Knowledge and Attitudes Toward Genetic Testing in Parkinson's Disease

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The following research that involved surveying human subject was conducted under the supervision of a professional research institution and followed all state and federal regulations applicable to the ethical conduct of the research.

Introduction

Parkinson's disease, a degenerative neurological disorder, is thought to be caused by a combination of environmental and genetic factors and is most commonly identified by three cardinal symptoms: a resting tremor, rigidity, and bradykinesia – slowness (1). Within the past decade, researchers studying the correlation between Parkinson's disease and genetics have discovered several gene mutations that might directly cause or at least increase the risk of developing Parkinson's. In light of these discoveries, genetic testing for the parkin and PINK1 genes has become available (2,3). See Appendix A for further information about newly discovered genetic links to Parkinson's disease.

To determine attitudes that Parkinson's patients have towards genetic tests, such as the tests offered for parkin and PINK1 genes, and to evaluate the level of knowledge Parkinson's patients have about genetics, I administered a knowledge and attitudes survey to a population of 97 Parkinson's patients with three objectives:

- To identify attitudes Parkinson's patients have toward diagnostic, predictive, and prenatal genetic testing;
- To establish the level of knowledge patients with the disease have about Parkinson's, the relationship between the disease and genetics, as well as the specifics of genetic testing;
- To identify the most heavily used and most beneficial sources of information concerning Parkinson's disease.

Previous knowledge and attitudes studies on other genetic and degenerative neurological diseases have shown favorable attitudes toward diagnostic, predictive, and prenatal genetic testing. A general population study by Aro et al. revealed that 90% of the participants agreed that a genetic test should be "available to anyone who wishes to have information about disease genes she/he carries." Between 71% and 74% of the participants responded positively toward the

offering of a predictive genetic test for family planning, and between 67% and 77% agreed that a prenatal test should be available to pregnant women (4). A study by Bluman et al. revealed similarly high interests for genetic testing for the BRCA1 and BRCA2 genes that cause both breast and ovarian cancer. Of the 200 female subjects, 84% were interested in a predictive or diagnostic genetic test for these genes (5).

In 2001, an attitudes survey by Jacobs et al. concerning presymptomatic and prenatal genetic testing was delivered to a population of 111 young-onset[1] Parkinson's patients. The results showed that 72% would take a presymptomatic genetic test, and 57% were interested in the availability of a prenatal genetic test for Parkinson's (6). My study was unique in that I included participants from both the young-onset and the old-onset categories. The Jacobs study assessed the attitudes of patients with young-onset Parkinson's toward genetic testing but did not include questions about the level of knowledge or sources of information. The Jacobs study was conducted in a German population, while my study was delivered to an American subject pool (6). Based on these studies by Aro et al., Bluman et al., and Jacobs et al., the hypothesis for my study was that patients with Parkinson's disease would respond with a positive attitude toward the offering of diagnostic, predictive, and prenatal genetic testing for the disease.

Methods

I presented the survey that I designed to the Protocol Review Committee (PRC) at the Park Nicollet Institute. The survey can be seen in Appendix B. A formal letter requesting approval was written and sent to the Institutional Review Board (IRB) at the Park Nicollet Institute. Approval was granted.

[1] Young-onset Parkinson's refers to patients diagnosed at 50 or younger, and old-onset refers to those diagnosed after 50.

I administered the survey to 97 patients with Parkinson's disease at both the Struthers Parkinson's Center in Golden Valley, Minnesota and at a Young-Onset Parkinson's Disease Conference hosted by the National Parkinson Foundation in Phoenix, Arizona. Each patient was asked to sign a consent form, which had been approved by both the PRC and IRB. The consent form addressed confidentiality, possible benefits, possible hazards, and gave a brief summary of the study. Then, I orally administered the survey and gave the subjects an informational pamphlet that I had developed (See Appendix C for the information sheet).

After entering the data collected from each subject into a series of Microsoft Excel spreadsheets, I created a spreadsheet for each section of the survey that included a column for further comments or observations. I looked at the final data in terms of < 50 years at onset and $\geq$ 50 years at onset, which is the clinical division between young-onset and old-onset. Next, I created a percent-correct chart to view data from the knowledge section of the survey and generated a percent-approval chart to display data from the attitudes about genetic testing section. For the sources of information section, I developed a chart showing the percent of subjects that used each of the ten sources of information. I also developed a table to present the overall demographics of the study subjects. To test the significance of the data, I performed t-tests using χ^2 calculations. Significant data were determined by a p-value of $p \leq 0.05$.

