## A Letter from Michael J. Fox

**Dear Friend,**

In the years since my diagnosis, the love and support of my family have been vital to living well with Parkinson's disease. Today, the role of all families supporting Parkinson's research is more crucial than ever.

Studying the genetics of Parkinson's disease could revolutionize the development of new treatments for patients worldwide. Families connected to people who carry genetic mutations of Parkinson's play a unique role in the pursuit of a cure.

A decision to get genetic testing in PPMI is an opportunity to join forces with thousands of families worldwide committed to speeding scientific progress toward cures for diseases that touch countless lives.

We're all in this together. I hope you'll consider joining our movement.

All my best,

**Michael J. Fox**

## Who is Eligible to Participate in PPMI?

Parents, children, brothers or sisters of an individual who carries a LRRK2 mutation are invited to receive genetic testing free of charge through the PPMI study. PPMI needs volunteers both with and without Parkinson's disease.

### PPMI Sites Worldwide

Clinical sites in the following locations offer genetic counseling and testing for the LRRK2 gene free of charge.

| United States | | International |
|---|---|---|
| Atlanta, GA | Portland, OR | Athens, Greece |
| Baltimore, MD | Rochester, NY | Barcelona, Spain |
| Birmingham, AL | San Diego, CA | Innsbruck, Austria |
| Boca Raton, FL | Seattle, WA | Kassel, Germany |
| Boston, MA | Sun City, AZ | London, United Kingdom |
| Chicago, IL | Sunnyvale, CA | Paris, France |
| Cincinnati, OH | Tampa, FL | Salerno, Italy |
| Cleveland, OH | | San Sebastian, Spain |
| Houston, TX | | Sydney, Australia |
| New Haven, CT | | Tel Aviv, Israel |
| New York, NY | | Trondheim, Norway |
| Philadelphia, PA | | Tübingen, Germany |

PARKINSON'S PROGRESSION MARKERS INITIATIVE

Play a Part in Parkinson's Research

*Participate in PPMI.*
**www.michaeljfox.org/PPMI/genetics**

# BE PART OF THE GENETICS REVOLUTION:

## THE ROLE OF FAMILIES IN PARKINSON'S DISEASE RESEARCH

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## Introduction

Increased understanding of Parkinson's disease (PD) genetics has breathed new life into PD drug development over the past decade and continues to form the building blocks for next-generation treatments. The participation of families in this groundbreaking research is essential to help researchers identify genetic traits that may contribute to disease onset and progression. **You have received this brochure because at least one of your family members carries a mutation in the LRRK2 gene**—a promising target of PD research.

### What is LRRK2?

- LRRK2 is the single most common genetic contributor to Parkinson's disease. It is the subject of intense investigation by Parkinson's researchers around the world because of its potential to lead to medical breakthroughs for PD.
- Mutations, or changes, in the LRRK2 gene are related to the onset and progression of Parkinson's disease. Having a LRRK2 mutation increases the risk of developing PD; however, many people who carry the mutation never go on to develop the disease.
- Each child, parent, brother or sister of a person carrying a LRRK2 mutation has a 50% chance of also carrying the mutation. That's why it is critical for family members who may carry a LRRK2 mutation to participate in PD research to help speed progress toward treatments that can benefit everyone with the disease.

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*To learn more, visit*
**www.michaeljfox.org/PPMI/genetics**.

## Why is the LRRK2 Mutation So Important to Parkinson's Research?

Over the past decade, studies of genetic changes associated with Parkinson's disease have revolutionized the pursuit of a "disease-modifying" treatment—a therapy that can slow or stop the progression of the disease. To date, no treatment that changes the progression of Parkinson's disease has been discovered. For this reason, families that carry LRRK2 mutations have a vital role to play in Parkinson's research. The Parkinson's Progression Markers Initiative (PPMI) is one study seeking to learn more about how genetic mutations may sometimes lead to PD.

### About PPMI

The Parkinson's Progression Markers Initiative is a landmark clinical study to better understand the progression of Parkinson's disease. The goal of PPMI is to identify and assess biomarkers, or indicators of Parkinson's disease progression to ultimately enable early and accurate detection and potentially help identify new and better treatments for future generations of PD patients.

**First degree family members of individuals who carry a LRRK2 genetic mutation are invited to receive genetic counseling and testing free of charge through the PPMI study.** PPMI seeks volunteers both with and without Parkinson's disease.

PPMI is the largest biomarker study in Parkinson's disease research. It is sponsored by The Michael J. Fox Foundation for Parkinson's Research.

## Genetic Counseling and Testing: What's Involved?

Genetic testing is a process of examining a person's DNA. Among other things, genetic testing can reveal changes in your genes that may indicate risk of or cause illness or disease. For example, having a mutation in the LRRK2 gene increases an individual's risk of Parkinson's disease.

**PPMI will provide free genetic counseling and testing for LRRK2 at no cost to people who have a family member who carries a LRRK2 mutation.** Here is a summary of the genetic testing process in PPMI:

### The Online Survey

To get started, visit **michaeljfox.org/ppmi/genetics** to take PPMI's brief online survey to find out if you may be eligible to receive genetic counseling and testing for the purposes of PPMI.

### The Genetic Test

Eligible volunteers may be mailed a genetic testing kit requiring a saliva sample to determine whether or not there is a mutation in your LRRK2 gene. Your saliva sample will be sent to a central laboratory for testing.

### Talking with a Genetic Counselor

You will be contacted by a genetic counselor to review your test results together. You will also discuss your personal and family medical history and the genetics of Parkinson's disease. Some volunteers may be invited to participate in additional tests and evaluations.

*If you are interested in receiving free genetic counseling and testing for a LRRK2 mutation through PPMI, visit* **www.michaeljfox.org/PPMI/genetics**.