



Summer 2023 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 how Parkinson's starts and changes over time.

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 in person. PPMI data — downloaded more than 15 million times — has been used to launch over 20 human studies testing new treatments and cited in more than 1,200 scientific publications. PPMI also helped validate a biomarker test that can detect abnormal alpha-synuclein protein — a hallmark of Parkinson's.

Dear Friend,

Whether you joined PPMI yesterday or 10 years ago, your contributions to the study are leading to remarkable progress. Since our last newsletter, enrollment has grown, more clinical sites have signed on to the study, and PPMI scientists announced a new biomarker. This biological marker of disease opens many doors for continued research and is an important milestone on our way to cures. Read more about the breakthrough that you've made possible on page 2.

PPMI is expanding too through myPPMI, our new web-based portal designed for participants. On page 4 you can read more about this platform as well as a recap of this year's PPMI Annual Meeting.

Your dedication to research is deepening understanding of Parkinson's risk and disease and helping scientists develop new treatments. We cannot thank you enough for being part of the study that's changing everything.

Sincerely,

Your PPMI Study Team

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Biomarker Breakthrough: You Have Made History

You may have heard the news. Scientists have made a major breakthrough toward a biological marker for Parkinson's disease (PD). **This is a direct result of your contributions to PPMI.** Thank you!

The biomarker test is called an alpha-synuclein seeding amplification assay. This tool can detect abnormal alpha-synuclein protein, a hallmark of Parkinson's disease. Studying spinal fluid, contributed through lumbar punctures at PPMI medical centers, made this breakthrough possible. This discovery opens a new chapter for research and could transform care.

"This biomarker enables us to move to another level in effecting new strategies for prevention of disease," said Ken Marek, MD, PPMI principal investigator.

Parkinson's is primarily diagnosed through subjective clinical assessments. Now, thanks to your contributions, we are closer to defining Parkinson's based on biology.

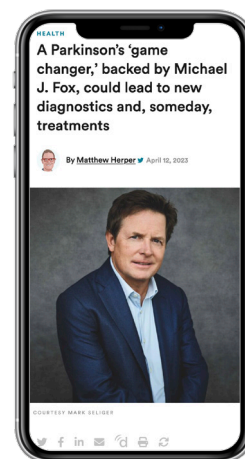


The biomarker breakthrough has been featured in more than 30 local, national and international media outlets.



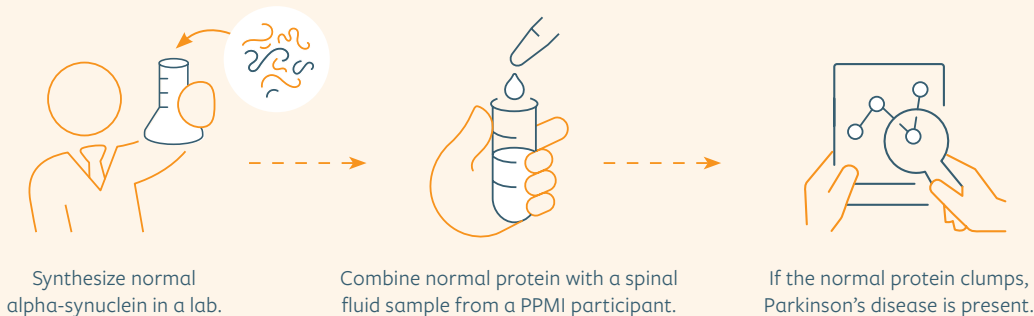
Read All About It!

- + Read an opinion piece authored by Michael J. Fox in *USA Today*: bit.ly/3I3ceUj
- + Read an article in *STAT* announcing this news: bit.ly/3HXRGwn
- + Watch Michael J. Fox on *CBS Sunday Morning*: bit.ly/3BEZn7s



Here's how it works:

A Powerful Tool for Detecting Parkinson's



Making Drug Trials Faster, Smarter and Cheaper



Our Roadmap Forward



Currently, this test is mostly used for research but may be available through your doctor. If you or a loved one are considering it, please talk to your doctor to learn more and discuss what the test can and can't tell you.

