Looking Forward to 2012

Thanks to you, PPMI continues to work toward the goal of identifying biomarkers that reveal the progression of Parkinson’s disease – critical to developing disease-modifying treatments that could transform millions of patients’ and caregivers’ lives.

Since the Parkinson’s Progression Markers Initiative (PPMI) began in summer 2010, it has continued to expand steadily across the United States and Europe. In 2011, some important benchmarks were achieved: PPMI reached the halfway point in recruiting the 600 participants necessary for the study’s completion, and for the first time, researchers and clinicians across the world gained access to the largest repository of data and biological samples that could unlock clues to the onset and progression of Parkinson’s disease (PD). 2011 also marked the development of an important tool that could be used to measure levels of the protein alpha-synuclein, a potential biomarker for the disease. In 2012, this tool will be made available to the PD research community at large, which could begin to help scientists more easily determine the role that alpha-synuclein, whose clumping is the pathological hallmark of PD, plays in PD. (Read more about this tool on p. 3).

2012 will also mark the emergence of the first research tools and scientific results from PPMI. “Scientists across the world are already collaborating to verify promising findings that could speed the process of biomarker discovery in PD,” said PPMI’s principal investigator Ken Marek, MD, president and senior scientist of the Institute for Neurodegenerative Disorders in New Haven, Connecticut. “In the coming months, new findings and scientific tools that could dramatically alter the search for a biomarker will be shared with the research community atlarge.”

We continue to celebrate the contributions of our PPMI participants. Each PPMI participant has their own unique reasons for signing up: Denise Dvorak, an educator diagnosed with PD in February 2011, decided that she would not take the news lying down, and immediately looked for opportunities to help find a cure. Jon Surine’s family gave him the support he needed to tackle his PD head-on following his 2010 diagnosis (See Volunteer Stories, p. 2).
Participant’s Perspectives

“Ultimately, it is the commitment of PPMI’s participants that drive the study’s progress. Meet two of the dedicated volunteers whose efforts keep this study going.”

Denise Dvorak: “Go big or go home.”

When Rhode Island educator Denise Dvorak, 44, was first diagnosed with PD in February 2011, she went to the MJFF Web site to learn more about the disease. Once there, she learned about PPMI, and was immediately intrigued to find that she could get involved in the search for a cure. By July, she was visiting Boston for her screening visit.

Since her diagnosis, Denise has adopted a “go big or go home” mentality. She has not yet needed to start medication and credits her regular participation in yoga, dance, and aquatic exercise classes for people with PD. Thanks in part to the staff at the Boston University Medical Center, PPMI has been an incredibly positive experience, she says. “Going into a five-year study, it was important for me to get a good feeling about the staff that would be working with me. It became clear very quickly how much they cared about me and my well-being.”

Jon Surine and his wife Mary on vacation.

Jon Surine: “I don’t want to be defined by PD, I want to help define it.”

Jon Surine of Plainwell, Michigan was diagnosed with PD in 2010 after consulting his physician about a mild tremor. Jon wasn’t the first in his family to hear this news from his doctor — both his mother and father-in-law had PD — so he and his wife were familiar with some of the realities of living with the disease. Still, they knew they needed to do everything they could to stay educated on the latest in PD research. Jon’s wife Mary was a particularly avid reader on the subject — it was she who first found out about PPMI, which Jon subsequently joined. Mary accompanies Jon on all his visits to the Northwestern University PPMI site.

Jon says is grateful for the love and support of his family, which helped lay the groundwork for his participation in PPMI. “I want to do what I can to help in the fight against this disease. I don’t want to be defined by PD, I want to help define it.”

PPMI Update

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Ultimately, it is the commitment of PPMI’s participants that will drive the study’s progress. With every new volunteer who enrolls and every scientist who gains access to study data and biosamples, the search for a biomarker that could forever change the face of PD marches on.

Share your PPMI story with us

So many PPMI participants have compelling stories about deciding to take part in PPMI, and we’d love to hear yours. Contact the clinical coordinator at your study site and tell them you want to share your story.

Where in the World Is PPMI?

