



Parkinson's
Progression
Markers
Initiative

PPMI Participant 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.

The data you share through PPMI could lead to insights and tools that can help better diagnose, treat and even prevent Parkinson's disease. PPMI data — downloaded nearly 10 million times — has been used to launch over 20 human studies testing new treatments and cited in more than 400 scientific publications.

Dear Friend,

Whether you've been sharing data for years or just joined the study recently, you're helping PPMI grow its size and impact. Read about recent scientific findings made possible through your contributions on page 2. Also explore new PPMI sites, meet some of your fellow volunteers and discover educational resources from study sponsor The Michael J. Fox Foundation.

Now, we're asking you to continue helping PPMI grow and reach its ambitious goals. PPMI has launched a new initiative inviting everyone over age 60 without Parkinson's to take a smell test. Learn more about the initiative and how you can help spread the word on page 3.

We're so glad you're part of the PPMI community dedicated to stopping Parkinson's disease (PD). Thank you for being part of the study that could change everything.

Sincerely,

Your PPMI Study Team

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Your Contributions Speeding Breakthroughs

The information you provide is 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.

Impulse Control Disorder Risk Score

Some Parkinson's medications are associated with the experience of impulse control disorders (ICDs). These can include compulsive gambling, shopping, eating and sexual behavior. A team at the University of Pennsylvania and genetics company 23andMe found genetic and clinical factors that may make ICDs more likely in some people with PD. The scientists created a tool for ICD risk from looking at data from PPMI and other studies. That scoring tool may help people select the most appropriate PD medication based on their ICD risk. Read the paper at doi.org/10.1002/acn3.51569.

Brain Changes with RBD and Thinking Problems

Some people with PD have memory and thinking problems beyond what is expected with normal aging. This is called cognitive impairment. These changes can be more common in people with Parkinson's who act out their dreams. That condition is called REM sleep behavior disorder (RBD). Researchers in Spain found significantly more changes in brain scans from people in PPMI with PD and RBD (compared to people with PD without RBD or control volunteers). These changes correlate with cognitive impairment, including problems with processing speed and word finding. These findings help scientists better understand cognitive changes in Parkinson's. They may also suggest the need for cognitive screening earlier, especially for people with RBD. Read the paper at nature.com/articles/s41531-022-00326-7.

PPMI by the Numbers

1,500

study participants
currently enrolled in clinic

4,000+

participant recruitment goal in
clinic

50+

sites across 12 countries

32,000+

study participants
currently enrolled online

10 million

downloads of PPMI data
by researchers

20+

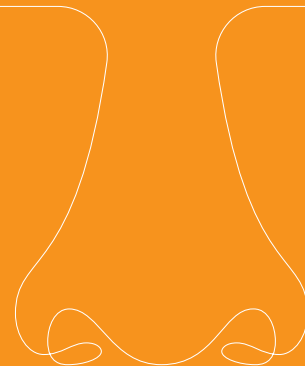
clinical trials informed
by PPMI data

35+

industry partners providing
funding support

Find more on PPMI's
scientific impact at
michaeljfox.org/in-ppmi.

Spread the Word: Scratch and Sniff for PPMI



Smell loss may be one of the most important signals of Parkinson's risk. To help explore this link, we are asking people aged 60 and up without Parkinson's disease to take a smell test.

This initiative is currently open in the United States, but the study is planning to expand internationally.

As a participant in PPMI, you're our best ambassador. We need your help getting everyone to get involved.

Participants will answer a few questions, and we'll mail them a smell test. Then they'll enter their answers online. Their results may make them eligible for PPMI.

Please tell everyone you know — friends, family, community members, neighbors — to request a simple scratch-and-sniff test today at mysmelltest.org/partners.

