educational qualifications you have obtained?

- Did not go to school
 Left school at or before 15 years
 Left school after 15 years of age
 Trade/Certificate/Apprenticeship
 Diploma
 Bachelor degree
 Post-graduate degree

5. How many children do you have?

- No children
 1 child
 2 children
 3 children
 More than 3 children

6. Do you identify yourself as belonging to a particular ethnic group?

- Yes
 No

If yes, which group?

7. Is someone helping you to complete this questionnaire?

- Yes
 No

8. What is your religion?

- No religion
 Catholic
 Other Christian
 Jewish
 Other (please state)

9. How important are religious values to you when making major decisions?

- Very important
 Somewhat important
 Only a little important
 Not at all important

10. Do you have Parkinson's disease?

- Yes
 No

11. How many of your relatives (grandparents, parents, siblings, children, aunts, uncles, nephews, nieces) have Parkinson's disease?

- 0
 1
 2
 3 or more

12. What is your net household income?

- Less than \$25,000
 \$25,000 to \$50,000
 \$50,001 to \$100,000
 More than \$100,000

Section 2: Knowledge

This section asks some questions on what you know about genetics and Parkinson's disease.

13. What do you think causes Parkinson's disease?

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For each question, please mark one box only

14. Please indicate how you rate your own level of genetic knowledge?

- A lot of knowledge
 Moderate knowledge
 A little knowledge
 No knowledge

15. Can Parkinson's disease be inherited?

- Agree
 Disagree
 Don't know

16. If you have Parkinson's disease or were to develop Parkinson's disease, do you think all the other members of your family will develop Parkinson's disease someday?

- Agree
 Disagree
 Don't know

17. Genes come in pairs, with one copy from each parent.

- Agree
 Disagree
 Don't know

18. If you do not have genes that can cause Parkinson's disease, you can still get Parkinson's disease.

- Agree
 Disagree
 Don't know

19. It is possible to have a gene that causes Parkinson's disease and not have symptoms of the disease.

- Agree
 Disagree
 Don't know

20. A genetic test to determine whether or not one has a genetic form of Parkinson's disease is available right now?

- Agree
 Disagree
 Don't know

Section 3: Attitudes

This section asks what you think about genetic testing for Parkinson's disease.

21. If a blood test were to become available that would accurately show whether or not an individual has inherited a Parkinson's disease gene, do you think that test should be offered to people with symptoms of Parkinson's disease?

- Strongly agree
 Agree
 Disagree
 Strongly disagree

22. Do you think that the blood test should be offered to people without symptoms of Parkinson's disease?

- Strongly agree
 Agree
 Disagree
 Strongly disagree

23. Do you think that a pre-natal test for Parkinson's disease should be offered to pregnant mothers?

- Strongly agree
- Agree
- Disagree
- Strongly disagree

24. If a blood test were to become available in the next 6 months that would accurately show whether or not you had inherited a Parkinson's disease gene, would you want to have that test?

- Strongly agree
- Agree
- Disagree
- Strongly disagree

25. It would be too upsetting to learn I have a gene for Parkinson's disease, so I am happier not knowing.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

26. Do you think genetic testing will help scientists find a cure for Parkinson's disease?

- Very likely
- Likely
- Unlikely
- Very unlikely

27. Do you think genetic testing will help in the prevention of Parkinson's disease?

- Very likely
- Likely
- Unlikely
- Very unlikely

The following list includes reasons some people give for wanting, or not wanting, to be tested for a Parkinson's disease gene. Indicate if you agree or disagree that the following are reasons for you.

28. I could plan for the future.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

29. I could learn if my children are at risk of inheriting Parkinson's disease.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

30. A test showing that I had a gene for Parkinson's disease would make me more likely to find out about new therapies and treatments for Parkinson's disease.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

31. Treatment and prevention options for Parkinson's disease are limited, so learning I had a gene for Parkinson's disease wouldn't help much.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

32. I would be concerned about my emotional reactions.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

33. I would be concerned about my partner's reaction.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

34. I would be concerned about my family's reaction.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

35. I would not be sure if the test is accurate.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

36. I would worry about how it would affect my health and/or life insurance.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

37. I would worry that it would affect my chances of finding a job.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Section 4: Genetic information services.
This section asks for your view on services about genetic information.

For each question, please mark one box only

38. If there was a service where a health professional could inform you about genetic inheritance and Parkinson's disease, I would use that service.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

39. If you were to talk with an health professional about the genetic inheritance of Parkinson's disease, who would you most prefer to talk with?

Please mark one box only

- General practitioner
- Pharmacist
- Medical specialist
- Genetic counsellor
- Nurse
- A special help desk
- An allied health professional who specialises in genetics

40. Where would you most prefer to talk with a health professional about genetics of Parkinson's disease?

Please mark one box only

- At a hospital
- At a General practitioner rooms
- In your own home
- At a support group

41. How would you most prefer to receive information?

Please mark one box only

- Face to face in person
- By telephone
- Information sheets
- Internet

Section 5: Future studies

42. Would you be willing to take part in any future studies about Parkinson's disease?

- Yes
- No

Contact details will only retained if you answer 'yes' to this question.

