



PARKINSON'S  
PROGRESSION  
MARKERS  
INITIATIVE

Play a Part in Parkinson's Research

# PPMI News

The newsletter for PPMI participants

Issue 4, Fall 2012

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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](http://www.michaeljfox.org/PPMI) or call (877) 525-PPMI.

## PPMI at Two Years: Much to Celebrate, But Still Work to Be Done

This fall marks the Parkinson's Progression Markers Initiative's (PPMI) two-year anniversary. To date, PPMI has recruited more than 250 people with PD and over 150 control participants. As of this summer, all 24 sites across the United States, Europe, and Australia are actively recruiting toward the 600 total participants needed for the study's completion. PPMI aims to have the trial fully enrolled by early 2013.

2012 also marked the first time that researchers have presented study findings using data and samples from the PPMI biorepository. Five study teams were highlighted at this summer's Movement Disorder Society International Congress in Dublin, Ireland (read more about these presentations on p. 4). While PPMI is in its early stages, these presentations show that scientists are already learning from baseline measurements of enrolled participants (read more about how samples of cerebrospinal fluid are helping scientists to make hypotheses about PD biomarkers on p. 3). And in the coming year, the amount of data available is going to explode. As more follow-up appointments take place, researchers will be better able to make comparative analyses of longitudinal data (taken over specific intervals over a period of time) to understand changes in the body that are taking place in PD volunteers and compare them to the same measures in control participants. The hope is that such changes could provide clues about potential biomarkers for the disease.

It is so important for those enrolled in PPMI to keep coming back for follow-up appointments. As the study sponsor, The Michael J. Fox Foundation (MJFF) recognizes how important this commitment truly is, and celebrates those who have signed on to give so much of their time and energy to support the study. Through PPMI events the Foundation has hosted with sites for study participants, MJFF staff has already met more than 270 volunteers and their guests. The events take place at sites around the country and provide updates on PPMI, while bringing together site teams and study participants. They also give participants an opportunity to ask site teams questions about the study.

Claire Meunier, director of clinical trial strategies at MJFF, has attended most of these events. "I spend most of my time behind a computer thinking about how to get and keep people engaged in PPMI," she says. "But the best part of my job is meeting the people who are contributing to the study." Meunier and her team hope to hold events like these at all PPMI sites annually. So far, they've hit 13 cities in the United States. This fall, they make their first trip to Europe.

"So many are working so hard to keep PPMI moving forward behind the scenes, but we couldn't do any of this without those who have volunteered to participate," she says. "It is truly an honor to get to know the study volunteers, and to hear the stories of why they have committed to the search for PD biomarkers."

# The Burden of Secrecy in Parkinson's Disease



Karen Jaffe, an obstetrician in Cleveland, hid her PD diagnosis from family, patients and colleagues. Karen (far right) is pictured with her husband and three daughters.

writes reporter Kate Yandell. "But the secrecy is not just stressful to maintain; experts fear that it also may be slowing down the research needed to find new treatments."

Many studies, including PPMI, need newly diagnosed people with Parkinson's to participate, because the earlier that researchers can identify what may be happening in the disease, the better equipped they are to test new therapies against these processes. This could translate into potential drugs to stop the disease before extensive neurological damage may occur. But researchers report that people at this early stage of disease are the hardest to find. The "burden of secrecy" is likely a major contributor here.

As the *Times* reports, Karen Jaffe, an obstetrician living in Cleveland, Ohio, was diagnosed with PD at the age of 48. In the midst of a successful career, she was afraid of what her patients might think if they were to learn that she had Parkinson's disease. For a while, Karen even kept her diagnosis from her children, a reality that

changed abruptly when her daughter learned she had PD by reading Karen's journal. Then, Karen tells the *Times*, she even swore her children to secrecy.

In the end, Karen unburdened herself and, since then, has become an active member of the PD patient community. Her husband, Marc, is participating in PPMI as a control.

To read the entire story from *The New York Times*, visit <http://well.blogs.nytimes.com/2012/07/09/keeping-parkinsons-disease-a-secret/>.

## Where in the World Is PPMI?

Visit [michaeljfox.org/PPMI](http://michaeljfox.org/PPMI) for information on all 24 clinical sites where PPMI is taking place across the United States, Europe and Australia.

Many people with Parkinson's feel compelled to hide their disease out of concern for how their diagnosis might affect their standing at work, alter relationships with friends and family, or impact their health insurance status. In June, *The New York Times* profiled the reality of "Keeping Parkinson's Disease a Secret."

"Doctors and researchers say it's not uncommon for people with Parkinson's to conceal their diagnoses, often for years,"

## The Parkinson's Minute Highlights PPMI

In this episode of the ongoing video series, Dave Iverson reports on the search for biomarkers for Parkinson's disease (PD), and The Michael J. Fox Foundation's role in driving this search through PPMI. Watch this episode in the series on YouTube:

<http://www.youtube.com/watch?v=qQ8zPXN32tc>



## Share your PPMI story with us.

Ultimately, PPMI is about each and every one of our participants and the gift of their commitment. So many of you have compelling stories about why you have chosen to participate, and we'd love to hear your story. Contact the clinical coordinator at your study site and tell them about yourself, and you may be featured in media stories about the study or a future edition of PPMI News!

# What Happens to My Cerebrospinal Fluid Sample?

When you get a lumbar puncture during a PPMI visit, your clinician is taking cerebrospinal fluid (CSF). CSF is found around the brain and spinal cord and may provide vital clues toward identifying PD biomarkers. And each sample goes a long way toward research — just one lumbar puncture yields 150 samples that can be used by researchers in biomarker validation studies.

