Returning Secondary Health Findings in the PD GENEration Study

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Abstract

Objective: To provide secondary health findings (SHF) results to participants enrolled in the PD GENEration study via CLIA genetic testing using whole genome sequencing (WGS) with disclosure of 21 genes linked to parkinsonism or Parkinson's disease (PD) and 10 non-PD related genes to people with PD (PwP) globally (Fig. 1). **Background:** The PD GENEration study (NCT04994015), sponsored by the Parkinson's Foundation with support of the Global Parkinson's Genetics Program (GP2), has provided genetic testing and counseling for seven PD related genes to 22,000+ PwP. In 2024, the study transitioned to WGS from targeted exome sequencing, opening the door for return of results (ROR) beyond the primary seven gene panel. **Methods:** Rare variants in secondary PD-related genes were formally evaluated by GP2 and the PD GENEration team and two gene panels were designed. One panel captures 21 genes linked to parkinsonism, PD or PD mimickers and the other focuses on non-PD related genes known as the CDC-10 Tier 1 genes (e.g., *BRCA1*). Participants can consent to receive results from one or both new panels during genetic counseling for the results of the primary panel. **Results:** In Nov 2024, participants began to receive SHF results. As of Feb 2025, 5041 participants consented to receive SHF (96% of participants with WGS). Of those, genetic testing has been completed for 506 (10%) participants, of which 24 (5%) were positive for genetic variation on the expanded parkinsonism panel and 2 (0.4%) were positive for genetic variation on the CDC-10 Tier 1 panel. Gene specific counseling strategies and fact sheets were developed to align with the established workflow used for the primary seven gene panel. **Conclusion:** A flexible framework has been created for the implementation and return of results of SHF to participants. This flexibility allows for the periodic re-evaluation of genes for SHF panels to remain current with clinical genetic literature. Future studies will test the impact, satisfaction or decision regret of PwP receiving results from these panels.

Background and Methods

Figure 1: SHF Consent Process and Selection

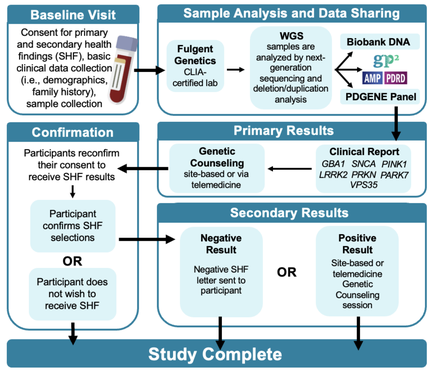
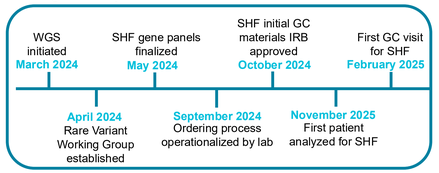


Figure 2: Operational Timeline for Initiation of SHF



PD GENEration is a multi-center observational clinical research study that offers genetic testing and counseling to people living with PD (PwP) in the US (including Puerto Rico), Canada, Dominican Republic, El Salvador, Colombia, Brazil, Peru, Mexico, and Israel. In March 2024, the study transitioned from a targeted exome sequencing backbone to a whole genome sequencing backbone. All the de-identified data produced from this study is shared with researchers and scientists, most notably with the Global Parkinson's Genetics Program (GP2), a program of the Aligning Science Across Parkinson's. The full study pipeline is shown below in Figure 1. With this transition, the study expanded beyond its primary panel of 7 genes related to PD to two additional option secondary panels: 1) 21 PD-related gene panel, 2) 10 non-PD related gene panel called CDC10 Tier 1 (Table 1). PwP consent to receiving negative or positive results for the primary panel and have the option to consent to receive both or either secondary panel. The study's operational workflow was updated to allow for participants to choose each panel individually and re-confirm their consent for the secondary panels prior to reporting to allow for autonomy in which panels they want results on through the study (Figure 1).

Table 1: Panels Offers in PD GENEration

Primary 7 Gene Panel	Secondary Gene Panels
GBA1 *LRRK2* *PRKN* *SNCA* *PARK7* *PINK1* *VPS35*	**21 PD related** *RAB39B, VPS13C, PTRHD1, SYNJ1, POLG, DNAJC6, ATP13A2, DCTN1, ATP1A3, SLC6A3, TH, GCH1, FBXO7, PLA2G6, ATP7B, MAPT, GRN, TBK1, VCP, RAB32, CHCHD2* **10 Non-PD related (CDC Tier 1)** *BRCA1, BRCA2, MLH1, MSH2, MSH6, PMS2, EPCAM, LDLR, APOB, PCSK9* Hereditary Breast and Ovarian Cancer Syndrome (HBOC) Lynch syndrome (LS) Familial hypercholesterolemia (FH)

Results

Enrollment

Figure 3: Total Enrollment in WGS Per Month

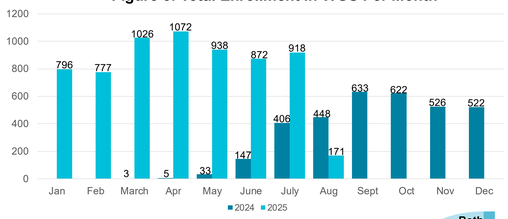


Figure 4: PD GENEration Participant SHF Selection

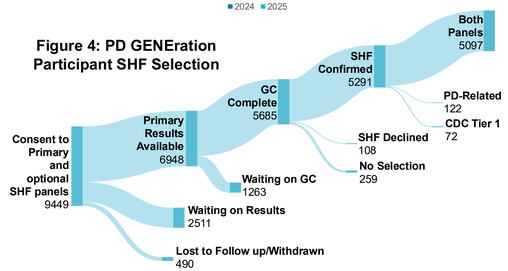
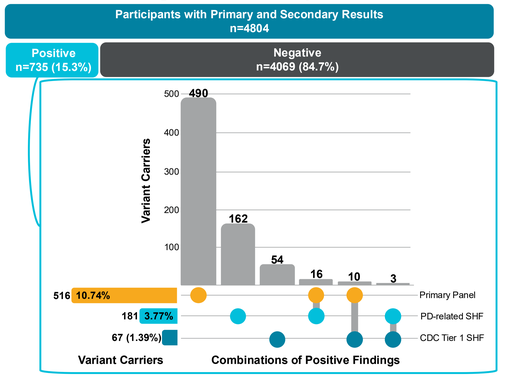


Figure 5: SHF Distribution by Country

Figure 6: Numbers Reported



Above: There were 735 variant carriers identified across the three panels (orange, teal, and dark blue dots). Of those, 706 carried a variant in one panel (left three gray bars) and 29 carried variants in more than one panel (right three gray bars). This provides insight on: 1) the relative positivity rate for each specific panel and 2) the positivity rate for any given combination of the panels. Percent positivity shown is based on 4,804 total tested. Only participants who have confirmed consent for secondary health findings are included.