Want to learn more?

- + Read a blog that explains what this test means, today, for you and your loved ones: michaeljfox.org/pdtest
- + Watch a webinar hosted by PPMI study leadership: bit.ly/3MkZk6A
- + Watch a webinar hosted by MJFF: bit.ly/3O5o6Jl

Your Contributions Speeding Breakthroughs

The information and samples you provide are leading to new insights into how Parkinson's starts and changes. Those findings will fuel future tests and better care for the disease. Here we share some recent results made possible through your participation in PPMI.

Identification of Parkinson's Subtypes and Progression Using Machine Learning

Parkinson's presents in different ways. Scientists aimed to create a model to identify disease subtypes. They analyzed PPMI data using machine learning. Computers can group and predict activity by learning from data. The study revealed three disease subtypes: slow, moderate and fast progressors on measures of movement, sleep and cognition. It used demographics, biospecimen results, vital signs, genetics, and motor symptom scores to predict progression type. Predicting disease course can help inform personalized care, treatment selection and important areas for future research. Read the paper at bit.ly/3B8EfpF.

Predictors of Cognitive Impairment in People with Parkinson's

Some people with Parkinson's have thinking and memory (cognitive) issues. When these issues interfere with everyday life, this is called cognitive impairment. Researchers looked at cognitive data from PPMI participants with Parkinson's at enrollment and after five years. Out of 232 participants, 94 developed cognitive impairment in those five years. Age and hypertension were both linked to developing cognitive impairment. Not everyone with hypertension and PD will develop cognitive impairment. But these findings could help make people aware of their risk and be more proactive in self-care. They also could help scientists select participants for clinical trials. Read the paper at bit.ly/3M9GQWQ.

Learn more in the latest Scientific Update, available through myPPMI at myppmi.org. Learn more about myPPMI on page 5.

PPMI by the Numbers

2,000+
study participants
currently enrolled in clinic

50+
sites across 12 countries

38,000+
study participants
currently enrolled online

22,000+
smell tests distributed

15 million
downloads of PPMI data
by researchers

20+
clinical trials informed
by PPMI data

1,200+
scientific publications
citing PPMI

35+
industry partners providing
funding support

Please help spread the word that PPMI is recruiting volunteers! Find a toolkit with materials at michaeljfox.org/ppmitoolkit.

Redefining Parkinson's

PPMI Meeting in New York City

In May 2023, over 325 PPMI representatives gathered in New York City for the study's Annual Meeting. Study leaders from 14 countries came together to discuss challenges, opportunities and scientific findings. They also discussed next steps for future research, with a focus on entering the biological era of Parkinson's research.



myPPMI: Your One-Stop Shop in PPMI

Have you logged into myPPMI yet? myPPMI is a web-based portal designed just for PPMI participants. It can be considered a one-stop shop for your participation in PPMI. Explore the latest scientific findings, find available resources and discover new ways to add to this research.

myPPMI is now available to U.S. participants. The portal will expand into other countries in the near future.

Learn more about myPPMI at michaeljfox.org/myppmi. Questions? Email support@myppmi.org.

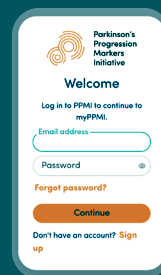
The new biomarker test (featured on page 3) was among many conversations at the meeting. "This test allows us to move from 'game changing' to a 'paradigm shift,'" said Dr. Marek.

This "paradigm shift" was a key theme of the meeting as we enter this new age of Parkinson's research. More information on the biology underpinning disease risk, onset and progression will enable the development of new, varied treatments for people at every stage of disease: recently diagnosed, living with Parkinson's for years, or even at risk without any visible symptoms.

Read more at michaeljfox.org/ppmi-news.