Visit michaeljfox.org/Sites for information on all 24 clinical sites where PPMI is taking place across the United States and Europe.
In 2002, Michael Schlossmacher, MD, FRCPC, then at Harvard University, first received funding from MJFF to develop a lab test that can measure levels of alpha-synuclein, a protein in the brain whose abnormal function is implicated in the onset and progression of PD. In a pilot study of 30 people, the test pinpointed altered levels of alpha-synuclein in individuals with PD. As with any new research finding, this result required replication, but pointed the way toward a potentially reliable, consistent, and inexpensive test to detect PD and track its progression. If a test like this proves replicable, it could open new avenues to develop treatments capable of slowing the progression of the disease.

Fast forward to 2012: Schlossmacher’s lab test, called an assay, has now been replicated in other labs and is being made available to any researcher who would like to use it. The assay also has been approved for use in PPMI, and will be used to test alpha-synuclein levels in the cerebrospinal fluid (CSF) samples taken from study participants. Results from tests of PD and control samples will be compared and may help researchers better understand how alpha-synuclein changes over time in people with PD, speeding development of treatments that could exploit these changes to slow or stop the progression of the disease.

Today, the assay is fully integrated into PPMI, and is being used to test every CSF sample collected. Researchers will input the results back into the PPMI scientific database so that future studies can build on these findings. This assay is one example of how researchers are using PPMI as a critical resource to define biomarkers for PD.

In addition to the 24 PPMI sites worldwide, a robust infrastructure has been established to make the study operate effectively. There are nine PPMI “Study Cores” — groups behind the scenes that do everything from developing and managing the study data entry system, to receiving and processing samples, and conducting quality control analyses. The study cores also make data available online to the research community at large and are starting to analyze PPMI findings. This is the first in a series highlighting these cores and the crucial role they play in PPMI.

PPMI’s Bioanalytics Core, located at the University of Pennsylvania School of Medicine, performs key biomarker verification studies associated with the samples being collected in PPMI. The Bioanalytics Core works closely with another core, the PPMI Biorepository, to monitor and perform quality control on collected samples to ensure the integrity of the study.

Last year, the Bioanalytics Core made an important observation: When participants ate high-fat meals prior to their PPMI visits, blood tests returned abnormal results. Thanks to this observation, PPMI leadership instituted a new protocol to encourage participants to fast before their visit, or, if impossible, to adopt a low-fat diet, with specific recommendations as to what a low fat diet might include. Thanks to the Bioanalytics Core, study leaders are able to make adjustments to PPMI in real time to ensure that the data and sample collection is optimized for the research community.

“I want to do what I can to help in the fight against this disease.”

- Jon Surine, PPMI Participant
PPMI Modeled on Alzheimer’s Study that Is Bearing Fruit

When members of The Michael J. Fox Foundation’s (MJFF) Scientific Advisory Board (SAB) first began thinking about conducting a study like PPMI in 2007, they were fortunate that a similar corollary study had already been launched: The Alzheimer’s Disease Neuroimaging Initiative (ADNI), a multi-year biomarkers study to identify markers of Alzheimer’s progression, which debuted in 2004. As MJFF’s SAB worked to refine the infrastructure of a comprehensive biomarker validation effort, it became clear that PPMI was becoming an “ADNI for PD.”

Today, the PPMI and ADNI studies are similar in scale, duration, and methodology. They share a model whereby data from multiple sites is directed into one central database and then made available for access to the research community at large. To access both the ADNI and PPMI repositories, researchers must agree to share their findings. In the PPMI study, the data is easily accessed at ppmi-info.org. A quality control review is also built into the process.

ADNI is already showing promising results. One such discovery could change the landscape of Alzheimer’s drug development: Researchers using the ADNI samples have found a test in cerebral spinal fluid (CSF) that can identify patients with significant memory loss who will later go on to develop Alzheimer’s disease. ADNI’s findings are encouraging, and boost the optimism of the PPMI community that biomarkers for PD could also be discovered.

While PPMI isn’t as far along as ADNI, already more than 5,000 data downloads have been made by scientists worldwide. With PPMI only in its second year, there is still a ways to go before PPMI leaders would expect to report results like those gleaned in ADNI. Still, thanks largely in part to the strong base provided by ADNI, PPMI’s collaborative community of researchers may truly be on the brink of promising discoveries that could have major implications for those living with PD.