PROGENI

Parkinson's Research: The Organized Genetics Initiative

A group of neurologists from throughout the United States and Canada, known as the Parkinson Study Group (PSG), have formed a collaborative effort with Indiana University School of Medicine, to study genetic and other risk factors which may be important in the development of Parkinson's disease.

This study, “Parkinson's Research: The Organized Genetics Initiative”, also known as PROGENI, is being sponsored by the National Institutes of Health and will involve people throughout North America who are affected, or possibly affected, with Parkinson's disease (PD) and who have a history of other relatives with PD.

PROGENI is a multi-center study funded by the National Institutes of Health.

For more information about the PROGENI study please call 1-888-830-6299

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IS THERE PARKINSON'S DISEASE IN YOUR FAMILY PORTRAIT?
Who can participate in this study?
To be eligible to participate in this study participants must be diagnosed with or have symptoms of PD. In addition, they must also have a family history of PD in other relatives.

What would I have to do if my family were to participate?
Participants will be asked to complete a Family History Questionnaire, providing information about the history of Parkinson’s disease in the family. They will also be asked to discuss the symptoms they have experienced and their response to PD medications. This information will be used by study personnel at Indiana University School of Medicine, Department of Medical and Molecular Genetics, to determine further eligibility for the study.

What else might we have to do if we were selected to be a part of this study?
You could be asked to undergo a Study Visit at the Parkinson Study Group (PSG) site closest to your residence. At this Study Visit you will be asked to complete questionnaires regarding PD symptoms, medical history, places of residence, occupations, mood, mental status and activity level. A blood sample will be drawn for DNA extraction. This visit will take about 2 hours.

What is DNA and how will it be used?
DNA is the genetic material that determines such things as hair color, eye color or other more complex traits. The DNA samples obtained from my blood sample, will be used in an attempt to find genes that may cause an increased risk for a person to develop Parkinson’s disease.

Where might the Study Visit be conducted?
We are collaborating with many PSG sites located across North America, including sites in the US, Canada, and Puerto Rico. If you or your sibling is unable to travel to one of these sites, arrangements may be made for the Study Visit to be conducted at your home.

Is there anything else we might be able to do as part of this study?
Upon completion of the Study Visit, you will be eligible to take part in a voluntary autopsy program. This autopsy would be done to definitively diagnose PD. Costs associated with the autopsy will be paid by the study.

What else should I know about this study?
- Participation is totally voluntary.
- Information you provide to us will be kept confidential.
- There will be no cost to you to take part.
- There is no payment for participation.

Where can I get additional information?
More information about PROGENI is available on our web site at: http://progeni.iupui.edu/

You may also contact Cheryl A. Halter, MS via email at progeni@iupui.edu.

I want to participate. What should I do?
Please call 1-888-830-6299 or 1-317-274-5734 to enroll in PROGENI.