



Parkinson's
Progression
Markers
Initiative

Winter 2022 Newsletter

About PPMI

The Parkinson's Progression Markers Initiative (PPMI) is a landmark study launched by The Michael J. Fox Foundation (MJFF) in 2010 to better understand Parkinson's onset and progression.

Through PPMI, participants are completing clinical exams, undergoing brain scans and contributing biological samples in pursuit of a cure. PPMI data — downloaded more than 8.5 million times — has been used to launch over 20 human studies testing new treatments and cited in more than 400 scientific publications.

Dear Friend,

Since our last newsletter, a lot has happened in PPMI! Thanks to your contributions, we had a solid foundation to expand the study. We welcomed new participants, added more sites and launched the online part of PPMI. This part of the study is currently open to anyone over age 18 in the United States. Through this online platform, we aim to collect health information from hundreds of thousands of people with and without Parkinson's disease (PD). This could change everything about how Parkinson's is diagnosed, treated and, ultimately, prevented. We're also exploring ways for international volunteers to participate online.

Scientists have not stopped turning to PPMI as a source for understanding Parkinson's and ways to treat it. More than 75 scientific papers using PPMI data came out this year alone. Read about recent findings emerging from the study on page 2.

We're so glad you're part of the PPMI community dedicated to speeding better treatments and a cure for Parkinson's. We look forward to seeing you at your next study visit!

Sincerely,

Your PPMI Study Team

Table of Contents:



Page 2

Recent Scientific Findings

PPMI by the Numbers



Page 3

PPMI Online FAQ



Page 4

Meet Other Participants



Page 5

Spread the Word About PPMI

Educational Resources

Your Contributions Speeding Breakthroughs

Scientists around the world have accessed PPMI data more than 8.5 million times — an average of 2,200 times a day. The information and samples you provide is leading to new insights into how Parkinson's starts and changes. Those findings will fuel a future of new tests and treatments for the disease.

Here we share some recent results made possible through your participation in PPMI.

Connection between Gut and Mood Issues:

Researchers reviewing PPMI data found a connection between gastrointestinal (GI) symptoms (e.g., constipation) and mood changes. More severe GI symptoms predicted more severe anxious/depressive symptoms. They also found the reverse: mood changes predicted GI issues. This finding could help scientists look at the biology behind these symptoms. They also could help doctors and patients better predict, diagnose and treat these symptoms. This research was led by scientists at California State University, San Bernardino.

Better Brain Scan for Dopamine Loss?:

As a PPMI participant, you're familiar with a DaTscan (a brain scan which measures dopamine, a brain chemical that decreases with Parkinson's). Through the PPMI Early Imaging study, we are looking at another scan to measure changes in the pathway through which dopamine travels in the brain. This new brain scan is called VMAT2. Early data show that VMAT2 may be more sensitive at detecting brain changes seen in Parkinson's. Better imaging means trials could enroll fewer participants, speeding studies and results. VMAT2 testing is currently available at three PPMI sites: Boston University, the Institute for Neurodegenerative Disorders and the University of Pennsylvania. Stay tuned for more on the future of VMAT2 in PPMI and research overall.

PPMI by the Numbers

829
study participants
currently enrolled in clinic

4,000+
participant recruitment
goal in clinic

49
sites across 12 countries

4,700+
study participants
currently enrolled online

100,000+
participant recruitment
goal online

8.5 million+
downloads of PPMI data
by researchers

20+
clinical trials informed
by PPMI data

35+
industry partners providing
funding support

Find more on PPMI's scientific impact in our annual Scientific Update Packet (ask your coordinator for a copy). Or visit michaeljfox.org/ppmi for the latest PPMI research news.

PPMI Online FAQ

If you're in the United States, your study coordinator might have already spoken with you about joining the online part of PPMI. Here we share some answers to common questions.

Should I join online if I'm already in the clinic?

Yes! The more data you share through PPMI, the more valuable it becomes.

What happens to my data?

PPMI has put multiple measures in place to safeguard the information you contribute.

