



THE INSTITUTE FOR
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PARS UPDATE

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WELCOME!

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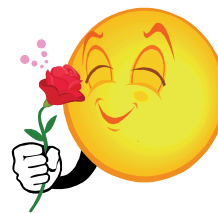
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Welcome to the first issue of the PARS Newsletter! We thank you all for your interest and participation in this study. One of the goals of this newsletter is to provide you information regarding the progress of the study and new information that we learn as a result of the study.

We are pleased to report that there has been tremendous interest in the PARS study! Recruitment for the study has been better than anticipated. To date, over 5,000 people have completed eligibility forms and more than 2,500 people have completed the initial smell test for the study. Many of the participants in this study have a family member affected by Parkinson's disease. We have recently also expanded the population through a sub-study we call the MINDSPAN study. The MINDSPAN study consists of nurses and veterans over the age of 50 who are willing to

participate in the study activities. We have received an overwhelming response to MINDSPAN.

Our biggest resource for this study is you, the participants! We thank you for completing all of the forms and smell tests. We are grateful for your commitment to the study and anticipate with the help of the participants we will be able to better understand the factors that predict who may be at risk for Parkinson's disease. If we can develop a means to detect early changes in Parkinson's disease we may be able to delay or prevent the onset of disease.



PARTICIPATING CENTERS:

- Baylor College of Medicine, Houston TX
- Beth Israel, New York, NY
- Boston University, Boston MA
- Emory University, Atlanta GA
- The Institute of Neurodegenerative Disorders, New Haven CT
- Mayo Clinic, Scottsdale AZ
- Medical College of Georgia, Augusta GA
- Northwestern University, Chicago, IL
- Portland VA Medical Center, Portland OR
- University of Rochester, Rochester NY
- University of South Florida, Tampa FL
- The Parkinson's Institute, Sunnyvale CA
- UCLA, Los Angeles CA
- University of North Carolina, Chapel Hill NC
- University of Pennsylvania, Philadelphia, PA

WHO IS CHOSEN TO PARTICIPATE IN THE PARS STUDY?

The PARS Research team is interested in learning about the sense of smell and how it may relate to neurologic conditions. In this study, we are evaluating individuals that have a decreased ability to smell as well as individuals who have a good sense of smell. Whether you have a good or bad sense of smell, you are important to the study.

Once you have completed the smell test, you will be asked to join one of two groups in this

study, the mailing group or the clinical evaluation group. People participating in the clinical evaluation are asked to complete a visit every year at the center closest to where they live and also travel to New Haven, CT to undergo brain imaging. The clinical visits occur every year and the imaging visits at the beginning of the study and two years later. In addition, participants in the clinical evaluation group will be sent a smell test and question-

naire to complete every year. People who are participating in the mailing group will be sent questionnaires every year and smell tests every other year.

Regardless of which group you are in, your continued participation in this study is critical to its success. We appreciate the time you have committed to completing the questionnaires and traveling to centers for visits. The success of the PARS study relies on the dedication of all its participants.

**SCREENING FOR PARKINSON'S DISEASE: HOW, WHO AND WHEN
BY ANDREW SIDEROWF, MD**

Screening in medicine has become so common that we take it for granted when the doctor checks our blood pressure or cholesterol. Screening tests are done to detect risk factors for illnesses so that these conditions can be caught and corrected before serious problems develop. Throughout medicine, from diabetes to osteoporosis to glaucoma, screening and prevention have become the standard approach. It is only a matter of time before the same is true for Parkinson's disease (PD).

How do currently available screening tests work?

The ability to detect PD before motor features develop already exists. Imaging tests such as fluorodopa-PET (positron emission tomography) and dopamine transporter SPECT (single photon emission computed tomography) (right) create pictures of the dopamine neurons in the brain. Up to 30-50% of these neurons are lost before the motor symptoms of PD become apparent. PET and SPECT scans are sensitive enough to show abnormalities that are less than this threshold. Several studies using imaging have shown abnormalities in at-risk people several years before they are diagnosed with PD.

