

PD GENERation

MAPPING THE FUTURE OF PARKINSON'S DISEASE

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Every Person's Journey with PD is Unique



Genetics may serve as a **key** to understanding the biology of **PD**
And we may be able to use genetics to help **diagnose** and **treat PD**



Most people with PD do not receive genetic testing due to:

- Cost; Results does not influence care = Lack of insurance coverage
- Accessibility of comprehensive tests

Direct to consumer PD panels only test limited gene variants

- *LRRK2* G2019S; *GBA* N409S
- Often not accompanied by genetic counseling

Major barrier to the success of genetic trials in PD

- Clinicians and people with PD do not know their genotype



PD GENERation

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A multi-center, observational and registry, clinical trial offering genetic testing and genetic counseling.

Adults 18+ with a PD dx in English & Spanish

NCT04994015

Objective:

- Collect and share Parkinson's disease genetic testing data from up to 500,000 study participants for research use
 - Initial goal is to enroll 15,000 PWP by 2026
- Help improve our understanding of PD and help participants and their clinicians understand their genetic status to improve care, which includes determining eligibility for clinical trial participation

PD GENERation Overview

Eligibility: Adults 18+ with PD

What: Genetic testing and genetic counseling
(English and Spanish)
Bank DNA for future research

When: 2-4 years

Where: US, Canada, Puerto Rico, Dominican Republic

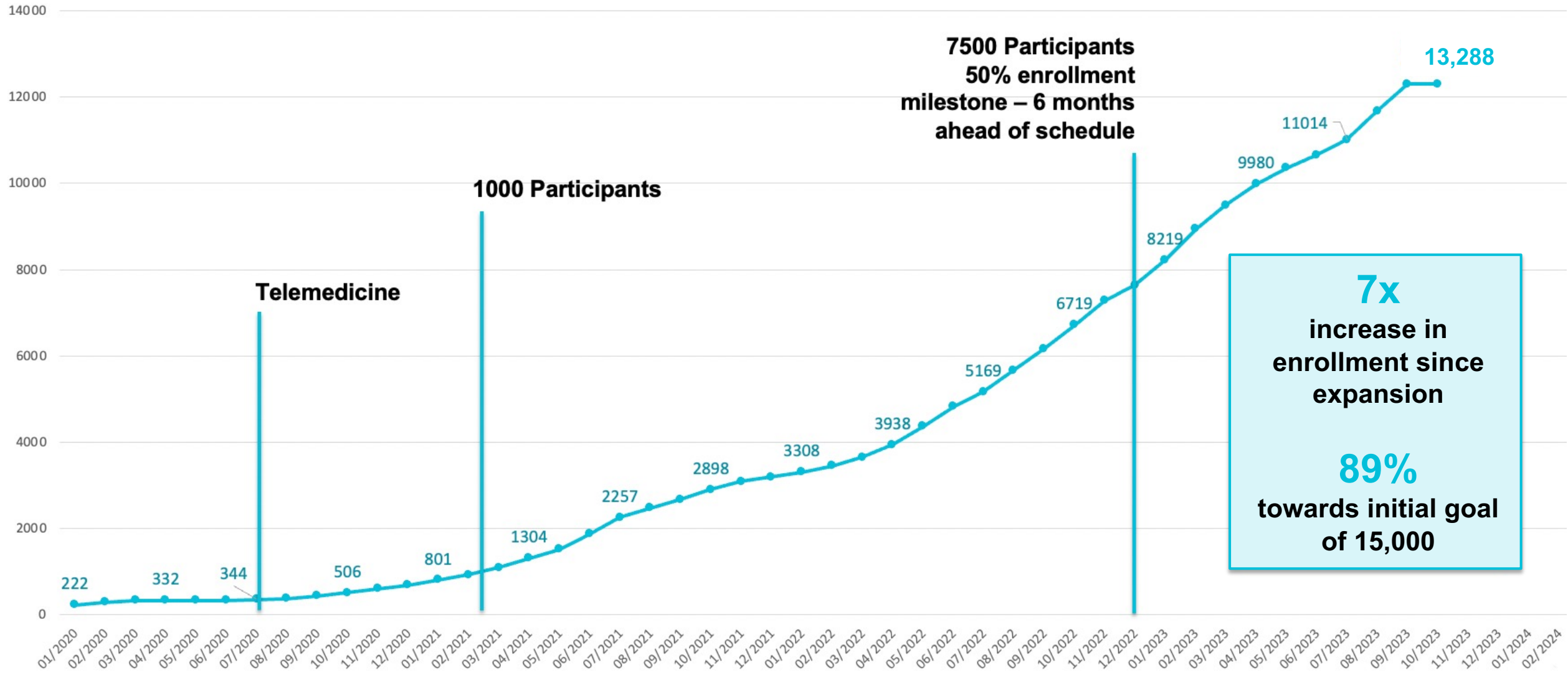
7 PD GENES:

GBA1
LRRK2
SNCA
PRKN
PINK1
PARK7
VPS35

PD GENERation

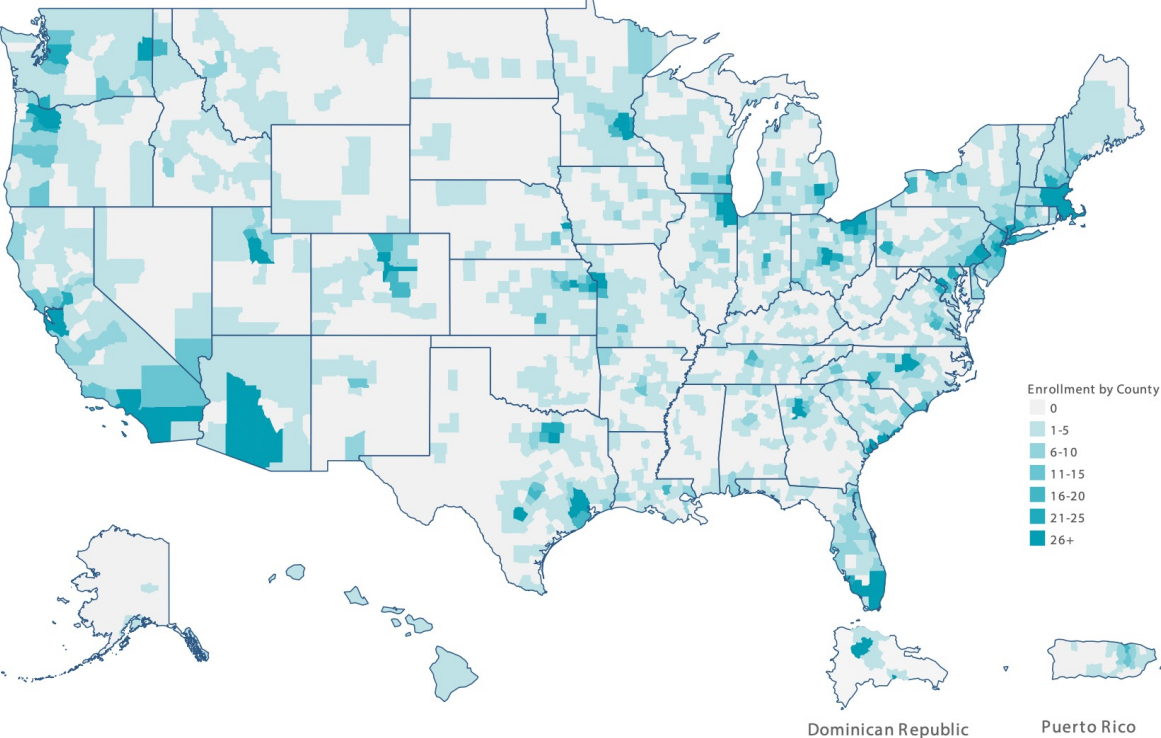
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Current Overall Recruitment