Results (Results tables are found in Appendix E)

As shown in Table 1, of the 97 subjects surveyed, 58% were male and 42% were female. The mean age was 60.1 years, with a range of 29 to 86 years of age; 47% of the subject population developed Parkinson's before age 50. Subjects were well educated; 65% earned a college degree or higher. Subjects had a relatively low percentage of familial Parkinson's; only 3% had two or more biological family members diagnosed with Parkinson's disease, and 15% had one family member diagnosed with the disease. Ninety-nine percent of the survey subjects self-reported

their diagnosis as Parkinson's disease, and 1% as Multiple Systems Atrophy, a similar condition. This was a self-reported diagnosis since no medical records were consulted.

As shown in Table 2, the 97 subjects expressed an overall favorable attitude toward offering genetic testing for Parkinson's disease. For a 100% accurate diagnostic genetic test, a total of 79% claimed they would take the test themselves. Eighty-six percent of the old-onset Parkinson's subjects answered positively to the question regarding the 100% accurate diagnostic test; this was a statistically significant difference between the young-onset and old-onset subjects ($p = 0.050$). The young-onset survey subjects were more favorable to predictive and prenatal genetic testing[2] than the old-onset subjects. A 90% accurate predictive genetic test for Parkinson's was favorable for 70% of the young-onset survey subjects, yet only 49% of the old-onset survey subjects agreed that this test should be offered ($p = 0.050$). The young-onset survey subjects were favorable toward a prenatal genetic test at both the 90% and 60% accuracy levels; 50% responded positively toward a 90% accurate prenatal test ($p = 0.050$) and 46% answered positively to a 60% accurate prenatal test ($p = 0.050$). Only 29% of the old-onset survey subjects responded favorably to the 90% accurate prenatal test, and 25% answered in favor of a 60% accurate prenatal test. Overall, a majority of the survey subjects favored diagnostic and predictive genetic testing at all accuracy levels; there was no significant difference between the young-onset and old-onset subjects for favoring these genetic tests.

Table 3 shows that the survey subjects had an understanding of their disease; over 90% of the survey subjects answered four of the five Parkinson's disease specific questions correctly. However, only 27% answered the fifth question correctly, which was more detailed than the other four questions and asked whether Parkinson's disease is less common in people who smoke.

[2] Predictive genetic tests are given to patients before they develop Parkinson's disease, and prenatal genetic tests are given to pregnant mothers to determine if the child will develop Parkinson's disease

The survey subjects also displayed a high level of knowledge about genetics, and over 80% answered two of the three questions about genetics correctly. Subjects were least knowledgeable about the correlation between Parkinson's disease and genetics. Only 21% of the survey subjects were familiar with a mutation in a gene called parkin, 51% of the survey subjects answered correctly that scientists have identified genes that are associated with a higher risk of developing Parkinson's disease, and 26% correctly responded to the question concerning the existence of a genetic test that predicts onset of Parkinson's disease.

Young-onset survey subjects were more knowledgeable than the old-onset survey subjects. Ninety-eight percent of young-onset survey subjects responded correctly concerning the onset age of the disease, compared to the 90% of old-onset survey subjects; however, this was not a statistically significant difference in knowledge between the onset populations ($p = 0.120$). Of the young-onset subjects, 93% answered correctly about whether it is possible to have an abnormal gene without having symptoms of the disease, and only 76% of the old-onset responded correctly ($p = 0.020$). Sixteen percent of the young-onset subjects responded correctly to the question about the mutation of the gene parkin compared to only 8% of old-onset ($p < 0.001$). There was also a statistically significant difference between the level of knowledge about the genes associated with a higher risk of developing Parkinson's disease; 65% of young-onset responded correctly while only 37% of old-onset responded correctly ($p = 0.005$).