Genetics

Figure 7: 21 PD-Related Secondary Gene Panel Results (Aug 2025)

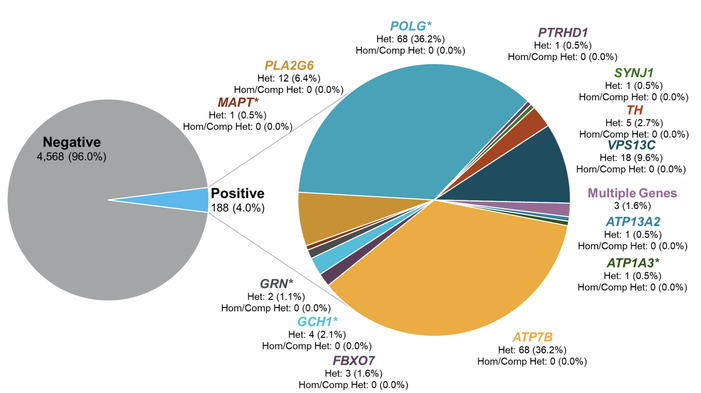
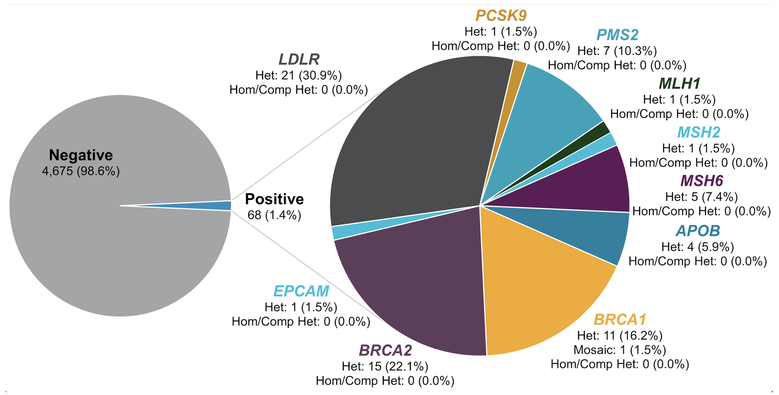


Figure 8: CDC10 Tier 1 Secondary Gene Panel Results (Aug 2025)



Conclusion Future Directions

A flexible framework has been created for the implementation and return of results of SHF to participants. This flexibility allows for the periodic re-evaluation of genes for SHF panels to remain current with clinical genetic literature. Future studies will test the impact, satisfaction or decision regret of PwP receiving positive results from these panels. With more SHF from a diverse participant population, we plan to study and expand our understanding of the causal impact of these genes in relation to Parkinson's Disease.

Learn more about the study findings and SHF genes:

More about PD GENEration

Engagement of PD GENEration Participants: Insights into Genetic Counseling Recall and Clinical Trial Interest

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1) Parkinson's Foundation, New York, NY; 2) Spyglass Consulting LLC; 3) Neuron23, Inc., San Francisco, CA; 4) Tel Aviv Sourasky Medical Center, Tel Aviv, Israel

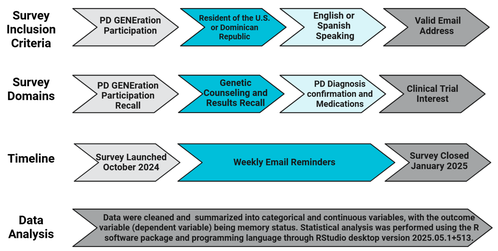
Abstract

Objective: To assess the impact of participation in PD GENEration, a large-scale genetic and counseling study for Parkinson's disease (PD). We evaluated the recall of genetic counseling, self-reported changes in PD status, and interest in clinical trials. **Background:** PD GENEration is a global research initiative providing genetic testing and counseling at no cost to individuals with PD. Since 2019, it has expanded to nearly 70 sites across Israel and the Americas, enrolling over 22,000 participants. Historically, data collection occurred only at enrollment, limiting long-term insights. This study represents the first re-engagement of participants to evaluate their evolving experiences and willingness to participate in clinical research. **Methods:** An English and Spanish survey was distributed via REDCap to PD GENEration participants who had completed genetic counseling by October 2024. Survey domains included genetic counseling recall, PD status updates, and clinical trial interest. The survey launched in October 2024 with weekly email reminders and remained active until January 2025. **Results:** A total of 4,234 responses (43%) were received from 9,891 valid emails, with 3,839 responses linked to participant study IDs. Of these, 94% completed the entire survey, demonstrating high engagement. Most respondents (86.9%) reported no change in PD diagnosis, while 1.9% indicated a new diagnosis. Additionally, 85.2% reported they were taking PD medications, with levodopa being the most common. Over 25% (n=965) of respondents either did not recall receiving genetic counseling or did not recall receiving their genetic test report—8% of whom had a positive genetic report. Notably, 79% (n=253) of those who did not recall participation had enrolled in 2022 or 2023, suggesting recall discrepancies were not time-dependent but may be influenced by other factors. A strong interest in research was evident, with 77.8% expressing willingness to be contacted for clinical trials. While participants favored smartphone-based trials, many were hesitant about placebo-controlled studies, indicating a need for targeted educational efforts. **Conclusion:** Most participants in PD GENEration recalled receiving genetic results and were very enthusiastic about additional participation in larger, more demanding studies. However, the substantial minority that did not recall details of their genetic testing highlights the importance of the development of methods for continuous engagement.

