



PARKINSON'S
PROGRESSION
MARKERS
INITIATIVE

Play a Part in Parkinson's Research

PPMI News

The newsletter for PPMI participants

Issue 8, Fall 2014

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About PPMI

The Parkinson's Progression Markers Initiative (PPMI) is a landmark, five-year international clinical study that aims to find reliable and consistent biomarkers of Parkinson's disease (PD) progression. The study is testing today's most promising biomarker candidates through neuroimaging, the collection of blood, urine, and spinal fluid, and clinical and behavioral tests. Valid measures could allow scientists to predict, objectively diagnose and monitor diseases as well as definitively determine which medications work and which will not. PPMI is sponsored by The Michael J. Fox Foundation for Parkinson's Research and funded by a consortium of industry partners and individual donors. To learn more or volunteer to participate in the study, visit www.michaeljfox.org/PPMI or call (877) 525-PPMI.

Data from PPMI Confirms Depression More Common in Parkinson's Disease

As more and more data is collected from our dedicated group of PPMI participants, the opportunity to validate and improve our understanding of disease as it progresses over time and foster new discoveries continues to grow. A recent paper shared the first longitudinal findings from the Parkinson's Progression Markers Initiative (PPMI). As you already know, one of the unique advantages of PPMI to researchers analyzing its data is that the study design allows investigators to follow hundreds of patients and control volunteers from around the world over time, or longitudinally.

Researchers from the University of Pennsylvania affiliated with PPMI published in the journal *Neurology* that depression, anxiety and fatigue are more common in newly diagnosed Parkinson's disease patients compared to the general population.

The researchers' examined data from the initial cohort: 423 newly diagnosed, untreated Parkinson's patients and 196 control volunteers. Of these, 261 PD patients and 145 controls were evaluated at 12 months, and 96 PD patients and 83 healthy controls evaluated at 24 months.

We've long known that depression, anxiety and fatigue are symptoms of Parkinson's so these findings aren't very surprising to the research field and probably not to the patient population, either. However, one of the primary goals of PPMI is to validate our

knowledge of the disease with objective data. And your participation in PPMI is the only way researchers can gather this data and put it to use for validation and further discovery.

"PPMI is building comprehensive data sets — detailed information on many participants — that can confirm some of the 'truths' we believe and may point to new findings, especially as we follow these volunteers over the next few years," said Mark Frasier, PhD, vice president of research programs at MJFF.

"It's really a chance to assess the frequency and characteristics of psychiatric and cognitive symptoms in PD, compare it with control volunteers, and then also look at its evolution over time," said Daniel Weintraub, MD, the senior author on the paper.

One illuminating finding from Dr. Weintraub's study is that depression may be under-treated in the Parkinson's population. Two-thirds of patients who screened positive for depression during the study were not taking an antidepressant. Teasing out important findings like this are critical to driving improvements in Parkinson's research, treatment and care — and these learnings are only made possible because of the invaluable contributions made by participants in this study and others. ■

Participant Profile: Cecily Harmon Shares Her Story

Cecily Harmon is a control participant in PPMI and, below, her daughter Kate interviews her about her research participation.

Kate: What are your hopes for the PPMI study?

Cecily: I can't wait to hear what the researchers find out from studying us participants for five years. For example, we've already heard that alpha-synuclein proteins in spinal cord and brain fluids are less present in the PPMI participants who have Parkinson's than in the control volunteers. Not to mention, I hope for a biomarker that could help with earlier diagnosis.

Kate: Because with Dad it took several years and a lot of doctors to get the correct diagnosis, right?

Cecily: I think about your Dad and how he had the disease for years before he was diagnosed. It's a common complaint of people we know. Wouldn't it be great to have an early test? A Parkinson's biomarker could lead to a test similar to the blood test that identifies diabetes. It's accurate and could eliminate the time some people waste being treated for other diseases they don't have before it's revealed that they have PD.

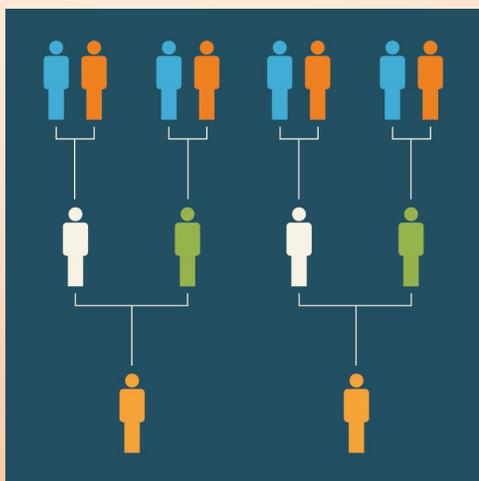
Kate: What is your favorite part about participating?