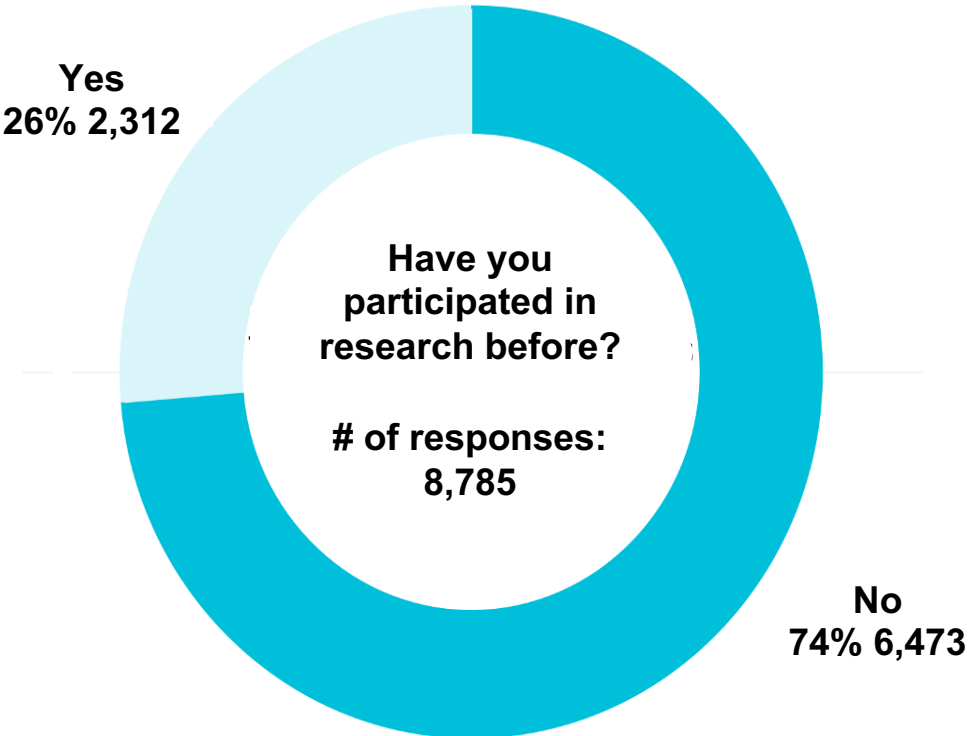


Participant Characteristics

PD GENERation Cohort Density in US, DR, PR

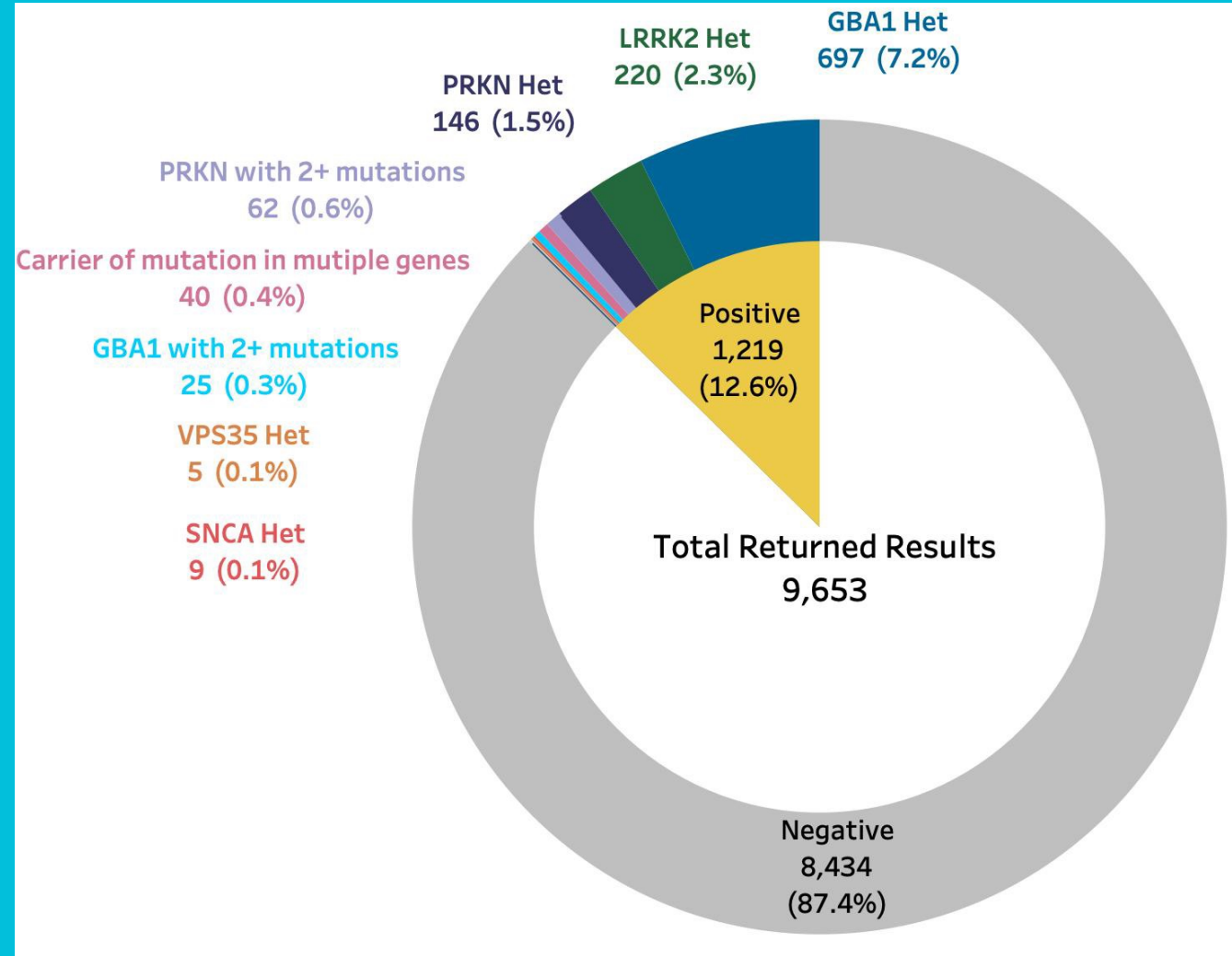


74% New to Clinical Research



This was not collected in Pilot and Clinical studies

Genetic Makeup of PD GENE (n=9,653)



Study Enrollment Criteria

Inclusion

1. Confirmed Diagnosis of PD
2. Willingness to undergo genetic testing and choose to be informed of genetic testing results
3. Capacity to give informed consent
4. Ability to perform all study activities

Exclusion

1. Diagnosis of an atypical parkinsonian disorder (i.e. multiple system atrophy, parkinsonism, dementia with Lewy bodies)
2. Received a blood transfusion within the last 3 months
3. Has an active hematologic malignancy such as lymphoma or leukemia
4. Has received a bone marrow transplant within the last 5 years
5. Under the age of 18 years

Key Appointments

Online (Virtually)

1. Consent Visit (30 min)
 - Online questionnaire
 - Buccal swab kit (at home)