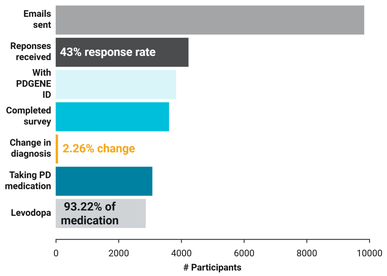
Background & Methods

PD GENEration offers genetic testing and counseling to people living with Parkinson's Disease (PD). While the primary study is cross-sectional, this post-engagement survey was designed to re-engage PD GENEration participants.

The goal of this survey was to build from previous studies where participants of genetic testing for PD reported a high rate of personal utility (77-81%) and moderate levels of clinical trial interest (~45%). (doi: 10.1038/s41531-024-00805-z)



Response Rate, Diagnosis & Medications



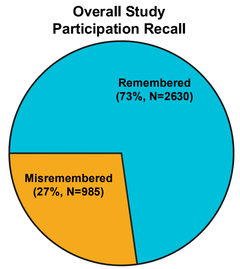
The re-engagement survey was sent to just over 9,000 PD GENEration participants who had completed genetic counseling by October 2024.

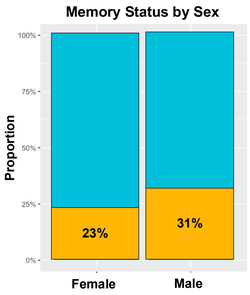
- The response rate was 43%
- 3,615 responses were cleaned for analysis
- 2.26% of participants reported a change in diagnosis
- 91.67% reported taking a PD medication
- Levodopa being the most prevalent at 93.22%

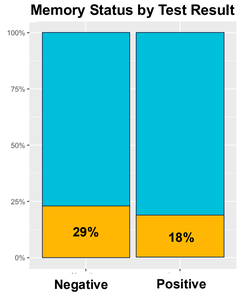
Results

Analysis and data updated 9/12/25

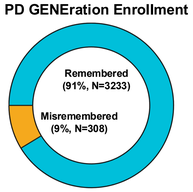
Participant Recall

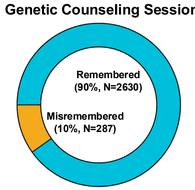


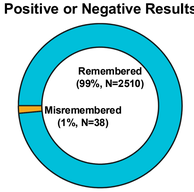




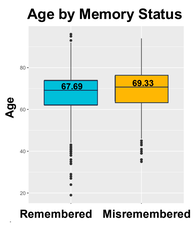
- 27.25% (985/3615) of respondents either did not recall receiving genetic counseling or did not recall receiving their genetic test report—8.12% (80/985) of whom had a positive genetic report.
- Men were more likely to misremember than women (OR = 1.64, 95% CI 1.38 to 1.94).
- Those with a negative genetic test result were more likely to misremember than with a positive result (OR = 1.71, 95% CI 1.30 to 2.28). *(OR= Odds ratio, CI= Confidence interval, numbers = proportions, logistic regression).*



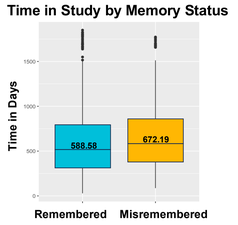




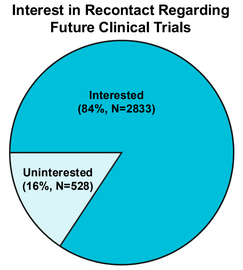
When breaking down overall study recall 9-10% of participants misremembered their enrollment or whether they had a genetic counseling session. Only 1% misremembered their actual genetic testing results, with slightly more of those misremembered responses coming from negative result recipients.



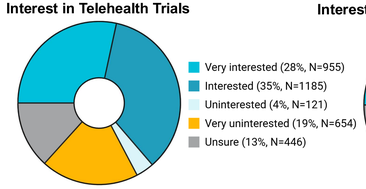
- Older respondents were slightly more likely to misremember their PDGENE status than younger (Age OR = 1.04, 95% CI 1.02 to 1.06).
- With each passing day in PDGENE, the odds of misremembering increased by 1.001 times. (OR = 1.0009 95% CI 1.0006 to 1.0012). *(OR= Odds ratio, CI= Confidence interval, values= numeric mean, logistic regression).*

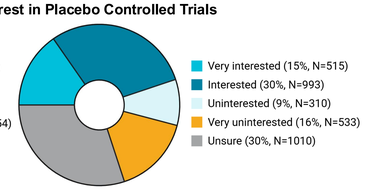


Clinical Trial Interest



- Clinical trials, including those for PD, are notoriously difficult to enroll (reviewed in: doi: 10.1016/j.conctc.2018.08.001). With lack of trial awareness, limited access, fear or distrust in the research system, and cost issues are just some barriers to enrollment (doi: 10.1007/s13311-020-00960-0).
- Nearly 85% of respondents reported that they were interested in being recontacted about future trials.





- Almost 64% of respondents had some level interest in telehealth smartphone-based studies
- The interest in trials was dramatically lower when a placebo control was included at 45%
- Wariness around placebo also highlights the importance of open-label extensions as a mechanism of drug dissemination following an original trial.

Conclusions

Strikingly a substantial minority did not recall details of their PD GENEration enrollment or genetic counseling session. Men, those with a negative test result, or a longer enrollment period were slightly more likely to misremember their PD GENEration experience. These results highlight the importance of the development of methods for ongoing engagement and information sharing, via mechanisms such as an online portal. Most participants in PD GENEration, however, did recall their experience and many were interested in learning more about future clinical trials.

