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What is PDBP?

PDBP (Parkinson's Disease Biomarkers Program) is a group of researchers and doctors investigating Parkinson's disease (PD) across the US. Our goal is to discover biomarkers that would help design better clinical trials for PD treatments.

What Are Biomarkers? A biomarker is an indicator of a biological state which can be used to measure progression of a disease. Examples of biomarkers include cholesterol (for heart disease) and blood pressure (for heart disease or stroke risk). No biomarkers currently exist for PD.

Why Participate? By participating, you may help us identify treatments that will slow down PD and introduce them to the clinic more quickly.

What Does Participating Involve? The study includes a physical examination as well as paper and pencil testing to access memory. You will be asked to answer questions about your mood and your sleep. You will also be asked to do a "scratch and sniff" smell test. You will also be asked to give a blood sample and, in most cases, a sample of cerebrospinal fluid (CSF), the fluid that bathes the brain. People with PD, as well as people without PD, are needed for the study so we can do a comparison between them. ■



*Why the tulip?
J.W.S. Van der
Wereld, a Dutch
horticulturalist
with PD, created
a red and white
tulip, which he
named the 'Dr.
James Parkinson'
tulip, to honor Dr.
James Parkinson,
who was the first
to describe PD in
1812.*



Dr. Zimmet's visit to NINDS

Patients' Corner

PDBP Recruits 1000th Subject

By Chris Palmer, NINDS

Over the summer, the 1,000th subject was enrolled in the PDBP, marking a major milestone in the efforts of NINDS to develop a method to predict the early onset—and track the progression—of this debilitating neurological disorder.

To acknowledge this achievement, NINDS Director Story Landis penned a blog post about the program and applauded the efforts of the subjects who have enrolled as well as the staff at PDBP's seven specimen and data collection sites around the country. Also marking the occasion, the very first patient to join the program at the Johns Hopkins University site, Dr. Paul Zimmet, a retired dentist living in Northern Virginia, accompanied by his wife, Marcia, visited with PDBP program staff in late August to share his thoughts about improving recruitment of Parkinson's patients in research studies.

Please see 1000th Subject on page 3

PDBP Patient Data Management Resource (DMR) Wins IT Award

PDBP recently received the 2014 Best Overall Excellence.Gov award for its patient data portal DMR.

“The award honors programs and projects that use innovative technology to improve the services government provides to its citizens.”

The award, sponsored by the American Council for Technology and Industry Advisory Council (ACT-IAC), honors exceptional government programs and projects that use innovative technology to improve the services government provides to its citizens. The finalists and winners are selected by a panel of government and industry judges. According to the ACT-IAC, award “celebrates ‘leap ahead’ technologies, strategies, or processes that demonstrate how it is possible to achieve groundbreaking results on government programs.” Prior to the ceremony, which was held on March 24, 2014 at the Arena Stage in Washington, DC, PDBP DMR was one of the top 5 candidates in the Excellence in Health Care IT category. During the ceremony, however, the group was selected for the Best Overall Award, topping their larger IT competitors.

The PDBP DMR Team: Dr. Margaret Sutherland, NINDS; Dr. Katrina Gwinn, NINDS; Dr. Matt McAuliffe, NIH CIT; Dr. Debra Babcock, NINDS; Dr. Beth-Anne Sieber, NINDS; Dr. Coryse St Hillaire-Clarke, NINDS; Susan Baker, NIH-CIT; Jenna Linde, NIH-CIT; Barry Landin, NIH-CIT; David Vismer, Sapient; and Matt Torrenzano, Sapient ■

How It Works?

PDBP projects are supported through the PDBP Data Management Resource (PDBP DMR) and the NINDS Repository.

Projects submit de-identified clinical data to the PDBP DMR through a web-based data entry system, using electronic clinical research forms including common data elements (CDEs). CDE captures standard diagnostic features that allow researchers to compare data from different study cohorts.

Clinical data is deposited in DMR. Researchers can request access to this data. The PDBP Data Access Committee (DAC) reviews such requests to assure that data will be used for research purposes only, and that subject's identity will not be revealed. All scientific information generated through the use of PDBP biospecimens will be submitted to the PDBP DMR for broad sharing among researchers.