2. Genetic counseling visit (15-30 min telemedicine call)

In-Person (Clinic)

1. Consent + Main Visit (1 hours)
 - Clinic visit
 - Blood draw or buccal swab (in-clinic)
2. Genetic counseling visit (15-30 min telemedicine call)

What to Expect for Telemedicine

Technology: participation will require

- Computer/phone
- Internet access
- Email address

Family Involvement: Consider having a loved-one or carepartner assist you



How to Enroll in PD GENERation

Visit

www.Parkinson.org/pdgeneration

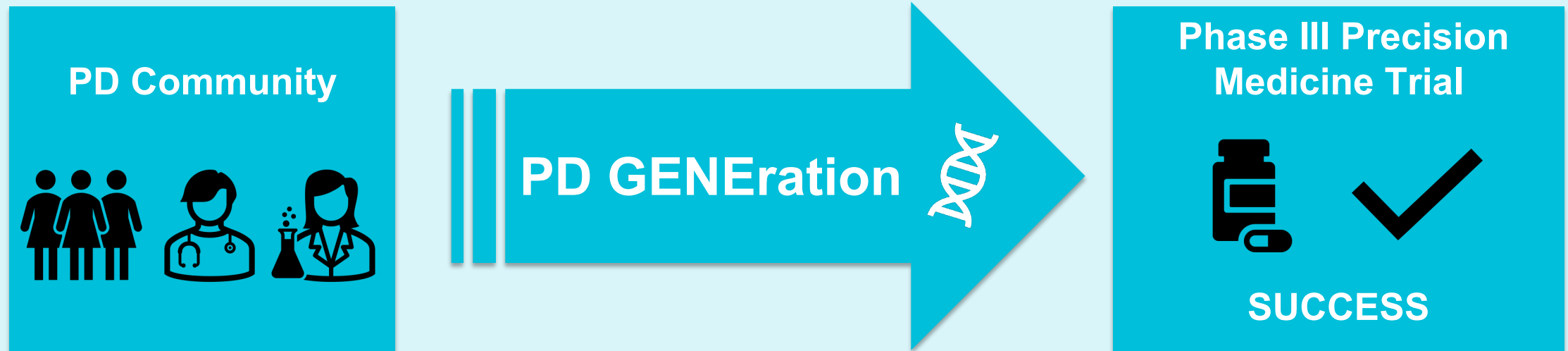
- Click Enroll Now and follow the prompted questions
- Select how you would like to enroll:

In-Person or Online

- Follow the prompts to schedule a visit

PD GENERation Beyond 15,000

- PD GENERation accelerates clinical trial recruitment
- 90,000+ individuals are diagnosed with PD annually



PD GENERation serves a CRITICAL ROLE in the success of PD clinical trials

Thank you!

Email: Genetics@parkinson.org

Helpline: 1-800-4PD-INFO

Visit: www.Parkinson.org/PDGeneration