Table 4 shows percent of survey subjects that used ten sources of information. Overall, 90% of subjects indicated that they used their neurologist as a source of information. The next most common sources, books and magazines, were used by 78% of the subjects. Sixty-six percent used lay organizations, and 66% attended support groups, conferences, and educational programs for people with Parkinson's. The Internet was used as a source of information by 64% of the subjects, with 83% of the young-onset using the Internet to find information compared to the

47% of old-onset survey subjects; this was a statistically significant difference ($p < 0.001$). For the young-onset group, the four most commonly used sources of information were a neurologist (91%); support groups, conferences, and educational programs (87%); lay organizations (83%); and the internet (83%). The top four most commonly used sources of information for the old-onset survey subjects were a neurologist (88%); books and magazines (82%); nurses (63%); and lay organizations (51%). There was a significant difference between the percent of young-onset and old-onset survey subjects that utilized information from lay organizations ($p < 0.001$), as well as a significant difference between the young-onset and old-onset survey subjects that attended support groups, conferences, and educational programs ($p < 0.001$).

Conclusion

The results supported my original hypothesis that patients with Parkinson's disease, especially young-onset subjects, would favor a genetic test. Age of onset affected attitudes toward prenatal genetic testing for tests that were 90% or 60% accurate (p-values for both tests = 0.050). This may be the case because young-onset subjects are younger and may be more interested in prenatal genetic testing. While a majority of the survey subjects (79%) expressed interest in diagnostic genetic testing, neither subject population, young-onset or old-onset, showed a greater interest in this form of genetic testing than the other ($p = 0.250$).

Although there was a trend favoring genetic testing, there was also a lack of knowledge among the survey subjects, especially with the old-onset subjects, about the connection of Parkinson's to genetics. Young-onset subjects more accurately answered questions regarding the correlation between Parkinson's and genetics ($p = 0.02$, $p < 0.001$, $p = 0.005$).

The young-onset and old-onset survey subjects found different sources of information about Parkinson's disease beneficial. Young-onset subjects used the Internet significantly more ($p <$

0.001). Young-onset subjects also utilized lay organizations, such as the National Parkinson Foundation, significantly more often than the old-onset subjects ($p < 0.001$).

Results on knowledge of genetic testing for different subject populations may have been skewed since a majority (85%) of the young-onset subjects were interviewed at a Young-Onset Parkinson's conference where they learned about their disease. Further studies could include administering the survey at a conference oriented toward old-onset patients or a conference for both young-onset and old-onset patients. To broaden the study further, the survey could be mailed to reach a more diverse group of Parkinson's patients. Also, a more detailed survey could be conducted to determine why subjects support or reject genetic testing; a study could also assess concerns subjects have about genetic testing at various levels of accuracy.

As the first survey of its type for Parkinson's disease, my study has several implications. The survey subjects did express a positive attitude toward genetic testing; however, the subjects lacked an in-depth understanding of current genetic discoveries relating to Parkinson's. Understanding the knowledge base of patients with Parkinson's disease will assist educational programmers in developing informational sources that will strengthen the population's knowledge of Parkinson's.

Acknowledgements

Dr. Martha Nance, my principal advisor, answered my questions and discussed with me a range of topics, including genetic testing, the effects of Parkinson's on patients and their families, as well as the relationship between Parkinson's disease and other degenerative neurological disorders. Catherine Wielinski taught me how to conduct statistical analyses and accompanied me to the Young-Onset Conference in Arizona. Ms. Fruen connected me with Dr. Martha Nance and also guided me through the paper-writing and editing processes. The research team and Mr. Peterson also helped me revise my paper.

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Appendix A:

Studies by Healy et al., Toft et al., and Hattori et al. have linked several gene mutations (such as those in the parkin, PINK1, α-Synulcein, and DJ-1 genes) to a heightened risk of developing Parkinson's disease (2,7,8,9). Research on Huntington's disease, a hereditary disorder with similar symptoms to Parkinson's disease, can be applied to Parkinson's disease (10). The Huntington's gene was discovered in 1993, and four years later the first gene mutation associated with Parkinson's disease was brought to light. The mutation is in the α-Synulcein gene, and it was found to cause autosomal dominant Parkinson's, meaning one of the parents of a patient with a mutated α-Synulcein gene had carried this mutated gene and had Parkinson's disease (7). These same studies have revealed that the mutation in the PINK1 gene causes autosomal recessive young-onset Parkinson's disease, meaning that both parents of a patient carried this mutation and each passed on one mutated gene, but since these genes are recessive, the parents did not have Parkinson's themselves (2). Studies by Kitada et al. showed that a mutation in the parkin gene also causes autosomal recessive Parkinson's disease, and a study conducted by Abou-Sleiman et.al revealed that autosomal recessive mutations in the DJ-1 gene cause Parkinson's, specifically young-onset (8).