Olfactory (smell) testing can also detect evidence of PD before tremor or rigidity become apparent. Unlike imaging, smell testing is inexpensive and can be done anywhere using portable scratch and sniff booklets such as the University of Pennsylvania Smell Identification Test (UPSIT) (see page 3).

Genetic tests can also be used to identify people who are at risk of developing PD. About 10% of PD is now thought to be due to genetic causes. This number could climb much higher as progress in genetics continues at a rapid pace. Tests for genetic variants (mutations) known to cause PD are currently performed in research laboratories, and one test, for the *parkin* gene, is commercially available.

However, each of these technologies has limitations. Genetic testing is limited because only a fraction of PD is genetic. In addition, genetic tests give no indication of the age at which PD will start. Imaging is probably very accurate, but is expensive and needs to be repeated every few years to catch the first evidence of brain degeneration. Olfactory testing, while inexpensive and portable, is less accurate than imaging, as there are many reasons for a reduced sense of smell other than incipient PD.

One solution to the limitations of individual tests is to use them in combination. For example, an individual who is at increased risk due to genetic factors could be screened periodically with an olfactory test and have imaging only when impairment in smell testing is noted. This staged approach to screening is common throughout other areas of medicine.

Who might be a candidate for screening?

General population screening is usually reserved for very

common disorders such as heart disease. Screening for PD is more likely to target high-risk groups, such as people with a family history of PD, or extremely high levels of exposure to environmental factors that may increase the risk of PD. Targeted screening is already used in other areas of medicine including some cancers and infectious diseases.

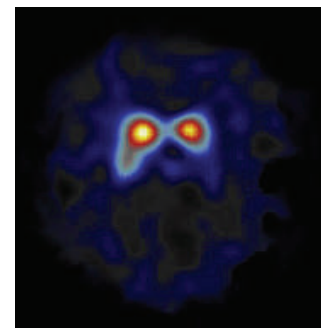
There are currently no guidelines that recommend routine screening for PD, and screening is not part of standard clinical practice, even at specialty clinics that care for families with multiple affected members. In select settings, individuals who are at high risk for PD may receive the results of genetic testing as part of a research protocol. In such cases, results of research screening tests needs to be accompanied by substantial counseling to help the at-risk individual put the meaning of the test into the proper context.

When will screening for PD become commonplace?

Preventive therapy is the key missing ingredient that would rationalize widespread predictive testing for PD. Some at-risk individuals may decide to be tested to help with life-planning or to reduce anxiety related to the belief that they may develop PD. However, without treatments that can delay the onset of motor symptoms once a person has a positive screening test, widespread screening programs for PD are probably not justified.



BCIT Image of Healthy Control



BCIT Image of Early PD

WORDS TO KNOW

- **Neurotransmitter—** Chemicals which relay messages between cells in the nervous system.
- **Dopamine—** A neurotransmitter responsible for important roles in the brain including motor activity, mood, cognition, and motivation. There is decrease in dopamine in people with Parkinson's disease.
- **SPECT—** An imaging test-scan using a radio-labeled pharmaceutical to capture multiple 2-D images from various angles.

SCREENING FOR PARKINSON'S DISEASE (CONTINUED)

On the other hand, now is an appropriate time to develop and test screening strategies so they will be ready to use when they are needed. At some point in the future, effective neuroprotective therapies will exist, and efficient and reliable screening strategies should be in place so that these therapies can be used in a preventative fashion. As a clinical research agenda, screening tests and neuroprotective treatments should be developed in parallel to achieve the goal of preventing PD.