Visit myppmi.org to get started.

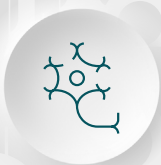
Log in with your PPMI account. (You could have made this account with an email and password when you joined the PPMI online study platform.) If you don't have a PPMI account yet, click "Login" then sign up to create one.



Collecting Important Data Online

In 2021, PPMI expanded with an online platform, open to anyone aged 18 and older in the U.S. — with or without Parkinson's disease. The PPMI online study platform sends out surveys on health and wellness every 90 days. This information is helping scientists understand disease experience and progression, normal aging and brain disease risk.

To date, more than 38,000 participants are sharing data through the PPMI online study platform.



62%

do not have PD



55%

aged 60-69



44%

male

Some interesting findings from the study data thus far:

- + More than five percent of male participants aged 60 or older without Parkinson's reported a REM sleep behavior disorder (RBD) diagnosis. And 20 percent reported acting out dreams (without an RBD diagnosis). RBD is a disorder of acting out dreams when asleep and is a risk factor for a PD diagnosis. PPMI is learning from this group about how Parkinson's begins.
- + People without PD living with depression or anxiety reported higher rates of cognitive changes (problems with memory and thinking) than people without depression or anxiety. This could help doctors provide more personalized care, such as routine mood checks as part of standard care and more frequent screening for cognitive impairment in those with anxiety and depression.

All the data you provide is helping scientists better understand how Parkinson's starts and changes over time. This ultimately gets us closer to better treating the disease and one day preventing it altogether.

Get started or continue your participation in the PPMI online study platform at ppmionline.org.

Meet Fellow Volunteers



Allen Dance

60; Richmond, Virginia

"My partner told me I was gesturing and laughing while asleep," said Allen. A sleep study confirmed Allen had REM sleep behavior disorder (RBD). RBD can be a possible precursor to Parkinson's disease.

A former athlete, Allen was shocked to learn about his risk for developing Parkinson's. But he decided to immediately take action. He joined PPMI at the New York University site.

"I felt a responsibility to step up and be part of it," said Allen.



Mike Kinnett

66; Gainesville, Florida

"When I was growing up, my grandmother had lilacs, and their aroma evoked wonderful memories," Mike recalls. "But the smell began to fade in my 50s, along with my overall sense of smell."

Once Mike developed a tremor, on top of diminished smell loss, he sought answers. At 62, he was diagnosed with PD. Mike chose not to start Parkinson's medication right away, and discovered he was a prime candidate for PPMI.

"They've made me an active participant in the search for a cure," Mike says about the PPMI site team at the University of Florida.



MJFF Events Coming to a City Near You

Want more ways to become involved? Join study sponsor The Michael J. Fox Foundation at an upcoming in-person event. The Run / Walk series brings together walkers and runners of all ages for a fun-filled day to raise funds for PD research. MJFF also has two more Parkinson's IQ + You events this year. These are educational events designed to empower people with Parkinson's and their loved ones to manage the disease, learn about the latest research and connect with local resources. Find the dates and learn more at the links below. We hope to see you there!

Parkinson's IQ + You

Seattle, WA: September 9, 2023

Columbus, OH: October 14, 2023

michaeljfox.org/pdiq

Run / Walk

Denver, CO: October 8, 2023

Boston, MA: October 29, 2023

runwalk.michaeljfox.org



Coming Soon: PPMI Mobile App

In the coming months, PPMI will launch a mobile app. This will be another critical way participants can share data with the study. Collecting more frequent data will help scientists look for ways to treat or prevent disease.

The Roche PD Mobile App will first launch in the U.S. It will expand to other countries in the future. Stay tuned for new opportunities like this one by checking myPPMI often at myppmi.org.

myppmi.org

PPMI is sponsored by MJFF and funded by the Foundation in partnership with biotech and pharmaceutical companies, nonprofit organizations and individual donors.





Parkinson's
Progression
Markers
Initiative