

Information Sheet

Title: Parkinson's Progression Markers Initiative Personal Profile

Principal Investigator: Thomas F Tropea, DO

Contact Information: support@myPPMI.org

You are invited to take part in a research study. You will complete a Parkinson's Progression Markers Initiative (PPMI) Personal Profile as part of this study. This document has information regarding the study to help you decide if you want to participate. Please read the information below. It is your choice to complete the profile or not. Your decision about participating in this study is voluntary. You may choose not to participate in this study, in which case you will not lose access to any benefits to which you are otherwise entitled.

Purpose

The Personal Profile collects basic personal and health information and populates a profile linked across different studies that you may participate in as part of PPMI. If you have provided this information in a different study in PPMI, it may be pulled into your profile to reduce the need for you to enter the same information repeatedly. Your information helps accelerate Parkinson's research and may help identify other studies for which you may be eligible to participate in.

This research is conducted by the Michael J. Fox Foundation for Parkinson's Research. This study has been reviewed by an Institutional Review Board (IRB), which is responsible for protecting the rights and welfare of research participants.

Participation

If you decide to take part, you will complete the Personal Profile. The questionnaires may ask about your background, health and genetic history, medications, and other personal or medical information. Some fields, such as your preferred language, may be automatically filled in from your participation in PPMI. Other information will be self-reported, meaning you will answer questions about yourself. It will not pull information from your medical record. You may complete the profile with help from another person, such as a family member or friend. Completing the Personal Profile will take about 10–20 minutes. You may save your answers and return later. The study team may ask you to confirm, update, or provide additional information in the future. You may update your Personal Profile in myPPMI at any time.

Completing the Personal Profile does not enroll you in a specific research study. Based on the information you choose to share, PPMI may have the ability to inform you about other studies that you may be eligible for. If you do not complete all the required fields, you may not be presented with future research opportunities. It is your choice to join any future studies. Those studies will require separate consents to participate. You should consider your interest in participating in future studies before joining.

Information you share will not be used to provide medical advice, give a diagnosis, or guide your medical care. No procedures, samples collections or interventions will be completed as part of this study.

Your Choice to Participate

Your participation is completely voluntary. You may choose to discontinue entering your information into the Personal Profile at any time. If you choose to stop participating, your information collected prior to withdrawal may continue to be retained and used in coded or de-identified form for research purposes.

Risks

The risks of completing the profile are minimal. There is a potential loss of confidentiality if your personal information is accidentally disclosed. PPMI uses many privacy safeguards to reduce this risk. There is also a potential risk that you may feel anxious about completing the questionnaire. You may skip any non-required questions or withdraw from the study at any time.

Benefits

There are no direct benefits in participating in this study. Your information may help improve recruitment and planning for future Parkinson's studies. Completing this Personal Profile also may reduce your need to repeatedly provide the same information across multiple PPMI research studies.

Confidentiality and Data Use

Your research records will be kept confidential to the extent permitted by applicable laws and regulations. Efforts will be made to keep your personal information private; however, total confidentiality cannot be guaranteed. Your information will be protected and stored securely with only authorized members of the PPMI study team having access. Your information will be assigned a code. Identifiable information (such as your name or date of birth) will be stored separately from your research data. Researchers who receive your data will not have direct identifiers, but in some cases coded data may be linkable by authorized PPMI study team. Some data may be coded and stored in secure research databases, including the Laboratory of Neuro Imaging (LONI). Data shared with researchers will not include direct identifiers. Qualified researchers may use your data for approved research projects and must abide by PPMI data policies.

You can learn more about how your data is protected in the [PPMI Privacy Policy](#).

Questions

You may contact the study team through the myPPMI [Contact Us](#) section.

Consent

By checking the box below and completing the Personal Profile, you are indicating your consent to participate in this study and are confirming:

- You have read and understand this information sheet.
- You voluntarily agree to participate in this research project.
- The information you provide is true and accurate to the best of your knowledge.

[checkbox] I agree that I have read and understood the Personal Profile information sheet.

[button] Create My Profile