



Parkinson's
Progression
Markers
Initiative

Summer 2024 Newsletter

About PPMI

The Parkinson's Progression Markers Initiative (PPMI) is a landmark study launched by The Michael J. Fox Foundation (MJFF) in 2010. It aims to better understand how Parkinson's starts and changes over time to speed drug development for Parkinson's disease (PD).

PPMI is working with volunteers in different ways. Many respond to surveys online. Some complete smell or genetic testing. Others visit medical centers to complete assessments and share biological samples. PPMI data — downloaded more than 25 million times — has been used to launch over 40 human studies testing new treatments and cited in more than 1,200 scientific publications. PPMI also validated a biomarker that can detect abnormal alpha-synuclein protein — a hallmark of Parkinson's.

Note from the Study Team

Dear PPMI participants,

As PPMI embarks on another year, we wanted to take a moment to express our sincere gratitude. Your commitment to Parkinson's research continues to enable scientific breakthroughs. (Learn about recent findings on page 4.) It is because of your willingness to participate that we can continue to make meaningful progress in understanding Parkinson's disease.

We would like to extend a warm welcome to nearly 10,000 participants who joined PPMI in 2023 either online or at a medical center. We're so glad you've decided to join the PPMI community.

This newsletter is developed to keep you informed about what's happening in PPMI. Read about a research framework for staging Parkinson's disease (page 2) and various parts of PPMI (page 6).

Together, we form a diverse community united in our mission to find better treatments for Parkinson's. We thank you for your ongoing participation.

Sincerely,
Your PPMI Study Team

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Another Step Forward in Parkinson's Research



Taking another major step into the new biological era of PD, PPMI study leaders have proposed a research framework for defining and staging Parkinson's based on biology, rather than symptoms

A paper was published in *The Lancet Neurology* in January 2024.

The framework — called the neuronal alpha-synuclein disease integrated staging system — builds on the 2023 discovery of a biomarker, made possible through PPMI.

The biomarker — alpha-synuclein seed amplification assay — can detect abnormal alpha-synuclein in spinal fluid even prior to symptoms. (Alpha-synuclein is a protein that changes into an abnormal form and damages brain cells in people with PD.)

By defining PD by the presence of alpha-synuclein, doctors and researchers can determine where people are in the biological progression of the disease.



A similar biological framework in Alzheimer's disease led to successful trials and new drug approvals, with the first drugs to slow Alzheimer's-related cognitive decline appearing in 2022 and 2023.

"The success that the Alzheimer's field has had with its biological framework provides the inspiration and motivation to achieve similar accelerated timelines in Parkinson's," said Tanya Simuni, MD, lead author on the paper and PPMI site investigator at Northwestern University. "Ten years from now, we hope we will look back and say this framework was the key that opened the door to next-generation treatments in Parkinson's."

This framework is expected to have an immediate impact on research, speeding clinical trials and increasing the success of scientific discovery.



[Read more](#)

Your Contributions Speeding Breakthroughs

PPMI participants like you have helped build the most robust dataset in Parkinson's research.

Researchers and doctors are using this data to better understand how PD starts and changes. Study teams are using this data to design their clinical trials. By exploring PPMI data, study teams could gain insight into who might benefit from a particular therapy in clinical testing. With that information, they can recruit the right participants into the right trials.

PPMI volunteer Rick Grant realized the value of his participation after being on a roundtable panel in Washington, D.C., in January 2024. This roundtable aimed to drive collaboration across organizations and develop better measures to speed drug development.

"I had no idea how much research goes into drug development and designing trials," said Rick. "I was just amazed at the number of brains going into curing a disease."

PPMI by the Numbers

3,000+
study participants currently
enrolled in clinic

51 sites
across 12 countries

42,000+
study participants currently
enrolled online

60,000+
smell tests distributed

25 million+
downloads of PPMI data
by researchers

40+
clinical trials informed
by PPMI data

1,200+
scientific publications
citing PPMI

35+
industry partners providing
funding support



Researchers continue to use PPMI data to publish new findings.

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

+ **Exploring Link between Genetics and Anxiety:** Many people with Parkinson's experience anxiety. A [study](#) used PPMI data to evaluate if changes in GBA (a PD-linked gene) were associated with anxiety in people with PD. The researchers used a survey to measure anxiety in 385 PPMI participants — 39 with a GBA variant. They found that people with a GBA variant had a faster annual increase in their anxiety score. They also had a higher risk for developing anxiety than those without a GBA variant. While not everyone with a GBA variant will have anxiety, these findings could help doctors improve mental health screening and provide better care.

If you have anxiety, you're not alone. [Read a blog](#) from clinical psychologist and PPMI Executive Steering Committee member Roseanne Dobkin, PhD, on what to know and do about anxiety.

+ **New Findings around Impulse Control Disorders:** Impulse control disorders (ICDs) affect some people with Parkinson's. These can include compulsive gambling, shopping, eating or sexual activity. One study looked at data from 1,045 PPMI participants. The researchers found an increase in the probability of developing an ICD in people with PD who were on antidepressants compared to those not.

