Program Expands PPMI Data Capture Online

Through in-person PPMI study visits, you have built a robust personal profile that is helping researchers better understand and develop treatments for Parkinson’s disease (PD). Now PPMI is launching the PPMI FOUND program to further build that profile with data entered in an online portal through a partnership with the University of California, San Francisco (UCSF).

PPMI FOUND allows participants to contribute data to the study electronically; that data will be matched with the data and samples provided through in-person visits. Matching what we learn about, for example, dopamine levels and motor symptoms, with patient-reported data — such as on lifestyle and daily impact of Parkinson’s — can help us make connections toward greater understanding of disease. More data means more insights that may lead to identification of Parkinson’s biomarkers and new treatments.

Some validated surveys on topics relevant to Parkinson’s research (e.g., environmental exposures) are lengthy. FOUND allows participants to complete these surveys on their own time and at their own pace rather than at a clinic appointment.

The PPMI FOUND program also aims to extend data collection. If participants are no longer able to complete in-person visits, they can continue contributing to the study through FOUND. FOUND also allows PMI leadership to share study news and updates with participants electronically, making sure volunteers know the latest from their contributions.

The FOUND portal is available in all languages spoken by PPMI participants. Data submitted to PPMI through FOUND is encrypted and de-identified for security. This de-identified data, like all captured in PPMI, will be made available to the broader research community for analysis toward Parkinson’s understanding, biomarkers and treatments.

Talk to your study coordinator about the PPMI FOUND program at your next study visit. If you choose, consent to have your name, email and phone number shared with the UCSF FOUND team. (Email correspondence is preferred for efficiency.) FOUND team members will contact you to explain the project further and obtain consent if you choose to participate.

As always, thank you for your continued participation in PPMI and in the growing list of ways to contribute to our understanding of Parkinson’s disease. ■
Family Ties: Wife & Husband Participate in PPMI

Wife and husband Dr. Barbara and Jay Robinson spoke recently with Dave Iverson, contributing editor to The Michael J. Fox Foundation (MJFF), for a podcast on their decision to take part in the genetic arm of PPMI. Here we share an abridged transcript of their conversation. The couple also spoke of their experience in PPMI on a recent MJFF webinar. Visit www.michaeljfox.org/webinars to watch that February 2017 program on genetics.

Dave: Even though specific gene mutations account for a relatively small percentage of the Parkinson’s population, genetics give us a specific, detectable target that could reveal what goes amiss in the disease and how the disease process unfolds for everyone. Dr. Barbara Robinson is an obstetrician/gynecologist with a deep personal interest in genetics. Not only does she have two family members who received a Parkinson’s diagnosis, but she also had a sister who died in childhood of Tay Sachs disease, a rare genetic disorder.

Barbara: My brother was diagnosed with Parkinson’s disease when he was in his late forties. And my mother also developed Parkinson’s much later; she was in her seventies. My whole family was active in the genetic research relating to Tay Sachs disease. So when there was genetic research available for Parkinson’s, my whole family jumped on the bandwagon to find out what the gene status was and what was going on.

Dave: Providing additional reason to get involved with genetic research was the fact that Barbara’s husband, Jay, had his own family history with Parkinson’s disease.

Jay: My father had Parkinson’s. I think in his mid- to late-seventies is when we became aware and it presented itself. And I saw how it affected him. I became sensitized to the importance and the need to get involved, if possible, in research of things that hopefully can be prevented.

Dave: Fortunately, Jay and Barbara Robinson remain disease free. But their strong family history of Parkinson’s makes them perfect candidates to participate in genetic research.

Barbara: I carry two gene mutations. I have the GBA and the LRRK2 mutations. And it sort of knocked my socks off. It was like, wow, that really increases my odds of getting this disease.

Dave: The LRRK2 mutation Barbara Robinson carries conveys about a one-in-four risk of getting the disease. Carrying the GBA mutation carries less risk for Parkinson’s but increases the risk for another genetic condition called Gaucher disease. And it turned out Barbara’s husband Jay carries the GBA mutation, as well. Armed with both information and motivation, Barbara and Jay Robinson enrolled in PPMI. Participating in the project is a multi-year commitment, but the Robinsons couldn’t be more confident of its value.

Jay: It’s the issue of understanding what some people encounter and the possibility is that something could be done to prevent it for future generations.

