This fall marks the three year anniversary of the NINDS Parkinson’s Disease Biomarker Program (PDBP). As of August 28, 2015, PDBP has recruited 733 PD subjects, 428 controls, as well as 102 participants with related neurological disorders (Multiple System Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration, and Essential Tremor). Overall, more than 1,300 participants have been enrolled in the PDBP and enrollment is 96% complete! Furthermore, PDBP subjects have contributed over 550 CSF, 6,800 plasma, serum, whole blood, and 4,000 RNA and DNA samples to the NINDS biorepository.

Neurological Diagnoses of PDBP Participants

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Patients’ Corner

Parkinson’s Disease hits close to home

By Katrina Gwinn, M.D.

My dad, Joel Gwinn, was diagnosed with Parkinson’s disease when I was a neurology resident, in my last year, after I’d already decided to go into the field of “Movement Disorders”. People often ask, “Is that why you went into Parkinson’s research?” The answer is no; that is just one of the funny things about how the universe, or whatever you believe in, works. Seeing patients and their families experiencing Parkinson’s disease, at the same time that my father and our family was dealing with it, was an interesting, and at times, difficult situation, but it lent a great deal of personal zeal to my work as a practicing neurologist and to my

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Vitamin D and Parkinson’s Disease

Vitamin D is well known to help the body absorb calcium, which forms and maintains strong bones. Vitamin D may also protect against osteoporosis, high blood pressure, cancer, and other diseases. Recently, many studies have shown an inverse association between the level of vitamin D in the body and Parkinson’s disease (PD). Researchers, for example, observed that individuals with PD tend to exhibit lower levels of Vitamin D and its metabolites than age-matched controls.

How useful is this information?

a. Can vitamin D mitigate PD symptoms? PD patients are likely to have lower level of vitamin D. Although, scientists are actively investigating whether lower vitamin D is causal or an effect of PD, it is still of value to have your healthcare provider monitor your level of vitamin D. This is because vitamin D is not just important for bone health, but it may also protect dopaminergic neurons from toxic stimuli.

b. Can vitamin D levels be a biomarker of disease development or progression? Scientists such as those in the PDBP research teams are currently carrying out longitudinal studies to further confirm the association between vitamin D level and PD. These studies could lead to a new biomarker or new therapeutic approach that involves vitamin D supplementation.

What is DaTscan?

DaTscan is an imaging technology recently approved by the FDA in 2011. It uses small amounts of a radiopharmaceutical agent to help determine how much dopamine, a chemical that’s essential in controlling movement and other muscle functions, is present in a person’s brain. The machine is equipped with a device called a gamma camera that takes pictures of the brain. These pictures, along with a report can then be sent to a physician for evaluation. While DaTscans cannot diagnose Parkinson’s disease, they can be very useful in concert with other tests to help confirm suspected diagnoses.
This data will become even more valuable as more follow-up visits take place and researchers can perform longitudinal analyses of clinical and biospecimen data. This past summer was also notable, as an important milestone was reached: the first manuscript describing the PDBP cohort was accepted for publication in the journal *Movement Disorders*. The paper gives a broad overview of the scope of the PDBP including the critical need for biomarker discovery and validation in a standardized manner. The paper lays the comprehensive clinical and biospecimens data available, as well as how the data is housed within the Data Management Resource (DMR). Moreover, the paper provides a brief description of each of the ongoing funded projects within the PDBP consortium. Although the PDBP has met a number of successful benchmarks, work remains to be done. The study needs additional control participants. To achieve this, clinicians and clinical coordinators are reaching out to patients and their families for volunteers as well as performing community outreach. As you can see, your participation as a partner in this research has yielded an enormously rich dataset, which is helping drive Parkinson’s biomarker development. Thank you for your continued participation as we look forward to Year 4 of the PDBP.

*Dr. Katrina Gwinn is a Program Director in the Neurogenetics Cluster at NINDS and leads the PDBP.*

"This past summer the first manuscript describing the PDBP cohort was accepted for publication in the journal *Movement Disorders*."

_Patients’ Corner from page 1_

work later when I came to NIH as a program director. My area of research was the genetics of Parkinson’s disease—it is difficult to describe how it feels to study genetic risk factors of this disease, knowing that I too am at risk. My father was a physicist, and he always taught me to approach life with a scientific, as well as philosophical perspective. He was also a very funny man, and I have noted that humor is a large part of how many Parkinson’s disease patients cope. They have helped me learn to laugh at myself, a very valuable lesson. My father passed away from Parkinson’s disease in 2010. When I was given the opportunity to build the NINDS Parkinson’s Disease Biomarkers Program, which was established in 2012, I felt that I would truly be working to make a contribution to people who, like my father, need, and deserve better treatments for this disease. I continue to believe this to be true, and am grateful for all of the people who have participated as subjects, as caregivers, and as members of our research team to do this important research.

*Dr. Gwinn and his cat, Koschka, taking their evening walk.*
A recent paper was published in the journal Lancet Neurology aimed at developing a predictive formula to distinguish Parkinson’s disease vs. controls as well as pinpoint earlier stages of Parkinson’s disease. This model used genetic and clinical data (UPSIT smell test, family history, age, sex) from Parkinson’s patients and controls from the PDBP, as well as from 5 other studies (Parkinson’s Progressive Marker Initiative, the Parkinson’s Associated Risk Study, 23andMe, the Longitudinal and Biomarker Study in PD, and the University of Pennsylvania Morris K Udall Parkinson’s Disease Research Center of excellence). With this data incorporated into the algorithm, Drs. Michael Nalls, Andy Singleton and colleagues were able to correctly identify Parkinson’s patients from controls with 83% specificity and 90% sensitivity. This model may be used to help detect earlier stages of Parkinson’s disease and facilitate the development of biomarkers and therapies. When asked about the findings of this study, Dr. Singleton said, “clearly there is much progress that can be made in this area, and much work left to do, but we are excited by this first step forward in multi-faceted disease prediction in Parkinson’s.”


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