A Letter from Michael J. Fox

Dear Friend,

I wanted to personally welcome you to the Parkinson’s Progression Markers Initiative (PPMI). Whether you’re still weighing the possibility of joining, or you’ve already enrolled, you have my deepest thanks for being part of our mission to speed breakthrough treatments for Parkinson’s disease.

I’m grateful you’re here because, if there’s one thing I know for sure, it’s that better treatments aren’t going to fall from the sky. Real challenges stand in the way of the results we need, and it’s up to all of us to get involved and meet those challenges however we can. By participating in PPMI, you can do just that.

Our Foundation has been funding various biomarker projects for years. Now the time has come for a concerted, unified effort that will optimize our chances for results. With your help, we’re ready to roll up our sleeves and get it done. Everything we’ve learned up to now has put us in position to work with the hundreds of partners — study volunteers, scientists, clinicians, funders — who are coming together to make PPMI a reality.

At our Foundation, we don’t like to pat ourselves on the back. But I hope you’ll give yourself one for raising your hand to be part of this effort. The thoughtful engagement of people like you is the only thing that can help meet a major need for participants in clinical research. Across all diseases, 85 percent of trials finish late because of difficulty with enrollment. That is being felt by all of us in the form of slower progress toward cures. Today, you are part of the solution.

I have experienced profound benefits — some of the richest of my life — from taking action to meet challenges I never even saw coming. Parkinson’s was a choice that was made for me, but once I accepted that, I found a freedom to do incredible things that I would never have known about under other circumstances. It’s amazing; it’s a gift. And I believe we all have that freedom.

Thank you again for being part of something that could change everything for the five million Parkinson’s patients worldwide.

All my best,

Michael J. Fox

About Parkinson’s Disease

- An estimated one million people in the United States and over five million worldwide are living with Parkinson’s disease — a chronic, degenerative neurological disorder.

- Parkinson’s disease affects one in 100 people over the age of 60. In the United States, 60,000 new cases will be diagnosed this year alone.

- Average age of onset is 60, though some people are diagnosed under the age of 40.

- There is no known cure for Parkinson’s disease. Current treatments mask some symptoms but bring serious side effects, lose efficacy over time, and do not slow or alter disease progression.

PPMI is sponsored by The Michael J. Fox Foundation for Parkinson’s Research.
About PPMI
The Parkinson’s Progression Markers Initiative (PPMI) is an observational research study to identify biomarkers of Parkinson’s disease (PD) progression. A biomarker is a substance or characteristic in our bodies that is associated with the presence of disease, or that changes over time in a way that can be linked to the progression of disease. The discovery of a biomarker of Parkinson’s disease is critical to the development of new and better treatments for PD. It is particularly important for developing treatments that could slow or stop the progression of the disease. This is something no currently available treatment can do.

Study participants will undergo numerous tests and assessments related to PD, but will not receive an experimental drug or treatment. PPMI will use a combination of imaging techniques, collection of blood, urine, and spinal fluid, and clinical tests. The information gathered from these procedures is critical to the future development of new and better treatments for Parkinson’s disease. PPMI is the first clinical study to assemble a population of sufficient size to collect this information, draw meaningful scientific conclusions over time, and try to develop better ways to measure the progression of PD.

The study will be conducted in the United States and Europe. It is expected to take about five years. It is being sponsored by The Michael J. Fox Foundation for Parkinson’s Research and will be made possible through the efforts of agencies interested in PD drug development.

Frequently Asked Questions

AM I ELIGIBLE TO PARTICIPATE IN PPMI?
Your eligibility will be determined by staff at the study site during your screening visit. We are seeking 400 PD participants — recently diagnosed Parkinson’s patients who are not currently taking standard medications for Parkinson’s disease — and 200 control participants — adults who do not have PD and do not have a first-degree relative (parent, child or sibling) with PD.

HOW LONG WILL THE STUDY LAST?
PPMI will be conducted over the course of about five years. For individual participants, the duration will range from three to five years depending on their particular study entry date during an initial two-year enrollment period.

HOW OFTEN WILL STUDY VISITS TAKE PLACE?
After the first (screening) visit, you will visit the site upon enrolling and again at 3, 6, 9 and 12 months. Visits will then occur every 6 months until the study is over.

WILL I BE PAID FOR MY TIME AND TRAVEL?
Participants will be compensated upon completion of each visit — $50/£38 for each short visit and $200/£150 for each long visit. Additionally, all travel expenses will be reimbursed.

IF I ENROLL, DO I HAVE TO STOP SEEING MY CURRENT PHYSICIAN?
No, you are encouraged to maintain your relationship with your doctor. When you come for study visits as a PPMI participant you will be evaluated by an experienced clinical research team. All other decisions about your medical care outside of the study are up to you. PD patients who enroll in PPMI may elect to have the PPMI study site share test results and clinically relevant findings with their personal physician.

WHAT IF MY DOCTOR SUGGESTS THAT I TAKE MEDICATION FOR MY PARKINSON’S AFTER I ENROLL?
Your health is of the utmost importance. While our hope is that participants will not begin taking Parkinson’s disease medications for the first 6 to 12 months, physicians and patients should make the decision to begin a new medication regimen independent of participation in PPMI.

WHERE IS PPMI BEING CONDUCTED?
PPMI is occurring at sites across the United States and in Europe. For a complete list of site locations, visit www.michaeljfox.org/PPMI.

WHO IS SPONSORING THIS RESEARCH?
PPMI is sponsored by The Michael J. Fox Foundation for Parkinson’s Research.

I DON’T QUALIFY FOR PPMI, BUT I STILL WANT TO HELP. WHAT CAN I DO?
Please help us spread the word to people who might be interested in participating. If you know someone recently diagnosed with PD, or someone who does not have PD and is not a first-degree relative (parent, child, sibling) of a PD patient, please refer them to:

www.michaeljfox.org/PPMI
or
(877) 525-PPM I

You should also contact your nearest study site as they very likely are conducting other trials for which you may be eligible.