The data you contribute to PPMI is aggregated (meaning compiled with data from other participants) and de-identified (meaning your name and identifying information are removed). The data is then shared with qualified researchers for use in studies to advance understanding, treatment and potential prevention of Parkinson's disease.

The data you contribute at study visits will be integrated with data from the online part of the study.



What do I need to do to participate?

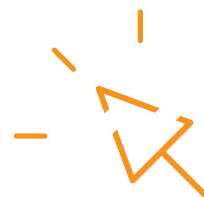
You will need an email address, and a computer or smartphone with internet access. Your study coordinator can share a unique link you can use to enroll. Once you complete the informed consent online, you will begin answering some health-related questions. You will then receive emails every 90 days letting you know when it is time to come back and answer questions again.



Who can take part in the online part of PPMI?

PPMI is open to anyone age 18 or older living in the United States. The PPMI study team is exploring ways for international volunteers to participate online.

Please contact your study coordinator to receive your unique registration link for PPMI online.



Meet Others Speeding a Cure

PPMI Participants

Whether you're new to PPMI or you've been in the study for years, we're grateful for your commitment to Parkinson's research. Here we highlight two PPMI participants contributing time and data in pursuit of a cure.



Brian Duggan

67, Mill Valley, California

Pictured left: Brian and his wife, Debbie

"For me, it started by falling out of bed. Then I would be moving at night during my dreams and flailing a bit," says Brian, who was diagnosed with REM sleep behavior disorder (RBD) in 2015. RBD is when you act out dreams while asleep. It can increase risk for developing Parkinson's or other brain diseases. (It can also be a symptom of PD.) Studying people who haven't been diagnosed with Parkinson's, but who may be at increased risk, is a critical step on PPMI's journey to ultimately prevent the disease.

"On one level, RBD is not the same as Parkinson's, but there's a continuum here. **My situation could be described as an early stage of Parkinson's,**" says Brian. He recently completed his first study visit at the University of California, San Francisco PPMI site.



Jen Gaudio

50, New London, Connecticut

Pictured left: Jen Gaudio at a neurologist visit

Jen was one of the first PPMI participants at the Institute for Neurodegenerative Disorders in Connecticut, where the study began back in 2010. She has been in the study ever since.

"I joke with the nurses at study visits because between the DaTscan, x-rays, MRIs and blood work — it makes you feel like you're going to get superpowers," Jen laughs.

As Jen plans for retirement, she points out why she continues in PPMI. **"I was always raised with the attitude: Make the world a better place. If you can't do it large, do it small. Do it local. That is something I try and fulfill as much as possible."**

Interested in sharing your story? We are always looking to feature PPMI participants in our communications. If you're interested, please contact your study coordinator.



Spread the Word

As a participant in PPMI, you're our best ambassador. You can speak to the power and promise of the study. We created a toolkit of materials to help you spread the word about PPMI across your community and networks. You can share on your social media, post flyers at places you visit regularly, or email your family and friends.



Thank you for spreading the word about PPMI!
Visit michaeljfox.org/ppmitoolkit to access:

- Email / letter template
- Social media posts
- Flyer
- Slide deck template
- Newsletter article

Learning More about Parkinson's through Online Resources

PPMI study sponsor MJFF offers educational resources to help people better understand Parkinson's disease.

From [articles on the latest research](#) to [podcasts](#) on different aspects of Parkinson's, there's something for everyone to engage with and learn more about.

Through videos, podcasts and blogs, MJFF Senior Vice President of Medical Communications and movement disorder specialist Rachel Dolhun, MD, discusses symptoms, treatments and care in the Foundation's [Ask the MD series](#).

Thousands of online viewers join MJFF's free monthly Third Thursday Webinars to hear doctors, researchers and people with Parkinson's dive deeper into common questions on care and research. Recently the webinar series covered sleep issues, "off" time and dyskinesia, and living with Parkinson's years after diagnosis. Join online at michaeljfox.org/webinars.

And follow MJFF's [Facebook](#), [Twitter](#) and [Instagram](#) for Parkinson's research updates, educational resources and opportunities to join its community.

michaeljfox.org/ppmi

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