So what happens to that CSF sample once it's been taken from your body? Alison Scutti, senior project manager at the Coriell Institute for Medical Research, the biobank which stores all CSF samples collected in PPMI, walked us through the process that brings your CSF from the PPMI site to research labs around the world.

“The process begins at each PPMI site, when a clinician collects the invaluable CSF. All of the medical supplies, including the antiseptic, needles and tubes that are used to conduct your lumbar puncture, are exactly the same at each site. This is critical in maintaining a uniform and standardized protocol throughout the study.

“The CSF is initially collected in large test tubes measuring 15 milliliters (ml). As quickly as possible, site staff divide each large sample into 10 smaller tubes measuring about 1.5 ml (see chart). These tubes are put into a deep freeze, all the way down to -80° Celsius (-112° Fahrenheit).

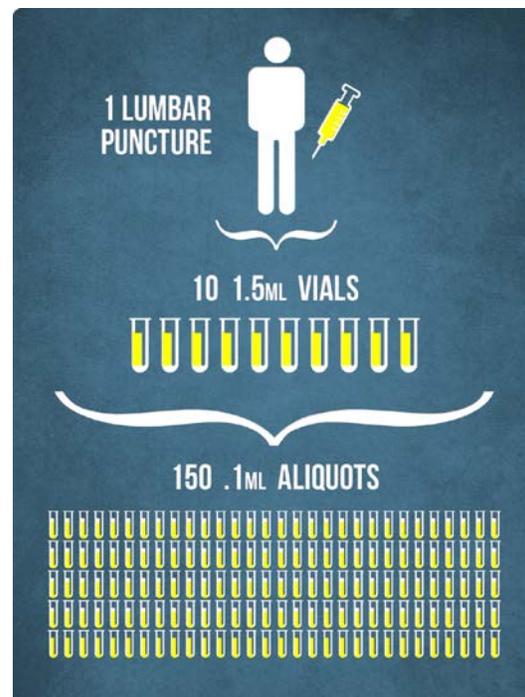
“Next, the PPMI site needs to get the sample to Coriell, where it will be housed. Sites pack samples with dry ice and ship them to our labs. Samples usually arrive at Coriell the next day, but the boxes are packed with enough dry ice for two days in case of any mail delays. These samples shipped to Coriell are de-identified, meaning Coriell never receives any personal information attached to the sample, such as name or date of birth. Neither do researchers receiving samples from the PPMI Repository. Instead, each sample is given a code number. This is crucial to protecting the participants' personal information, as it ensures that someone familiar with the study (say a PPMI site physician collecting data) can't tell which volunteers are from their site.

“When Coriell gets the samples, we unpack them and perform a quality check to make sure that all of the samples were collected according to PPMI protocol. We want to make sure that sites have used the right tubes, that the tubes are properly labeled, that samples haven't thawed and that tubes aren't broken. If problems are identified, we log them and let sites know of the issue to prevent it with future samples.

“We then log the de-identified tubes in a database, where we keep track of each sample — when it is accessed, by whom, for what study or scientific purpose — over the course of its life.

“Once the samples are logged, Coriell lab staff thaw the samples and divide them further, into 0.1 ml samples — large enough for what most researchers will need for their studies, but small enough to get the most out of each lumbar puncture. From here, researchers can apply for samples, conduct tests on them and share their results back, getting us one step closer to biomarker verification.”

Read more about one study using these samples to validate levels of alpha-synuclein in people with Parkinson's on page 4.



**Your CSF sample goes a long way.**

*Just one sample from a PPMI participant yields 150 .1ml aliquots that can be used by any researcher.*

**“Never before has the Parkinson's research community had so many standardized CSF samples available at our fingertips in highly annotated study subjects and at an early stage of the disease. These samples are making it so much more efficient to conduct research validating potential biomarkers for PD.”**

*— Leslie Shaw, PhD,  
co-director, Bioanalytics Core, PPMI study.*

## PPMI Takes Center Stage at Movement Disorder Society International Congress

This summer, five studies linked to PPMI were featured at the Movement Disorder Society International Congress in Dublin, Ireland, an annual meeting attended by more than 5,000 neurologists and researchers from over 80 countries worldwide. The five presentations marked the first published research results to be shared from PPMI.

A study presented by Daniel Weintraub, MD, was awarded Blue Ribbon status, an honor given to only about 30 projects of 1,500 presented at the conference. Weintraub's work focused on the link between Impulse Control Disorder (ICD) and PD. The study found that Parkinson's does not confer a higher risk for ICD, supporting other research that suggests the high

prevalence of ICD in people with PD is related to Parkinson's medications, and not the disease itself. Weintraub used data from the PPMI repository for his research.

"The PPMI dataset is a valuable resource for Parkinson's researchers like myself, and is now the largest of its kind worldwide," says Weintraub. "The fact that this data was available and easily accessible played an important role in our team's ability to generate meaningful results more quickly than we had ever been able to before. PPMI makes it possible to test new hypotheses in a fraction of the time it used to take."

Another project at the MDS meetings found that levels of the protein alpha-synuclein in cerebrospinal fluid were lower in people with Parkinson's than in healthy controls. While this had been found to be true in previous studies, it's the first time this finding was reproduced in a multi-site study like PPMI. One hypothesis is that lower levels of alpha-synuclein in the spinal cord mean that there is also more alpha-synuclein in the brain, where the protein forms clumps in all people with PD.

These results were based on data from the first 100 samples taken in the study. The results will need to be replicated in more subjects, and tracked over the duration of PPMI to see what kinds of changes are taking place over time. But if they hold true, these early findings could point to confirmed biomarkers.

*Want to stay informed of the latest scientific developments in PPMI? Visit [www.PPMI-info.org](http://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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