Cecily: Just being a small, but important, part of the outcome of such a significant project that could help so many people. I like to think about all of the PPMI volunteers contributing data, samples, their time and energy around the world. I just feel like I'm taking part in something really important. I feel good because I can do something. ■



Cecily and her husband, Bob Harmon

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 new effort.

How can I help?

Ask your friends and family members to visit www.michaeljfox.org/ppmi/genetics, and encourage them to take our genetics survey. PPMI is seeking individuals with or without PD who are of Eastern European (Ashkenazi) Jewish, North African Berber or Basque ancestry to take the survey to help determine eligibility for the genetics arm of the study.

What is the PPMI Genetics Ambassadors team?

PPMI is organizing a group of study participants who are interested in helping spread the word about PPMI Genetics in Eastern European (Ashkenazi) Jewish, North African Berber or Basque communities. If you are interested in joining this group, please contact a PPMI team member at your local site and let them know you're ready to get involved.

Join Our Next PPMI Study Update Call!

What: The PPMI Genetics Data: Unlocking the Code within Us

When: Tuesday, December 9, 1pm ET

How: Call (866) 901-2585 to join us!

By participating in PPMI, you're contributing valuable genetic information to Parkinson's research. Join us on December 9 to learn more about the role of genetics in PPMI and ask any questions you may have during an open Q&A session with a PD researcher using the PPMI genetics data.

Missed the last study update call?

As always, you can listen to past study update calls by visiting www.ppmi-info.org/participants.

A Special Thank You from Michael J. Fox



Michael thanks you for being part of the solution to Parkinson's by participating in PPMI. Visit ppmi-info.org/participants to view the video.

PPMI Shows Protein Levels in Spinal Fluid Are Lower in People with Parkinson's

The International Parkinson and Movement Disorder Society (MDS) is a professional society of clinicians, scientists and other health care professionals who are interested in Parkinson's disease and related neurological disorders. Each year, MDS gathers thousands of the field's clinicians, researchers, trainees and industry supporters at its International Congress. The MDS International Congress offers opportunities for key Parkinson's stakeholders to share ideas, form collaborations and advance the field of neurological research.

At this year's conference — held in Stockholm, Sweden in June — PPMI's principal investigator, Ken Marek, MD, president and senior scientist at the Institute for Neurodegenerative Disorders, presented the study's latest findings based on analysis of baseline data. Among the results is the observation that PPMI participants with Parkinson's show lower levels of tau protein in spinal fluid than do control participants. This finding is particularly interesting because people with Alzheimer's disease show elevated levels of tau, fueling more discussion around the related pathology of the two diseases.

Following the Congress, Dr. Marek spoke with online medical news source Medscape about the results. "We can't fully explain it at the moment. It is leading to much discussion, and additional research is needed to understand what we are seeing," he said in the interview. "We are hoping to develop an array of biomarkers that will be of value to track the disease, and to identify subsets of patients that may respond to specific therapeutics."

The PPMI findings were selected for a Blue Ribbon Award at the Congress, a commendation to a small group of exceptional projects.

Register for a free MedScape account to read the full article here: www.medscape.com/viewarticle/827121. ■

PPMI in the News

Seeking Objective Measures for New Parkinson's Disease Treatments

As PPMI continues efforts to recruit volunteers for the genetics arm of the study, outreach to certain populations, such as individuals of Ashkenazi Jewish descent, who have a higher incidence of carrying a LRRK2 mutation is key. Recently, the *San Diego Jewish Journal* spoke with PPMI's principal site investigator at the University of California San Diego, Dr. Douglas Galasko, about the study's investigation of the LRRK2 gene and the promise of genetics and biomarkers for Parkinson's research.

Shortly after researchers determined that LRRK2 is the most significant gene related to the onset of Parkinson's disease, they discovered that in people with Ashkenazi Jewish backgrounds, it is an even stronger predictor. Ashkenazi Jewish people are more likely to carry the gene (30-60 out of 100) and of the five-10 percent of people who have genetic causes of Parkinson's, 15-20 percent of them are Ashkenazi. Because of this, Dr. Galasko and the entire PPMI study are specifically looking for Ashkenazi Jews to participate in the genetics arm of PPMI.

"By identifying milestones within a very well characterized group of people who are LRRK2 carriers," he continues, "we may be able to identify markers that we can then generalize to a lot of other people who may be at risk for Parkinson's. We stand at a point where treatment studies are being planned to try to delay onset of certain types of symptoms," Galasko says, "or perhaps to slow progression, but we really need objective measurements to help us initiate these trials and measure their outcomes."

Read more at www.michaeljfox.org/ppmi-genetics-blog. ■

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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