

**INFORMED CONSENT FORM
AND
AUTHORIZATION TO USE AND DISCLOSE PROTECTED HEALTH INFORMATION**

Sponsor / Study Title: Parkinson's Foundation / Parkinson's Foundation Surveys

Protocol Number: PF-Surveys-01

Principal Investigator: James Beck, PhD

Telephone: 800-473-4636 (24-Hour)

Address: Parkinson's Foundation
200 SE 1st St, Suite 800
Miami, FL, 33131

Thank you for your interest in Parkinson's Foundation surveys! Please review the study information below. After you have read this form, you will be asked to check a box to indicate if you agree to participate in this study. By checking the box, you are confirming that you have reviewed and agree to the Parkinson's Foundation Information Sheet.

What is the purpose of this study?

Parkinson's Foundation Surveys is an initiative seeking to periodically survey people with Parkinson's disease (PD), their care partners and medical professionals to better understand specific aspects of living with PD.

Parkinson's Foundation will partner with people with PD, researchers and pharmaceutical companies to send out surveys of relevance to the Parkinson's disease community (for example, COVID-19, mental health and exercise). This initiative aims to make the lived experiences of people living with PD widely available to the public. By better understanding how people living with PD experience the disease, the Foundation and its partners can be better informed in programming, research, grant funding and policy initiatives.

Parkinson's Foundation requests permission to collect your demographic information, store it on a secure server and contact you for future survey opportunities.

You are eligible to participate in this registry if you are older than 18 years of age and identify as at least one of the following:

- Person with PD
- Care partner
- Health professional working with people with PD

This survey and all future surveys are entirely voluntary. No medical treatments, medical advice or medical interventions will be provided to you as part of this study.

Up to 1,000,000 people will participate in this study.

What will you be asked to do in this study?

If you choose to participate in this study, you will be asked to:

- Electronically sign and date this consent form
- Complete a short demographic questionnaire (participants will have an opportunity to update this annually)
- Agree to be contacted about future Parkinson's Foundation surveys as they become available

As surveys become available, you will be sent an email invitation or text message to participate. Your demographic information will remain confidential, and your data will only be used for research purposes. We plan to make this study's results public, but we will not include your name or other information that identifies you in those results.

Are there risks to being in this study?

All surveys are reviewed by people with Parkinson's disease or care partners to provide feedback on any questions that could be potentially uncomfortable to answer. Edits are made to minimize risk to the greatest extent possible.

This study involves collecting and storing personal, identifiable information about you, so there is a potential for invasion of privacy or breach in confidentiality. The Foundation takes data security seriously. Any information collected during this study that can identify you by name will be kept confidential. We will do everything we can to keep your data secure. Sensitive data, including data related to health or other information of individual persons that could be linked to a personal identifier, collected by the Foundation is stored behind a firewall and protected using secure encryption technologies. While no security steps can offer absolute protection, we utilize state-of-the-art, industry-standard protocols to prevent unauthorized access to the sensitive information we hold.

You will receive/have access to an electronic copy of this signed and dated consent form. There may be risks of loss of privacy and confidentiality if the electronic copy of this consent form is viewed and/or stored on a personal electronic device (PED), especially if that PED is shared with other users or is lost, hacked, or subject to a search warrant or subpoena. Also, the electronic copy of the consent may not be able to be permanently removed from a PED.

Are there benefits to being in this study?

You will not directly benefit from taking part in this study. Still, your participation may help people with Parkinson's Disease and their care partners in the future by informing future patient-centered research.

Will you be paid to participate in this study?

You will not be paid to participate in this study.

Are there costs to being in this study?

There are no costs to being in this study.

How will my data be managed?

All electronic survey data collected from our electronic data capture (EDC) system will be de-identified for analysis and kept on a secure server. The de-identified data will be retained by researchers at Parkinson's Foundation for future use.

The research information shared with people outside of Parkinson's Foundation will not include your name, address, telephone number or any other direct identifiers unless disclosure of the information is required by law or you have authorized the disclosure.

Are there alternatives to participation?

This research study is for research purposes only. The only alternative is to not participate in this study.

What happens if you do not wish to participate in this study?

This survey and all future surveys are entirely voluntary. You can decide not to participate, or you can end your participation in the study at any time by requesting to withdraw to the Parkinson's Foundation. We may keep and use information that we collected about you while you were in the study unless you ask for that information to be destroyed. If you so choose, you can opt-out of Parkinson's Foundation Surveys at any time by emailing survey@parkinson.org.

Whom to contact about this study

During the study, if you have questions, concerns, or complaints about the study, please contact the study Investigator at the telephone number listed on the first page of this consent document.

An institutional review board (IRB) is an independent committee established to help protect the rights of research subjects. If you have any questions about your rights as a research subject, and/or concerns or complaints regarding this research study, contact:

- By mail:
Study Subject Adviser
Advarra IRB
6100 Merriweather Dr, Suite 600
Columbia, MD 21046
- or call **toll free:** 877-992-4724
- or by **email:** adviser@advarra.com

Please reference the following number when contacting the Study Subject Adviser:
Pro00049566.

A description of this clinical trial will be available on <http://www.ClinicalTrials.gov> , as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

CONSENT

I have read and understand the information in this informed consent document. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I voluntarily agree to participate in this study until I decide otherwise. I do not give up any of my legal rights by signing and dating this consent document. I will receive a copy of this signed and dated consent document.

Agree

Please provide your first name

Please provide your last name

Please provide your email address

WITNESS SIGNATURE FOR PARTICIPANTS WHO CANNOT READ

The study participant has indicated that he/she is unable to read. The consent document has been read to the participant by an impartial witness, and the participant has been given an opportunity to ask questions of the study staff.

Printed Name of Impartial Witness

AUTHORIZATION TO USE AND DISCLOSE PROTECTED HEALTH INFORMATION

If you decide to be in this study, the Investigator and study staff will use and share health data about you to conduct the study. Health data may include:

- Your name.
- Address.
- Phone number.
- Date of birth.
- Medical history.
- Information from your study visits, including all test results.

Health data may come from your study records or from existing records kept by your doctor or other health care workers.

For this study, the study staff may share health data about you with authorized users. Authorized users may include:

- Representatives of **Parkinson's Foundation**
- Representatives of Advarra IRB (an Institutional Review Board that reviews this study).
- The Food and Drug Administration (FDA) and other US federal and state agencies.
- Governmental agencies of other countries.
- Other research doctors and medical centers participating in this study, if applicable.

Once your health data has been shared with authorized users, it may no longer be protected by federal privacy law and could possibly be used or disclosed in ways other than those listed here.

Your permission to use and share health data about you will end in 50 years unless you revoke it (take it back) sooner.

You may revoke (take back) your permission to use and share health data about you at any time by writing to the investigator at the address listed on the first page of this form. If you do this, you will not be able to stay in this study. No new health data that identifies you will be gathered after your written request is received. However, health data about you that has

already been gathered may still be used and given to others as described in this form.

Your right to access your health data in the study records will be suspended during the study to keep from changing the study results. When the study is over, you can access your study health data.

If you decide not to sign and date this form, you will not be able to take part in the study.

STATEMENT OF AUTHORIZATION

I have read this form and its contents were explained. My questions have been answered. I voluntarily agree to allow study staff to collect, use and share my health data as specified in this form. I will receive a signed and dated copy of this form for my records. I am not giving up any of my legal rights by signing and dating this form.

Printed Name of Subject

Signature of Subject

Date