Funding Partners

gp2 Global Parkinson's Genetics Program

asap Aligning Science Across Parkinson's

Learn More:

Join the PD GENEration

Study findings and updates

Distribution of Genomic Ancestries and Genetic Variation Among Individuals Enrolled in the PD GENEration Study

Allison Dilliott[1], Kamalini Ghosh Galvelis[1], Nicola Bothwick[1], Lark Caboy[1], Margaret Caulfield[1], Rebeca De Leon[1], Megan Dini[1], Ismail Khaderi[1], Shilpa Rao[1], Addison Yake[1], Anny Coral Zambrano[1], J Solle[2], Cornelis Blauwendraat[3], Andrew Singleton[4], James C. Beck[1], Roy N. Alcalay[5]

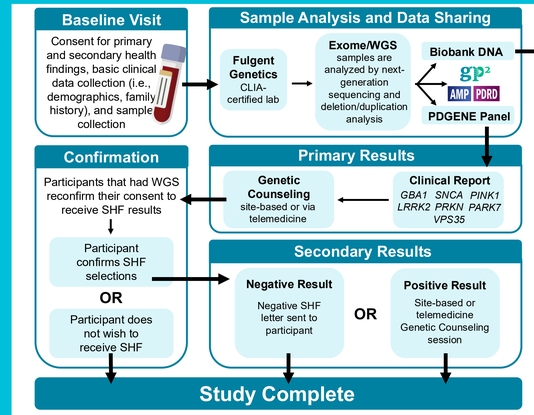
1) Parkinson's Foundation, New York, NY; 2) Michael J. Fox Foundation for Parkinson's Research, New York, NY; 3) Aligning Science Across Parkinson's, Bethesda, MD; 4) Global Parkinson's Genetics Program, Bethesda, MD; 5) Tel Aviv Sourasky Medical Center, Tel Aviv, Israel

PD GENEration

Abstract

Objective: To assess the distribution of genomic ancestries and rates of positive genetic findings in individuals enrolled in a large-scale return of results study for Parkinson's disease (PD). **Background:** PD GENEration (NCT04994015), sponsored by the Parkinson's Foundation with support of the Global Parkinson's Genetics Program (GP2), has enrolled >22,000 participants across the Americas and Israel. Although self-reported clinical data is captured, follow up genomic analyses have allowed for assessment of participant genomic ancestry. **Methods:** After targeted exome sequencing to capture pathogenic variants in seven PD genes, select participant DNA samples were sent to GP2 for further analysis and biobanking. Samples were assessed with the genome-wide Illumina NeuroBooster Array, which captures millions of variants, including >95,000 associated with neurological conditions. Statistical analysis of variant distribution was used to determine individual genomic ancestries. Here, we compare the genomic ancestries of participants to the self-reported race and ethnicity data captured upon enrollment and determine whether rates of disease-relevant variation differ between ancestral populations. **Results:** To date, the Illumina Neurobooster Array has been performed on 6036 PD GENEration participants. Unsurprisingly, the largest proportion of participants are of European ancestry (75.7%). However, we identified multiple sources of potential discordance between genomic ancestry and self-reported race or ethnicity throughout the dataset. For example, of the 681 individuals that identify as Hispanic/Latino, 22.8% were of European genomic ancestry and 2.2% were of Ashkenazi Jewish genomic ancestry. This may have implications for their likelihood of carrying genetic risk factors for PD. In agreement with the literature, we found individuals with Ashkenazi Jewish ancestry had higher rates of *GBA1* and *LRRK2* variants than individuals from other populations. **Conclusion:** Our results validate the need for genomic ancestral analysis in large-scale genetic studies of PD to accurately assess disease risk across populations. The high proportion of individuals of European ancestry in PD GENEration has driven efforts to prioritize greater ancestral diversity in recruitment to better capture genetic variation related to disease risk.

Background and Methods



Primary 7 Gene Panel	Secondary Gene Panels
GBA1 *LRRK2* *PRKN* *SNCA* *PARK7* *PINK1* *VPS35*	**21 PD related** *RAB39B, VPS13C, PTRHD1, SYNJ1, POLG, DNAJC6, ATP13A2, DCTN1, ATP1A3, SLC6A3, TH, GCH1, FBXO7, PLA2G6, ATP7B, MAPT, GRN, TBK1, VCP, RAB32, CHCHD2* **10 Non-PD related (CDC Tier 1)** *BRCA1, BRCA2, MLH1, MSH2, MSH6, PMS2, EPCAM, LDLR, APOB, PCSK9* Hereditary Breast and Ovarian Cancer Syndrome (HBOC) Lynch syndrome (LS) Familial hypercholesterolemia (FH)

PD GENEration is a multi-center observational clinical research study that offers genetic testing and counseling to people living with PD (PwP) in the US (including Puerto Rico), Canada, Dominican Republic, El Salvador, Colombia, Brazil, Peru, Mexico, and Israel. In March 2024, the study transitioned from a targeted exome sequencing backbone to a whole genome sequencing backbone. All the de-identified data produced from this study is shared with researchers and scientists, most notably with the Global Parkinson's Genetics Program (GP2), a program of the Aligning Science Across Parkinson's. The full study pipeline is shown above. Following the next-generation sequencing of the participant's DNA samples, DNA is biobanked through our partnership with GP2. DNA samples are also further genetically assessed by GP2 using the Neurobooster genotyping array. These data are then assessed to determine each participant's genetically defined ancestry. The Neurobooster array data and genetic ancestry data are all shared through the GP2 platform.

Results

Total Cohort

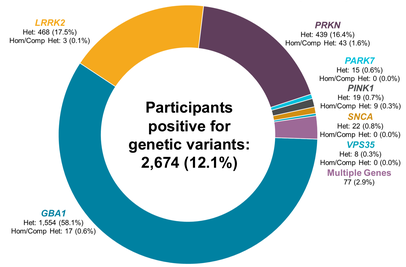
Self-reported races and ethnicities of the PD GENEration participants

Self-Reported Race	Primary Sequencing Completed	Genetic Ancestry Assessed
American Indian/Alaskan Native	55 (0.2%)	16 (0.3%)
Asian	715 (3.2%)	141 (2.3%)
Black/African American	597 (2.7%)	112 (1.9%)
Mestizo/Mulato	275 (1.2%)	243 (4.0%)
Native Hawaiian/Pacific Islander	33 (0.1%)	3 (0.05%)
White	18,702 (84.3%)	5201 (86.2%)
Other	844 (3.8%)	121 (2.0%)
Multiple	273 (1.2%)	84 (1.4%)
Unknown/Decline to Answer	695 (3.1%)	115 (1.9%)
Self-Reported Ethnicity	**Primary Sequencing Completed**	**Genetic Ancestry Assessed**
Not Hispanic or Latino	18,641 (84.0%)	5212 (86.4%)
Hispanic or Latino	2,692 (12.1%)	683 (11.3%)
Unknown/Decline to Answer	856 (3.9%)	141 (2.3%)

As of August 2025, next-generation sequencing and primary panel variant assessment was completed for 22,189 people with PD enrolled in PD GENEration, with a genetic positivity rate of 12.1% across the full cohort. Of the PD GENEration cohort, 6,036 participants have had their DNA samples further assessed using the Neurobooster array by GP2, all of which had been enrolled in the exome sequencing iteration of the study.