Biospecimens, i.e., samples of patient's biological fluids, will be banked by the NINDS Repository for distribution to researchers. A Biospecimen Resource Access Committee (BRAC) will review biospecimen requests. ■



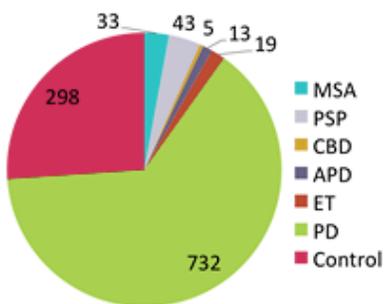
Who Is Currently Participating?

Participants recruited to the PDBP fall into three main diagnostic categories:

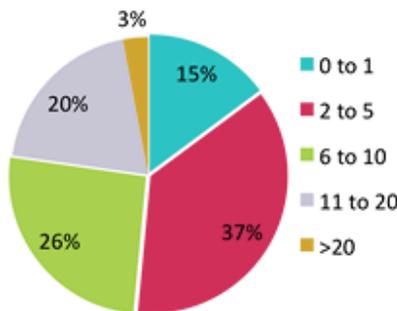
1. People with Parkinson’s disease
2. People who have neither Parkinson’s disease nor another neurological diagnosis, referred to as “controls”
3. People with a Parkinson’s-like disorder (Parkinsonism) which is not PD. Examples of parkinsonisms include:
 - Multiple System Atrophy (MSA)
 - Progressive Supranuclear Palsy (PSP)
 - Corticobasal Degeneration (CBD)
 - Atypical Parkinson's Disease (APD)
 - Essential Tremor (ET).

“The main purpose of this program is to enable academics or industry to come up with therapies that slow down the progression of Parkinson’s disease.” Dr. Walter Koroshetz, Deputy Director, NINDS, NIH

Number of participants by diagnosis



Participants -- years since diagnosis



1000th Subject from page 1

Dr. Zimmet, a veteran of more than a dozen Parkinson’s research studies since his diagnosis in 2007, told NINDS staff that his motives for participating in the study are to help others and to take charge of his disease and its treatment. He recognizes that the biological specimens he has contributed to the program won’t necessarily result in a treatment for his illness, but he hopes that they will be used by researchers to find Parkinson’s biomarkers that can lead to better treatments and methods for predicting disease onset or progression in others. As for what he gets out of it, Dr. Zimmet says that getting involved in studies makes him feel proactive and gives him purpose. He also values spending time talking with the movement disorder experts that run the studies. “To me, that’s worth its weight in gold,” he says, “to have that one-on-one time with a neurologist...just to pick their brains and say ‘Here’s what I’m doing, do you have any ideas you can suggest to make life better for me.’ ■

“About the prospect of submitting to a spinal tap, Dr. Zimmet says, “I was a little skittish. But after talking with Dr. Rosenthal [study coordinator at Johns Hopkins University], I became convinced that there’s no chance of really anything except maybe getting a headache, which has not happened to me.”

Spotlight on PDBP Projects

PDBP researchers use wearable wireless motion sensors to better diagnose PD

By Margaret Sutherland, NINDS

Gait abnormalities and postural instability are symptoms of Parkinson's disease which are believed to increase with disease severity and can be used as PD biomarkers.

Dr. Richard Dewey and colleagues at the University of Texas Southwestern Medical Center used a computerized system that involves attaching sensors to the wrists, ankles, chest, and back to measure postural sway, postural transitions, and trunk and limb movements. Each sensor contains an accelerometer, gyroscope and magnetometer. Using these devices, Dr. Dewey's laboratory measured gait and balance in 135 individuals with early to moderate Parkinson's disease and 66 age- and gender-matched healthy subjects. Both age and gender significantly influence gait and postural stability, and this is true both for individuals with PD as well as healthy controls, so these variables were taken into account in all analyses. In this cohort of individuals, who are part of the National Institute of Neurological Disorders and Stroke (NINDS) Parkinson's Disease Biomarkers Program (PDBP), quantitative measure of gait and postural stability demonstrated significant differences between individuals with PD in comparison to age and gender-matched healthy subjects. Differences in quantitative measures of gait and balance also correlated with disease severity. [J. Neurol. Sci. 2014, July 19.](#) ■



Source: APDM Mobility Lab

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