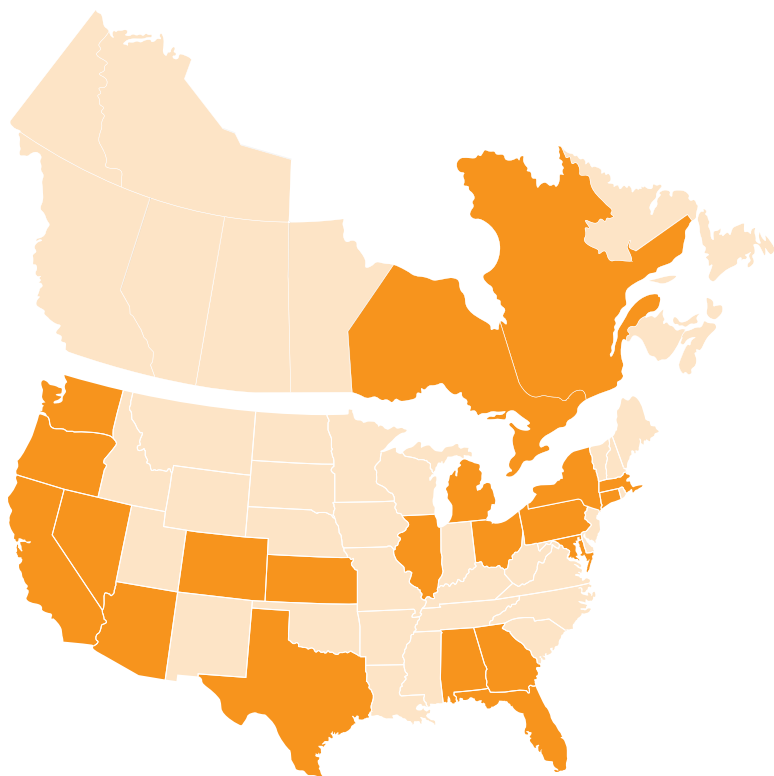


We developed a toolkit to help you spread the word. Visit michaelfox.org/in-ppmi for an email/letter template, newsletter blurbs, talking points, social media posts, a postcard, a flyer and a graphic for social media.

Thank you for sharing this important initiative with your community!

PPMI's Global Reach

PPMI is working with study volunteers in different ways. Like you, most complete questions online. Some share information at regular visits to a medical center. Here we share a map of 50 PPMI sites recruiting volunteers to contribute valuable data and biological samples.



United States

- + Alabama - Birmingham
- + Arizona - Phoenix, Scottsdale, Sun City
- + California - Los Angeles, San Diego, San Francisco
- + Colorado - Aurora
- + Connecticut - New Haven
- + Florida - Boca Raton, Gainesville, Tampa
- + Georgia - Atlanta
- + Illinois - Chicago
- + Kansas - Kansas City
- + Maryland - Baltimore
- + Massachusetts - Boston (Two sites)
- + Michigan - Ann Arbor
- + Nevada - Las Vegas
- + New York - New York City (Two sites), Rochester
- + Ohio - Cincinnati, Cleveland
- + Oregon - Portland
- + Pennsylvania - Philadelphia, Pittsburgh
- + Texas - Houston
- + Washington - Seattle

