Join the fight

Do you ever wish that you could do more to help your family member with their struggle against Parkinson disease?

Very little is known about the early phases of Parkinson disease. By the time the common symptoms, such as tremor appear, there have already been significant changes in the brain.

Early detection of Parkinson disease is the first step towards finding a cure, and could be as simple as testing sense of smell.

The help of one healthy volunteer can make a difference in the lives of many individuals with early parkinsonian symptoms.

More information about PARS is available on our web site at http://www.parsinfosource.com

You may also contact us at:

PARSinfo@indd.org
1-877-401-4300
or
1-203-401-4300

Sponsored by:

A study for relatives of Parkinson disease patients
The first step towards a cure

What is this study all about?
The PARS Study is the largest long-term study in the United States of relatives of individuals with Parkinson disease. It will evaluate 15,000 relatives for 3-5 years to determine whether specific tests are able to predict who may be at increased risk for developing Parkinson disease. The goal of the PARS study is to better understand who is at risk for Parkinson disease so that it can ultimately be prevented before it starts. The initial tool to be evaluated will be a test of the sense of smell.

Why are we interested in testing smell?
In many patients with Parkinson disease, the first symptom to appear is a loss in their sense of smell. Smell loss in Parkinson disease patients seems to occur even prior to the onset of symptoms like tremor or slowness in movement. By the time motor symptoms occur, there have already been significant changes in the brain. In order to prevent worsening of these symptoms or ultimately, prevent the onset of motor symptoms, we need to develop a test or set of tests that can detect signs that may represent early Parkinson disease. By using smell testing in combination with other tests we hope to develop a system to detect Parkinson disease before it starts.

You may be eligible to join if:
- You have a first-degree relative (mother, father, sibling or child) diagnosed with Parkinson disease.
- Your age is 50 years or older
- You have not been diagnosed with Parkinson disease yourself
- You have no history of nasal trauma or surgery involving your nose or sinuses

Participation in the PARS study is easy. If you choose to partake in this research...
- You will be asked to complete a form with your contact information.
- We will send you a scratch and sniff smell test and a brief questionnaire to be completed by you at home.
- You may be contacted to continue the mail-in questionnaires annually or to be evaluated by a neurologist near your home. Some individuals may be asked to undergo more extensive testing. The level of your participation is optional.

Why study family members of individuals with PD?
Studies have shown that first-degree family members have a slight increase in their risk to develop Parkinson disease compared to people who do not have a first-degree relative (a sister, for example) with Parkinson disease. First-degree relatives may share many of the same genes and risk factors. By studying relatives, we will have a greater chance of identifying those risk factors. In our experience of working with families of our Parkinson patients, relatives have an increased interest and commitment to participation in this research by virtue of having an affected family member.

Why would I want to participate in this research?
Most people who choose to participate in research hope it will improve our knowledge -- for example, the role of genetics and environment in the disease -- that will benefit themselves or others. Since there is no intervention or treatment offered in the study, the risks to the participant are very minimal and there is no immediate medical benefit. Most people who participate in studies like this do so because they want to help their affected relative or future generations. In this case, relatives who participate may want to help people learn how to prevent Parkinson disease.