Appendix B: Subject Survey

Causes of Parkinson's disease—a patient survey

Demographic and disease information

1. Diagnosis *(check one)*:
   - ❑ Parkinson's Disease (PD)
   - ❑ PSP (Progressive Supranuclear Palsy)
   - ❑ MSA (Multiple Systems Atrophy)
   - ❑ Other: _____
     (please specify)

2. Gender *(check one)*:
   - ❑ Male
   - ❑ Female

3. Current Marital Status *(check one)*:
   - ❑ Single
   - ❑ Married
   - ❑ Divorced
   - ❑ Widowed

4. Do you live in a *(check one)*:
   - ❑ City/town
   - ❑ Rural area

5. Age of symptom onset:

   _____
   (please specify in years)

6. Current age:

   _____
   (please specify in years)

7. Number of living biological brothers and sisters:

   _____
   (please specify)

8. Number of living biological children:

   _____
   (please specify)

9. Highest educational level *(check one)*:
   - ❑ Grade school
   - ❑ High school
   - ❑ Technical training program
   - ❑ Some college
   - ❑ College graduate
   - ❑ Master's degree
   - ❑ Doctorate degree

10. Primary occupation *(check one)*:
    - ❑ Homemaker
    - ❑ Farming
    - ❑ Manual labor
    - ❑ Outdoor labor
    - ❑ Office/business/clerical
    - ❑ Education/ministry
    - ❑ Medical/health care/personal care
    - ❑ Science/technical/engineering
    - ❑ Other

    _____

(please specify)

11. Biological family members with Parkinson's disease *(check all that apply)*:

    - ❑ None
    - ❑ Mother
    - ❑ Father
    - ❑ Aunts/uncles

      _____
      (please specify number with PD)

    - ❑ Siblings (brothers, sisters)

      _____
      (please specify number with PD)

    - ❑ Children

      _____
      (please specify number with PD)

    - ❑ Maternal grandmother
    - ❑ Maternal grandfather
    - ❑ Paternal grandmother
    - ❑ Paternal grandfather

12. Biological family members with the following neurological diseases *(check all that apply)*:

    - ❑ Essential tremor (also called familial tremor)
    - ❑ Alzheimer's disease or dementia
    - ❑ ALS (also called Lou Gehrig's disease)

Survey Continued

Sources of information about Parkinson's disease

Which of the following sources have you used for information about Parkinson's disease?

1. Neurologist *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____

2. Internet *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

Best website:_____

3. Primary Care Doctor *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

4. Nurse (check one):

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

5. Books or magazines *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

6. Lay organizations (e.g., National Parkinson Foundation, American Parkinson's Disease Association) *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

7. Physical/Occupational/Speech Therapists *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

8. Support groups/ Conferences/ educational programs for people with Parkinson's disease *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

9. Friends/ Family members *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

10. Radio or television *(check one):*

❑ No
❑ Yes

If yes, on a scale from 1 to 10, how important was this information (1 being the most and 10 being the least)?_____.

13. What is your current level of knowledge about Parkinson's disease?_____.

(on a scale from 1 to 10, 1 being very knowledgeable and 10 being not knowledgeable at all)

14. What do you think Parkinson's disease is usually caused by *(check one)*:

❑ Head injury
❑ A viral or bacterial infection
❑ Illicit drugs
❑ An abnormal gene
❑ Exposure to something in the environment

❑ Medications prescribed by doctors
❑ Cause is unknown
❑ Other cause

_____
(please specify)

15. What do you think caused **YOUR** Parkinson's disease *(check one)*:

❑ Head injury
❑ A viral or bacterial infection
❑ Illicit drugs
❑ An abnormal gene
❑ Exposure to something in the environment

❑ Medications prescribed by doctors
❑ Cause is unknown
❑ Other cause

_____
(please specify)

16. Scientists have argued for years about whether Parkinson's disease is genetic or environmental.

From your experience with the disease, what do you think it is caused by *(check one)*:

❑ Genetic
❑ Environmental
❑ Both genetic and environmental
❑ Neither genetic nor environmental
❑ Unsure

Knowledge about Parkinson's disease and Genetics :

Here are some statements about Parkinson's disease and about genetics. They may or may not be correct. Which of the following do you believe is true?