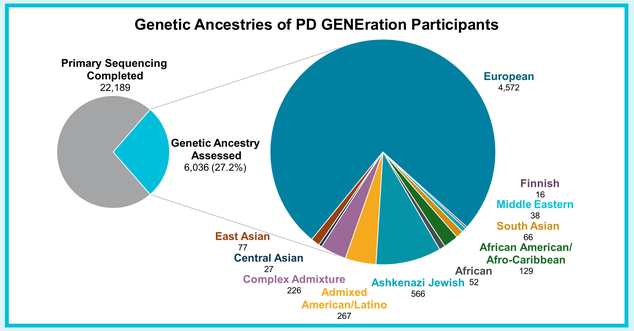
Unsurprisingly, most of those assessed thus far were found to be of European genetic ancestry; although, 9.4% were of Ashkenazi Jewish genetic ancestry. We also found multiple sources of potential discordance between the participant's self-reported races, ethnicities, and ancestries and their genetic ancestries. Further, we identified varying genetic positivity rates among the people with PD of different genetic ancestries.

Genetic results of all PD GENEration participants

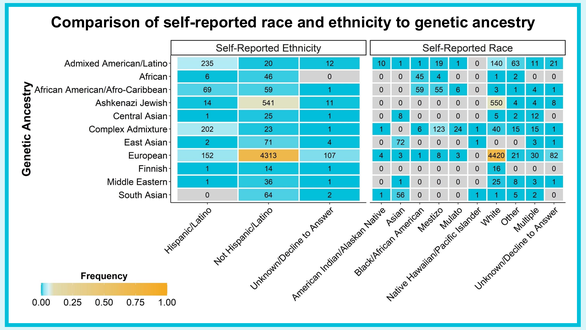


Genetic Ancestry

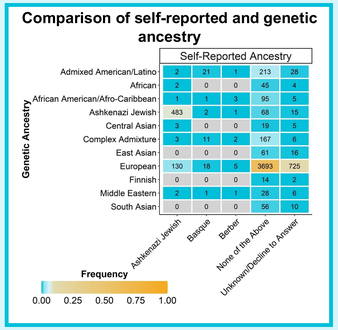
Genetic Ancestries of PD GENEration Participants



Comparison of self-reported race and ethnicity to genetic ancestry

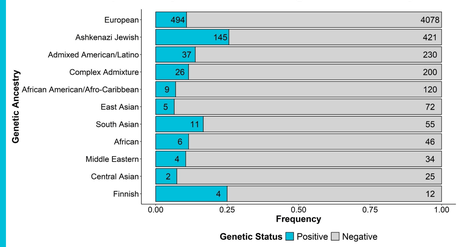


Comparison of self-reported and genetic ancestry

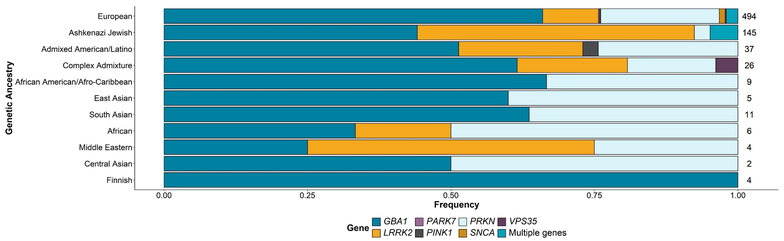


Genetic Results

Genetic positivity rates based on genetic ancestry



Genetic results by gene based on genetic ancestry



Future Directions

Through our partnership with GP2, we will continue to assess participants' genetic ancestries using data from the Neurobooster array. As larger sample sizes are obtained, large scale analysis of variant frequency by genetic ancestry will be performed.

Recently, PD GENEration transitioned to a backbone of whole-genome sequencing, allowing for assessment of a secondary PD-related genes. Upon Neurobooster analysis of these participant's DNA, we will also be able to compare the variant frequencies observed across genetic ancestries in the expanded selection of PD associated genes.

Conclusion

Our results validate the need for genomic ancestral analysis in large-scale genetic studies of PD to accurately assess disease risk across populations. The high proportion of individuals of European ancestry in PD GENEration has driven efforts to prioritize greater ancestral diversity in recruitment to better capture genetic variation related to disease risk.

More about PD GENEration

The Role of Research and Genetics Educational Events in Parkinson's Research: Overcoming Barriers in the Hispanic/Latino Community

Anny Coral Zambrano[1], Mayela Rodríguez Violante[2], Jorge Luis Orozco Vélez[3], Beatriz Muñoz Ospina[3] Miguel Inca Martínez[4], Ignacio F. Mata[4], Priscila D. Hodges[5], Rebeca De León[1]

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OBJECTIVE

To assess the impact of educational events that emphasize research and genetics, as well as culturally adapted recruitment strategies, on increasing Hispanic/Latino participation in the PD GENEration (PDGENE) research study.

BACKGROUND

Hispanic/Latino individuals remain underrepresented in Parkinson's Disease (PD) genetic research due to various barriers, including **limited awareness, language differences, and disparities in healthcare access.** To address this gap, in 2024 the PDGENE study initiated a strategic collaboration with the Latin American Research Consortium on the GEnetics of Parkinson's Disease (LARGE-PD) for the study expansion across Latin America, offering CLIA-certified genetic testing and counseling at no cost. This initiative aims to enhance diversity in PD research.