Canada

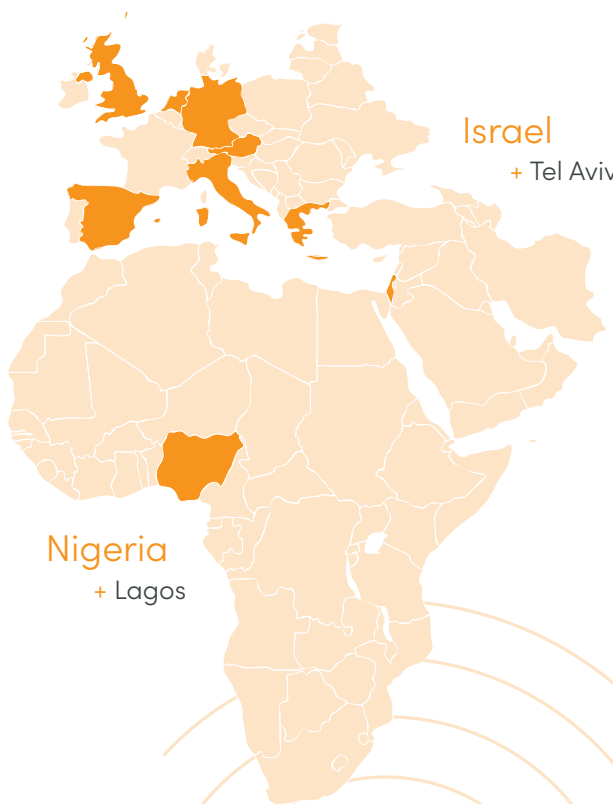
- + Montreal, Ottawa, Toronto

Europe

- + Austria - Innsbruck
- + Germany - Kassel, Lüneburg, Marburg, Tübingen
- + Greece - Athens
- + Italy - Salerno
- + Netherlands - Nijmegen
- + Spain - Barcelona, San Sebastian

United Kingdom

- + London, Newcastle upon Tyne, Oxford



Israel

- + Tel Aviv

Nigeria

- + Lagos

Meet Others Speeding a Cure

PPMI Participants



Charles Blatt

66, Tualatin, Oregon

“When I found out my neighbor and friend had Parkinson’s, I figured if I can help her and other people to get some kind of cure and do my little part, I thought, why not?” says Charles, a control participant in PPMI and retired military veteran.

Although Charles doesn’t have Parkinson’s, he has participated in the study at Oregon Health & Science University for several years.

“When you have the military mindset, it’s like an obligation. To be able to support other active soldiers, veterans, or family members with Parkinson’s — I think most people would realize the benefit of doing that for others.”



Otis Peeples

71, Chicago, Illinois

For Otis, a behavioral health therapist and retired police sergeant, participating in PPMI offered a unique opportunity to help him learn more about his own risk for Parkinson’s disease.

His wife, Linda, noticed he was acting out his dreams. He would punch, wrestle, get out of bed and talk while asleep. When Otis was diagnosed with REM sleep behavior disorder (RBD) and learned about its connection to Parkinson’s, he took action and joined PPMI. He has been participating in the study at Northwestern University for 10 years.

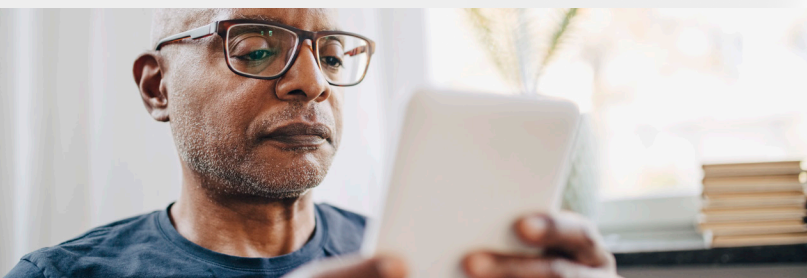
“Maybe that will be my purpose: to help find a cure for this disease,” says Otis.

Share Your Story

PPMI and The Michael J. Fox Foundation (MJFF) are always looking to feature study participants in communications. By sharing your story and experience, you can raise awareness about research, help motivate potential volunteers and connect with the community. If you’re interested, please fill out a form at michaeljfox.org/shareyourstory, and someone from MJFF may contact you.



Resources to Navigate Parkinson's and Boost Brain Health



MJFF offers educational resources to help people and families navigate life with Parkinson's disease. Here we share some recent guides and webinars.

Guides

In easy-to-read, downloadable guides, experts provide practical tips and real-world advice so that everyone — young or old, living with disease or not — can feel empowered to care for their brain.

michaeljfox.org/guides

- + **Paving Your Path Over Time**
practical tips to manage progressing Parkinson's
- + **Looking Ahead with Parkinson's**
advice for planning end-of-life care

michaeljfox.org/brainhealth

- + **Better Brain Health**
easy-to-follow steps to boost your brain health

Webinars

Thousands of online viewers join MJFF's free monthly Third Thursday Webinars to hear doctors, researchers and people with PD discuss Parkinson's research and care. Recently the webinar series covered:

- + Autonomic issues in Parkinson's (e.g., low blood pressure, bladder problems, constipation and sweating)
- + Parkinson's genetics
- + Telehealth
- + Sleep issues

Join online or watch on demand at michaeljfox.org/webinars.

michaeljfox.org/in-ppmi

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