1. Parkinson's disease is less common in people who smoke *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
2. Parkinson's disease always begins after age 50 *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
3. Parkinson's disease is caused by a problem in brain cells that use dopamine *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
4. A gene is composed of a group of proteins *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
5. Genetic diseases always begin in childhood (check one):

   ❑ True
   ❑ False
   ❑ Unsure
6. It is possible to have an abnormal gene without having symptoms of a disease *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
7. Parkinson's disease can be caused by a mutation in a gene called parkin *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
8. Scientists have identified genes that are associated with a higher risk of Parkinson's disease *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
9. There is a gene test that can identify who will get Parkinson's disease *(check one)*:

   ❑ True
   ❑ False
   ❑ Unsure
10. There is a gene therapy treatment that can cure Parkinson's disease *(check one)*:

    ❑ True
    ❑ False
    ❑ Unsure
11. There is an over-the counter, "natural" treatment that can cure Parkinson's disease *(check one)*:

    ❑ True
    ❑ False
    ❑ Unsure

Survey Continued

Attitudes about genetic testing

A. If a genetic test could accurately determine that a person would develop Parkinson's disease:

1. Would you take this test?

   ❑ Yes
   ❑ No
   ❑ Unsure

2. Do you think this genetic test should be offered to people without symptoms of Parkinson's disease?

   ❑ Yes
   ❑ No
   ❑ Unsure

3. Do you think that brothers and sisters of a person diagnosed with Parkinson's disease should take this genetic test?

   ❑ Yes
   ❑ No
   ❑ Unsure

4. Do you think this genetic test should be offered to young adults or children in a family with a person diagnosed with Parkinson's disease?

   ❑ Yes
   ❑ No
   ❑ Unsure

5. Do you think a prenatal genetic test should be offered to pregnant mothers?

   ❑ Yes
   ❑ No
   ❑ Unsure

B. If a genetic test could associate a person with a 90% risk of developing Parkinson's disease:

1. Would you take this test?

   ❑ Yes
   ❑ No
   ❑ Unsure

2. Do you think this genetic test should be offered to people without symptoms of Parkinson's disease?

   ❑ Yes
   ❑ No
   ❑ Unsure

3. Do you think that brothers and sisters of a person diagnosed with Parkinson's disease should take this genetic test?

   ❑ Yes
   ❑ No
   ❑ Unsure

4. Do you think this test should be offered to young adults or children in a family with a person diagnosed with Parkinson's disease?

   ❑ Yes
   ❑ No
   ❑ Unsure

5. Do you think a prenatal genetic test should be offered to pregnant mothers?

   ❑ Yes
   ❑ No
   ❑ Unsure

C. If a genetic test could associated a person with only a 60% risk of developing Parkinson's disease:

1. Would you take this test?

   ❑ Yes
   ❑ No
   ❑ Unsure

2. Do think this genetic test should be offered to people without symptoms of Parkinson's disease?

   ❑ Yes
   ❑ No

3. Do you think that brothers and sisters of a person diagnosed with Parkinson's disease should take this genetic test?

   ❑ Yes
   ❑ No
   ❑ Unsure

4. Do you think this genetic test should be offered to young adults or children in a family with a person diagnosed Parkinson's disease?

   ❑ Yes
   ❑ No
   ❑ Unsure

5. Do you think a prenatal genetic test for Parkinson's disease should be offered to pregnant mothers?

   ❑ Yes
   ❑ No
   ❑ Unsure

D. If a genetic test could determine that you are more or less likely to benefit from a particular medication to treat your Parkinson's disease symptoms, would you *(check one)*:

- ❑ Definitely take the test
- ❑ Definitely not take the test
- ❑ Take the test only if insurance would pay for it
- ❑ Unsure

E. If a genetic test could determine that you are more or less likely to develop side effects from a particular medication to treat your Parkinson's disease symptoms, would you *(check one)*:

- ❑ Definitely take the test
- ❑ Definitely not take the test
- ❑ Take the test only if insurance would pay for it
- ❑ Unsure

Appendix C: Information Sheet on Parkinson's Disease

Let's See How You Did!!!

Answers to the Parkinson's disease and genetic questions

Dana Lundberg
Research Associate

Dr. Martha Nance
Principal Investigator
Further questions? Please call: 952-993-5495

1. ***Parkinson's disease is less common in people who smoke:*** **TRUE**

   Studies have shown that Parkinson's disease is less common in people who smoke. However, that does NOT mean that smoking is good for people who have Parkinson's disease or for anyone else!