Figure 1. Collaboration between PD GENEration and the Latin American Research Consortium on the GEnetics of Parkinson's Disease (LARGE-PD)

- Certified genetic testing at no cost to the participants
- PwP can participate regardless of age, location, race, or gender, in English and Spanish
- Return of results are done through a genetic counseling visit

METHODS

In September 2024, research educational outreach events in Mexico City and Cali, Colombia, marked the launch of the PDGENE–LARGE-PD collaboration. These events integrated on-site participant recruitment with informative sessions focused on research and genetics, while also addressing broader topics relevant to the community. Culturally and site-based, tailored Spanish-language materials were developed to support these efforts, alongside the implementation of a participant-friendly recruitment workflow. Dissemination strategies leveraged principal investigator (PI) networks and institutional channels to maximize outreach, strengthen engagement, and foster trust within the community.

Figure 3. PDGENE presence across Latin America highlighting outreach events in Mexico and Colombia

Figure 4. Pillars of Participant Recruitment at Educational Events

Figure 5. Mexico recruitment event

Event flier

Educational outreach event

Figure 6. Cali recruitment event

***Day 1** – Clinic Recruitment*
All participants were scheduled for study participation

***Day 2** – Community Gathering*
Events included Zumba and tango classes as well as research participation

RESULTS

In early 2024, the launch of the PDGENE–LARGE-PD collaboration and the activation of new recruitment sites across multiple Latin-American countries greatly expanded the study's reach. Educational outreach events in **Mexico City** (September 6, 2024) and **Cali, Colombia** (September 20–21, 2024) combined **conference-style educational sessions** with **on-site participant recruitment**, engaging the Parkinson's community and local health professionals.

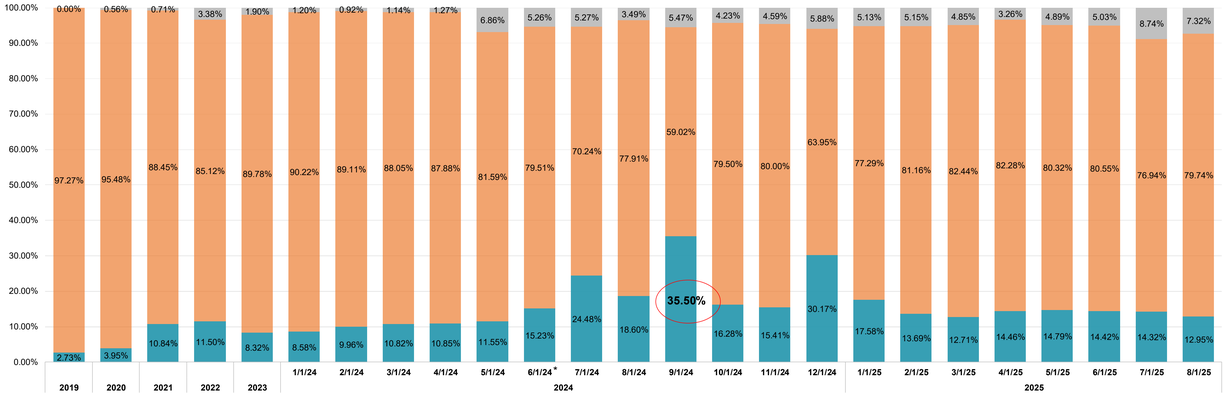
In **Mexico City**, about **200 attendees—including roughly 100 individuals with Parkinson's disease (PD)**—led to **85 enrollments in PDGENE**, with **82 samples collected**. More than 20 local physicians and nurses volunteered, a key factor in building trust since local providers best understand their communities.

In **Cali, Colombia**, about **100 attendees—including approximately 70 individuals with PD**—participated in **two days of outreach**: **Day 1** recruitment at the clinic and **Day 2** a community gathering. This resulted in **55 enrollments**, including **52 in PDGENE** and **45 in LARGE-PD**.

The proportion of PDGENE Hispanic/Latino participants—historically **~3% to ~12% (2019–2022)**—rose sharply in **September 2024 (Figure 6)**, reaching a **peak of 35.5 % which reflects recruitment events efforts**. The Hispanic/Latino enrollment averages ~16% since the events in 2024.

These findings underscore the impact of culturally tailored outreach strategies, the international site expansion through the LARGE-PD partnership, and other ongoing regional efforts that continue to strengthen recruitment and enhance ethnic diversity in PDGENE.

Figure 7. Enrollment Percentage by Ethnicity (2019–Aug 2025)



**Enrollment in Latin America for WGS began 6/24*
Participants with missing enrollment date excluded

Figure 8. Recruitment Details – Mexico City

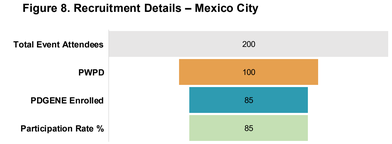
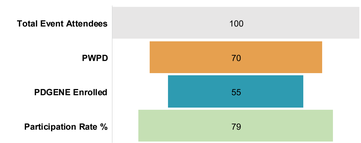


Figure 9. Recruitment Details – Cali (2 days)



CONCLUSION

Research and genetics educational events, along with culturally adapted recruitment strategies, help reduce barriers, raise awareness, and boost Hispanic/Latino participation in PD genetic research. Collaboration with clinicians and community leaders builds trust and enhances recruitment. Sustained, community-driven efforts are key to addressing disparities, and future initiatives should focus on ongoing engagement and expanded partnerships to improve representation in PD research.

ACKNOWLEDGEMENT

This project was supported by the Parkinson's Foundation and the Global Parkinson's Genetics Program (GP2). GP2 is funded by the Aligning Science Across Parkinson's (ASAP) initiative and implemented by The Michael J. Fox Foundation for Parkinson's Research (**https://gp2.org**). For a complete list of GP2 members see **https://gp2.org.** The authors express their sincere gratitude to all members of LARGE-PD, as well as to the Parkinson's disease patients and their families, whose participation and support have been essential to the success of this project.

Online Learning Preferences of Healthcare Providers Caring for People with Parkinson's Disease

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Parkinson.org

Background

Continuing education (CE) is a requirement for many healthcare professionals. Yet, there is limited data on their learning preferences for online CE activities.

Objective

This study aimed to identify the learning preferences and barriers to CE participation and completion among healthcare professionals caring for people with PD.