Barbara: I think that the only way we’re going to fight this is to have knowledge. And the only way we’re going to have knowledge is to collect data. And if I’m not willing to step up and volunteer myself to get knowledge and data, then nothing is ever going to change. If we want to find a cure, we have to be willing to do the footwork in order to get there. So one foot in front of the other, you’ve got to do what you can.

“If I’m not willing to step up, nothing will ever change.”
PPMI Analysis Names Biomarkers of Cognitive Changes

Thanks to your contributions, analysis of PPMI data published recently in the scientific journal *PLOS ONE* sheds light on potential biomarkers (objective measures) of cognitive decline in early Parkinson’s. Changes in memory, complex thinking or language abilities can arise at any time during the disease course and vary in severity. Not everyone with PD develops cognitive problems, and currently doctors are unable to predict definitively who will develop these changes.

We spoke to Daniel Weintraub, MD, professor of psychiatry at Perelman School of Medicine at the University of Pennsylvania and chair of the PPMI Cognitive/Behavioral Working Group, who led the investigation.

**MJFF:** What was the goal of your study? What did you find?

**Dr. Weintraub:** The goal was to learn if certain clinical tests, such as genetic, spinal fluid, and brain imaging scans, could predict cognitive changes in the early stages of PD. We analyzed these measurements up to three years in 423 newly diagnosed Parkinson’s patients who were not yet taking PD medication at the PPMI baseline visit. Over the same period, we looked at if and how their cognition changed through detailed memory and thinking tests. We found evidence that the brain chemical dopamine, changes in brain size, the protein amyloid-beta and genetics all could be independently contributing to cognitive changes in PD.

**MJFF:** What do these results mean for the Parkinson’s community?

**Dr. Weintraub:** These findings need to be confirmed with additional and longer-term studies, but they give us a window into how and why cognitive problems develop in PD, and who will develop them. Validating biomarkers to predict cognitive changes in early PD could fill the drug development pipeline with therapies focused on slowing or even preventing impairment, an area of unmet need for patients at this time.

**MJFF:** Why are studies like PPMI so important for Parkinson's research?

**Dr. Weintraub:** PPMI offers a bigger group of PD participants than most studies, and it includes data from a population of people without Parkinson’s. The study also collects many different measurements that often are difficult or expensive to obtain, and makes these assets available to researchers. Many volunteers have been part of PPMI for five years or more, allowing investigators to evaluate the evolution of symptoms over time. Studies such as PPMI lay important groundwork for future Parkinson’s research and increase our ability to develop better assessment tools, advance new or improved disease-management tools and therapies, and deepen understanding of the mechanisms involved in PD progression.

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**Plotting the Molecular Fingerprint of PD**

The cellular processes of life involve many players. Disease can disrupt these components and their important functions. New technologies are allowing us to define those players and their roles to then pinpoint where Parkinson’s interferes and where scientists may be able to intervene to prevent or stop progression. PPMI is using some of these so-called “omics” technologies to identify the “molecular fingerprint” of Parkinson’s disease.

Already piloted and deployed in PPMI:

**Genomics:** studying genes and their functions (genome is one’s full set of DNA)

**Epigenomics:** studying the chemical compounds that activate or deactivate specific genes in the genome, thereby altering the way that it behaves

**Transcriptomics:** studying RNA transcripts; DNA makes RNA, which helps make and process cellular proteins

Piloting in 2018 in PPMI:

**Proteomics:** studying cellular proteins, which play a number of roles in our health and function

**Metabolomics:** studying metabolism: chemical transformations in the cell to, for example, convert food to energy and get rid of cellular waste

**Lipidomics:** studying lipids, molecules such as fats that store energy and play other roles in the cell

These techniques are helping uncover differences in the cells of people with Parkinson’s disease where scientists may target treatments.
Be a PPMI Genetics Ambassador

Recruitment is underway for the genetics arm of PPMI! There is no better advocate for PPMI than those of you who are already participating in the study, and you can play a critical role in spreading the word about this effort.

How can I help?
Ask your friends and family members to visit www.michaeljfox.org/genetics and encourage them to take our screening survey.

PPMI is seeking individuals who are of Eastern European (Ashkenazi) Jewish descent with Parkinson’s or Gaucher disease or a first-degree relative with either to take the survey to help determine eligibility for the genetics arm of the study.

Want to stay informed of the latest scientific developments in PPMI? Visit www.PPMI-info.org. This is the portal for the scientific community to learn more about PPMI and to access the data and samples coming out of the study.

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