2. ***Parkinson's disease always begins after age 50:*** **FALSE**

   Although most Parkinson's disease cases develop when a person is in his or her 60's, early-onset Parkinson's disease often begins when the person is in his or her 40's. Researchers believe that up to 10% of Parkinson's patients are diagnosed at an even younger age.

3. ***Parkinson's disease is caused by a problem in brain cells that use dopamine:*** **TRUE**

   The level of dopamine in the part of the brain that controls motor function (substantia nigra) decreases, damaging cells and causing them to die off. To counteract this effect, drugs, such as Sinemet (carbidopa-levodopa), are used to restore the level of dopamine.

4. ***A gene is composed of a group of proteins:*** **FALSE**

   Genes are composed of nucleic acids. Each gene is a recipe that tells the cell how to make a particular protein.

5. ***Genetic diseases always begin in childhood:*** **FALSE**

   Every person is born with a set of genes, and throughout a person's life, these genes do not change. However, a person born with an abnormal gene that can cause a genetic disease may or may not experience symptoms when he or she is young. The symptoms of genetic diseases can begin to affect a person during any stage of his or her life.

6. ***It is possible to have an abnormal gene without having symptoms of a disease:*** **TRUE**

   A person that has an abnormal gene without displaying any symptoms of a disease is called a "carrier". Many carriers never know they have an abnormal gene and unknowingly pass it onto their children who then may be at risk of developing the disease. Even though a person with a gene abnormality may never develop symptoms, they may still be at a higher risk of developing the disease and may want to take extra steps to protect their health.

7. ***Parkinson's disease can be caused by a mutation in a gene called parkin:*** **TRUE**

   Studies have shown that a double dose (one from both the mother and the father) of a mutation in a gene called parkin can cause juvenile onset (before age 18) Parkinson's disease. Mutations in the parkin gene are also seen in up to 40% of people who develop Parkinson's disease before age 40, as well as in people with later onset. It is unclear whether a single dose of this abnormal gene directly causes Parkinson's disease, or whether it puts a person at a higher risk for developing the disease.

8. ***Scientists have identified genes that are associated with a higher risk of Parkinson's disease:*** **TRUE**

   Studies have shown that abnormalities in several genes, including parkin, DJ-1, PINK1, and alpha-synuclein may cause or put a person at a higher risk of developing Parkinson's disease.

9. ***There is a genetic test that can identify who will get Parkinson's disease:*** **UNSURE**

   This is a trick question. Testing for the parkin gene and the PINK1 gene is available in the United States, and may be useful to a person with a history of several affected family members or with a symptom onset under 40. Because these tests are so new, neurologists are not yet certain how a gene mutation relates to a person's symptoms. It is also uncertain whether the gene tests will identify all abnormal genes that are important to the patient (some abnormal genes lead to symptoms, but others may cause no problems at all). Environmental factors also seem to be important in Parkinson's disease. Although certain genes may cause people to develop Parkinson's disease later in life, we currently do not understand these genes well enough to use them for clinical testing. Until we learn more, we do not recommend genetic testing for Parkinson's disease unless there is a strong family history or a young onset age.

10. ***There is a gene therapy treatment that can cure Parkinson's disease:*** **FALSE**

    We wish there was! Currently, state-of-the-art treatments including Sinemet and other anti-parkinson's drugs combined with physical, occupational, and speech therapy, work to combat the symptoms.

11. ***There is an over-the counter, "natural" treatment that can cure Parkinson's disease:*** **FALSE**

    In some ways, Sinemet is an "all-natural" treatment. This drug restores dopamine (a chemical that already exists in the body) to the brain. Unfortunately, Sinemet is not a cure, and like all the treatments we have today, it only helps to ease symptoms. Do not lose hope though, the scientific community has yet to stop its search to prevent and cure Parkinson's disease!