Methods and Timeline

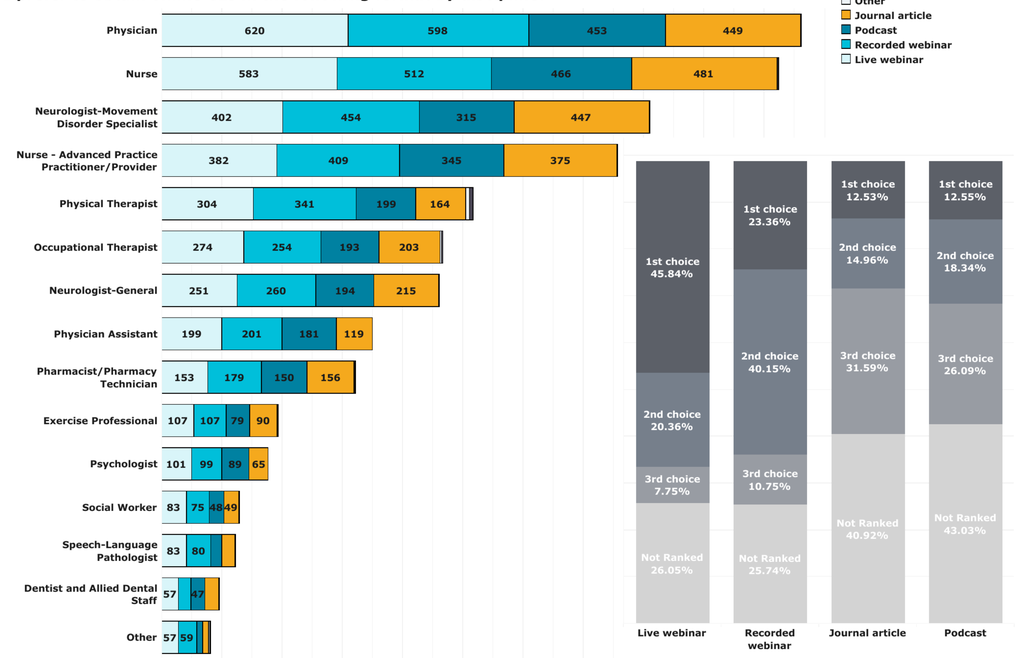
- 16-question (5 mins) online survey was developed by Parkinson's Foundation staff and healthcare professionals
- Sep 17-Oct 8, 2024: Survey open and shared with health professional networks through emails and social media
- Descriptive statistics and regression analyses (simple & multivariable) were used
- Determined to be exempt by Johns Hopkins University Institutional Review Board (IRB00373495)

Demographics

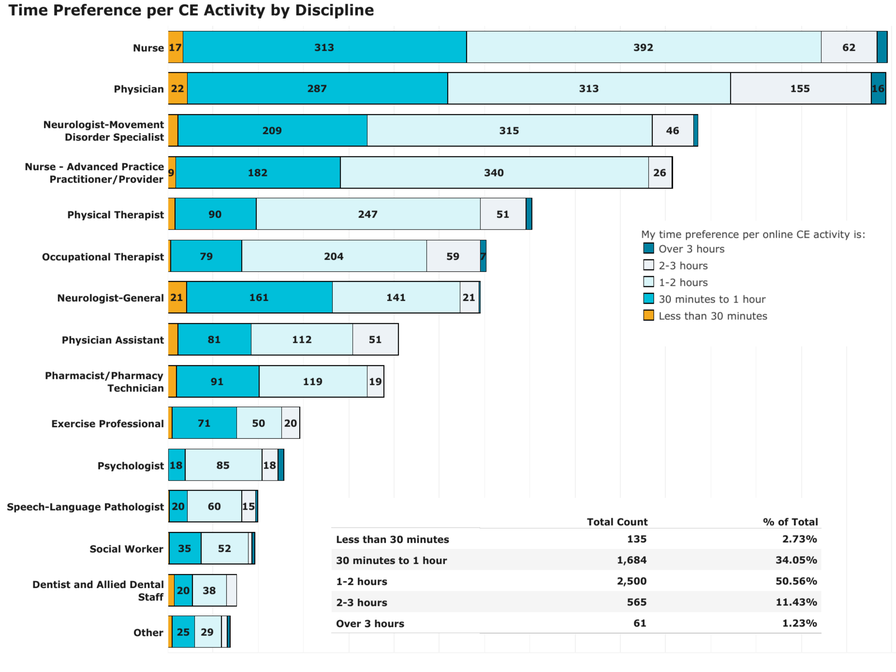
- **4,947** healthcare professionals completed the survey
  - 46% between 31–40 years old
  - 55.7% identified as women
  - 65.6% identified as White; 21.5% as Black; 45.7% as Hispanic/Latino

Key Findings

I prefer to obtain online CEs in the following format by discipline:

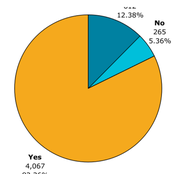


Time Preference per CE Activity by Discipline

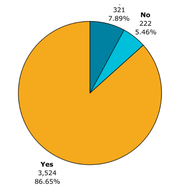


	Total Count	% of Total
Less than 30 minutes	135	2.73%
30 minutes to 1 hour	1,684	34.05%
1-2 hours	2,500	50.56%
2-3 hours	565	11.43%
Over 3 hours	61	1.23%

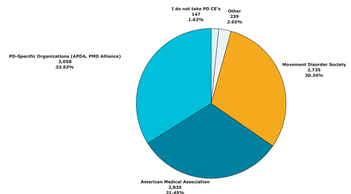
I am aware of Parkinson's Foundation's Online CE's



I have taken a PD online CE course in the Learning Lab



Other than Parkinson's Foundation, I take my online PD CE's from the following sources:



Results

- **Format:** Live & recorded webinars are the top 2 preferred formats
- **Preferences: (**50.5%) favored 1–2 hours course length. Relevance to practice was primary factor for CE selection (61%), followed by interactive simulations (37.5%) and case studies (36.1%)
- **Barriers to taking CE:** Time (40.1%), financial constraints (34.5%)
- **Barriers to not completing CE**: Course workload (28.5%), toggle speed of audio/video (20.2%)

Conclusion

Clinically relevant, live, interactive, and applied learning experiences are preferred learning preferences.
Time and financial constraints are barriers. Course workload and media playback speed affect completion rates. The Parkinson's Foundation seeks to implement preferences for future online CE development for healthcare professionals.