Another study found that individuals with PD and sleep issues (specifically excessive daytime sleepiness and REM sleep behavior disorder) had a higher chance of developing an ICD than those who did not have sleep concerns. It's important to note not everyone on antidepressants or living with sleep problems will develop an ICD. But these findings could help doctors select the best treatment option for a specific individual, to further personalize their care.

With your participation, PPMI is trailblazing the path for Parkinson's research. Every day we're getting closer to a cure.

What Part of PPMI Are You In?

PPMI is working with study volunteers in different ways. Some participants complete surveys online while others share information at a medical center. Many participants are in multiple parts of the study. Here we describe a few parts of PPMI.



Clinical Site:

Participants contribute valuable data and biological samples at 51 medical centers across the globe.

Available in the U.S., Canada, Austria, Germany, Greece, Israel, Italy, Luxembourg, Netherlands, Nigeria, Spain, U.K.



Online Platform:

Participants complete sets of questions on health and disease online every 90 days.

Available in the U.S.



Smell Test:

Participants complete a scratch-and-sniff smell test and may be invited to join online or at a clinical site.

Available in the U.S., Canada, Germany, Netherlands, U.K.; will expand to more countries



Web-based Cognitive Activities:

Participants complete thinking and memory tasks on their computer.

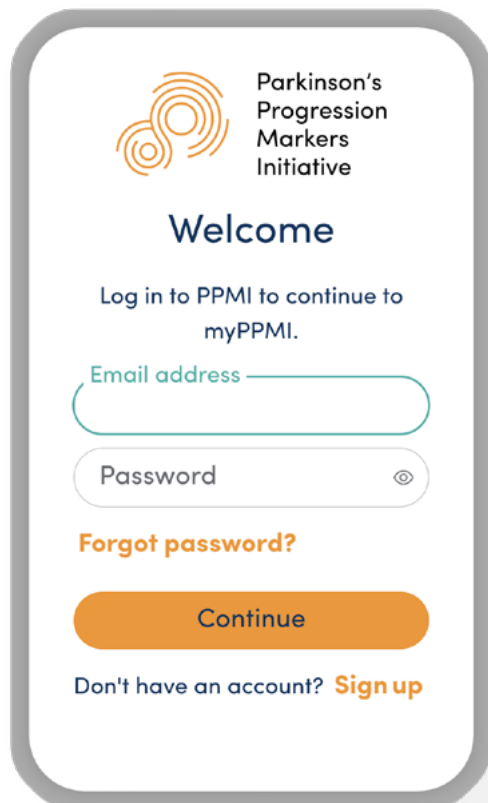
Available in the U.S.; will expand to more countries

These are just a few different parts of PPMI. Whether you are in one part of the study or all of them, your contributions are critical. Learn more at myppmi.org/parts-of-ppmi.

myPPMI: Your Personal Study Portal

The best way to stay connected to all parts of the study is through myPPMI. This participant portal can be considered your home base for your participation in PPMI.

myPPMI is currently available in the U.S., Canada, England, Germany and the Netherlands. We plan to expand to other countries in the future.

A mockup of the myPPMI login screen. At the top left is the Parkinson's Progression Markers Initiative logo, consisting of three concentric orange circles. To its right is the text "Parkinson's Progression Markers Initiative". Below the logo is the word "Welcome" in a bold, dark blue font. Underneath "Welcome" is the instruction "Log in to PPMI to continue to myPPMI." in a smaller, dark blue font. There are two input fields: "Email address" with a light blue border and "Password" with a light grey border and a small eye icon on the right. Below the password field is a link "Forgot password?" in orange. At the bottom is a large orange button with the word "Continue" in white. Below the button is a link "Don't have an account? Sign up" in dark blue, with "Sign up" in orange.

Get started today:

1. Visit myppmi.org.
2. Enter your country of residence then click Login.
3. Use the same login information (email address and password) that you use to log in to the PPMI online study platform.

Issues logging into myPPMI?

Email support@myppmi.org.

Meet Others in the PPMI Community



Fotini Skondra

56, Chalkida, Greece

Fotini Skondra was diagnosed with Parkinson's in 2013 at 46 and lives in a town called Chalkida, about an hour outside of Athens, Greece. She taught Greek Literature at a university for 15 years before retiring to take care of her children. Being a teacher for so many years, she was deeply familiar with her handwriting. She noticed right away when it started to change. (Parkinson's can cause small handwriting.)

Once she was diagnosed, she got involved in research and has been a PPMI participant at our Athens site since 2013.

"I think being a PPMI participant is one of the most important steps I have taken in my Parkinson's journey," said Fotini. "I was both excited and proud when I heard the news about the biomarker discovery. I also feel very lucky because in Greece there is a remarkable scientific team with accredited expertise in PPMI. They have been particularly meticulous and detailed at my study visits over the years. And they have provided continuous high-level medical support."

Do you have a PPMI story to share?

We'd love to hear it! Share your story at michaeljfox.org/shareyourstory.



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