Appendix D: Result Tables

Table 1: Demographic Characteristics of Subjects (n = 97)

Gender:	Male	58%
	Female	42%
Current Age (years):	mean	60.1
	range	29 - 86
Onset Age:	< 50 years	47%
	≥ 50 years	53%
Self-reported diagnosis:	Parkinson's disease	99%
	similar condition (i.e. MSA)	1%
Highest level of education:	High school	19%
	Technical training or some college	16%
	College graduate or higher	65%
No. of biological family members with PD:	none	79%
	1	15%
	2	2%
	2+	3%

Table 2: Attitudes toward Genetic Testing (Percent Yes) (n = 97)

Questions	< 50 years at onset n (%)	≥ 50 years at onset n (%)	Total (%)	p-value
If a genetic test could accurately (100%) determine that a person would develop Parkinson's disease:				
Would you take this test?				
Percent Yes	33 (72%)	44 (86%)	79%	P = 0.250
Do you think this genetic test should be offered to people without symptoms of Parkinson's disease?				
Percent Yes	36 (78%)	34 (67%)	72%	P = 0.250
Do you think a prenatal genetic test should be offered to pregnant mothers?				
Percent Yes	23 (50%)	17 (33%)	41%	P = 0.100
If a genetic test could associate a person with a 90% risk of developing Parkinson's disease:				
Would you take this test?				
Percent Yes	33 (72%)	41 (80%)	76%	p = 0.250
Do you think this genetic test should be offered to people without symptoms of Parkinson's disease?				
Percent Yes	32 (70%)	25 (49%)	59%	P = 0.050
Do you think a prenatal genetic test should be offered to pregnant mothers?				
Percent Yes	23 (50%)	15 (29%)	39%	P = 0.050
If a genetic test could associate a person with only a 60% risk of developing Parkinson's disease:				
Would you take this test?				
Percent Yes	23 (50%)	34 (67%)	59%	P = 0.100
Do you think this genetic test should be offered to people without symptoms of Parkinson's disease?				
Percent Yes	26 (57%)	25 (49%)	53%	P = 0.500
Do you think a prenatal genetic test should be offered to pregnant mothers?				
Percent Yes	21 (46%)	13 (25%)	35%	P = 0.050

Table 3: Knowledge about Parkinson's and genetics (Percent Correct) (n = 97)

Knowledge Questions:	< 50 years at onset n (%)	≥ 50 years at onset n (%)	Total (%)	p-value
Parkinson's Disease Knowledge Questions:				
Parkinson's disease is less common in people who smoke.	16 (35%)	10 (20%)	27%	P = 0.090
Parkinson's disease always begins after age 50.	45 (98%)	46 (90%)	94%	P = 0.120
Parkinson's disease is caused by a problem in brain cells that use dopamine.	44 (96%)	44 (86%)	91%	P = 0.110
There is a gene therapy treatment that can cure Parkinson's disease.	45 (98%)	47 (92%)	95%	P = 0.210
There is an over-the counter, "natural" treatment that can cure Parkinson's disease.	46 (100%)	48 (94%)	97%	P = 0.090
Specific Genetic Questions:				
A gene is composed of a group of proteins.	9 (20%)	4 (8%)	13%	P = 0.090
Genetic diseases always begin in childhood.	39 (85%)	40 (78%)	81%	P = 0.440
It is possible to have an abnormal gene without having symptoms of a disease.	43 (93%)	39 (76%)	85%	P = 0.020
The Genetics of Parkinson's Disease Questions:				
Parkinson's disease can be caused by a mutation in a gene called parkin.	16 (35%)	4 (8%)	21%	P < 0.001
Scientists have identified genes that are associated with a higher risk of Parkinson's disease.	30 (65%)	19 (37%)	51%	P = 0.005
There is a gene test that can identify who will get Parkinson's disease.	9 (20%)	16 (31%)	26%	P = 0.180

Table 4: Sources of Information about Parkinson's (Percent of Usage) (n = 97)

Source:	< 50 years at onset n (%)	≥ 50 years at onset n (%)	P-values	Total (%)
Neurologist	42 (91%)	45 (88%)	P = 0.650	90%
Books/ magazines	34 (74%)	42 (82%)	P = 0.320	78%
Lay organizations	38 (83%)	26 (51%)	P < 0.001	66%
Support groups/ Conferences/ Edu. programs	40 (87%)	24 (47%)	P < 0.001	66%
Internet	38 (83%)	24 (47%)	P < 0.001	64%
Nurse	19 (41%)	32 (63%)	P = 0.030	53%
Physical/ Occupational/Speech therapists	22 (48%)	21 (41%)	P = 0.530	44%
Friends/Family	19 (41%)	21 (41%)	P = 1.000	41%
Radio/TV	15 (33%)	18 (35%)	P = 1.000	34%
Primary Care Doctor	10 (22%)	21 (41%)	P = 0.040	32%