Parkinson's Exercise Guidelines: From Outdated to Updated

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Parkinson's Foundation
Parkinson.org

Background

- In 2021, the Parkinson's Foundation, in partnership with the American College of Sports Medicine, created new Parkinson's disease (PD) exercise recommendations to ensure that people with Parkinson's are receiving safe and effective exercise programs and instruction.
- Clinical guidelines are generally reviewed and updated every three to five years to ensure that the information remains relevant and contributes to high-quality, evidence-based care.

Objective

- To align the 2021 Parkinson's Foundation Exercise Guidelines with current evidence and stakeholder feedback.

Methodology

- An internal committee of four subject-matter experts (SMEs) conducted a focused literature search to identify and correct gaps in the recommendations.
- The revised professional-facing guidelines were then examined by a panel of 11 international SMEs and individuals with PD.
- The internal committee refined the guidelines based on the panelists' feedback, after which a public comment period was initiated.
- Eight comments were received during the public comment period, and the internal committee utilized these comments to further improve the guidelines and facilitate resource development.

Results

- SMEs collectively agreed on the importance of safety, referral to a physical therapist, and modifications based on the client's ability, medication status, and stage of disease.
- The BAM domain was expanded to more accurately describe the distinctive aspect of exercise prescription.
- The current literature dictated changes to the time component of strength training, flexibility, and BAM.
- SMEs provided valuable suggestions of PD-related considerations and examples of relevant activities across domains.
- Formatting was improved for clarity and flow, and concepts were widely simplified.

Conclusion

- SMEs achieved consensus aligning the guidelines with current evidence, disseminating this information as a practical, user-friendly guide for exercise professionals who work with people with Parkinson's.

Parkinson's Foundation

Parkinson's Exercise Guidelines for Exercise Professionals

2025

Exercise recommendations should be tailored to the client's ability, medication status, and stage of disease following health screening.

	Aerobic Activity	Strength Training	Flexibility	Neuromotor/Functional Training Balance, Agility, & Multitasking (BAM)
Frequency	At least 3 days per week.	At least 2-3 non-consecutive days/week	At least 2-3 days/week, with daily being most effective	At least 2-3 days/week, with daily integration as possible
Time	At least 30 minutes of continuous activity per session. Interval training may be considered.	Build to 30-60 minutes per session.	Static Stretching: Hold each major muscle group for 15-30 seconds. Dynamic Stretching: Actively move muscles and joints for 15-30 seconds.	Build to 30-60 minutes of focused BAM activity per session. May integrate with other exercise domains or activities of daily living.
Intensity	**Consider activities that combine domains to efficiently reach at least 150 minutes of exercise per week.**			
	Start at moderate intensity: 60-65% HRmax [HRmax=208-(0.7*age)] or Rate of Perceived Exertion (RPE) 12-13/20 or 3-4/10. **Progress** over time (6-8 weeks) to vigorous intensity: 75-85% HRmax or RPE 14-17/20 or 5-7/10, when physiologically appropriate and safe. Teach client to self-monitor.	Start at a comfortable weight that client can lift for 10 repetitions to fatigue. **Progress** to 2-3 sets of 8-10 repetitions to fatigue while maintaining integrity of movement.	Full extension, flexion, or rotation stretch to the point of slight discomfort. For **static stretch**: 2-3 repetitions of each stretch. For **dynamic stretch**: 8-10 movements in each direction. **Progress** range of motion and static hold as client can tolerate.	Appropriate challenge delivered in a safe manner given the setting (individual vs group). **Progress** time, motor, and cognitive challenges as client improves.
Type	Prolonged, rhythmic activities using large muscle groups (e.g., brisk walking or incline walking, running, fast cycling, swimming, rowing, elliptical, dancing).	Major muscle groups of the upper and lower body and core using weight machines, resistance bands, or body weight. Include both flexor and extensor muscles. Consider circuit training and resistance training with balance challenges.	**Static Stretching:** All major muscle groups after exercise. **Dynamic Stretching/Active Range of Motion**: Prior to intense aerobic and strengthening exercise; Include diaphragmatic breathing and meditation.	**Balance:** Static and dynamic balance activities include single leg stand, weight shifting, reaching, multi-directional large amplitude movements, and functional training (e.g., steps, floor-to-stand, sit-to-stand, using varied surfaces, perturbations). **Agility:** Activities that move the body quickly in different directions (e.g., multi-directional stepping, turning, backwards walking, obstacles, sport, dance). **Multi-Tasking:** Primary motor activity (e.g., walking, balance) with secondary motor (e.g., carrying, head turns, bouncing ball) or cognitive task (e.g., counting, listing, recall).
Parkinson's Related Considerations	Prioritize safety (i.e., ambulatory status, physical assistance, equipment). Risk of freezing of gait or dystonia that can be worsened with exercise. Consider comorbidities (e.g., musculoskeletal, cardio-respiratory & cognitive). Risk of Parkinson's-related autonomic dysfunction, including orthostatic hypotension, blunted heart rate response to exercise, and arrhythmias associated with PD or medications. Recommend using RPE to monitor intensity for PwP with blunted HR response to exercise.	Prioritize body mechanics and posture, with an emphasis on extensor muscles. Dystonia and dyskinesia may impact exercise selection. Progress with increasing weights. Use free weights with caution. Consider comorbidities (e.g., spinal stenosis, osteoporosis, osteopenia, arthritis, and injuries).	Consider rigidity (stiffness) & dystonia (fixed posture) and general worsening of flexed posture with disease progression. Consider comorbidities (e.g., osteoporosis, pain, arthritis, and spinal stenosis).	Consider **safety**: Anticipate needs for supervision or assistance due to varied physical ability, cognitive engagement, and attention. Allow upper extremity support when needed. Consider comorbidities (e.g., peripheral neuropathy, cognitive decline, orthostatic hypotension) and risk of freezing of gait.
	Consider collaborating with a licensed physical therapist specializing in Parkinson's disease to assist with full functional evaluation and individually-tailored exercise recommendations taking into account complex medical history.			