For the time being, screening for PD is being performed as clinical research rather than clinical practice. The Parkinson At-Risk Study (PARS) is a nationwide effort to test the screening strategy of olfactory testing followed by SPECT imaging in 1st degree relatives of PD patients. The PARS study will screen thousands of relatives of PD patients with olfactory testing over the next 4 years. People with a parent, sibling or child with PD, and who are either over 50 years old or within 10 years of the age of onset

of their affected relative may be eligible. The study is being conducted at 15 clinical centers and is being sponsored by the Telemedicine and Advanced Technology Research Center (TATRC) through the U.S. Department of Defense. For more information about TATRC, please visit their website at <http://www.tatrc.org/>.



The University of Pennsylvania Smell Identification Test (UPSIT) is made up of four scratch and sniff booklets. Many patients with Parkinson's disease lose their sense of smell some time before other symptoms develop.

PARS IN THE NEWS

The PARS study has been featured on several newscasts around the country and in many publications. We are pleased that the study has received so much attention.



Parkinson's Study at Northwestern Memorial Hospital

<http://media.vmsnews.com/MR.pl?id=103108-684076-S001559182>

"Sniffing out Parkinson's Disease"

<http://abclocal.go.com/wabc/story?section=news/health&id=6370608>

PARS IN THE RESEARCH COMMUNITY

Over the past year, the PARS study has been presented at several professional meetings and is gaining attention among Parkinson's disease researchers throughout the world.

Information obtained through the recruitment process has been presented at the American Academy of Neurology in Chicago (May, 2008) and at the Movement Disorder Society Congress in Chicago

(June 2008). Upcoming presentations include

- AD and PD International Congress in Prague (March 2009)
- American Academy of Neurology in Seattle (April 2009)
- The Movement Disorders Society Congress in Paris (June 2009)

PARS: GIVING BACK TO THE COMMUNITY

What do you do when you receive over three thousand number two pencils? At PARS, we've decided to donate them.

Every pencil participants send back with their smell tests is sharpened and sent out to the Vincent L. Mauro Elementary School in New Haven, Connecticut.

The school is a local magnet school for the sciences, as well as being one of the area's only bilingual elementary schools.

SPOTLIGHT ON DONNA MILES

THE PARS STUDY TEAM

The PARS study is a collaborative effort of researchers from the University of Pennsylvania (UPENN) and the Institute for Neurodegenerative Disorders (IND). The study is lead by Andrew Siderowf and Matt Stern at UPENN and Danna Jennings and Ken Marek from IND. Other members of the PARS team include Shirley Lasch, Jamye Mart, Susan Mendick, Donna Miles and Katrina Miles.



From Left to Right: Dr. Kenneth Marek, Dr. Matt Stern, Dr. Danna Jennings, and Dr. Andrew Siderowf

Each issue of the PARS newsletter will spotlight a member of the PARS Team. This issues spotlight is on Donna Miles. Donna has worked at IND for 4 years and has been working on the PARS study since its inception. Prior to working on the PARS study, she worked at IND in the clinical imaging department and has brought much of her knowledge and experience about B-CIT imaging to the PARS study. Donna has been very busy contacting subjects to ask them to participate in the study. Many of you may have already spoken to Donna on the phone and know first hand what an important member of our team she is.



RETURN OF SMELL TESTS AND QUESTIONNAIRES

You will all be receiving by mail a packet each year to complete. This packet will contain a questionnaire and a smell test. We ask that you complete these items within a week of receipt and mail them back to us.

SEND US YOUR STORIES AND QUESTIONS!

Do you have a story you would like to share with others about the Parkinson's Associated Risk Study? Or do you have questions you would like to ask our investigators? Send an email or mail a letter to the PARS Team! We're looking forward to including your experiences and inquiries in future newsletters.

SPREAD THE WORD!

The PARS study is still looking for people to participate! If you have relatives who may be interested in participating or friends with relatives who have PD please encourage them to contact us and complete an eligibility form.



CHANGE OF ADDRESS

Please contact us if your address, telephone numbers or email address should change.

Contact Us:
The PARS Study Team
60 Temple Street, Suite 8B
New Haven, CT 06510
203-401-4300
Toll Free 1-877-401-4300
www.parsinfosource.com
parsinfo@indd.org