Expanding the PD GENEration study to increase clinical genetic testing and counseling using whole genome sequencing among diverse Parkinson's disease (PD) populations

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PD GENEration

Abstract

Objective: To provide Clinical Laboratory Improvement Amendments (CLIA) genetic testing using whole genome sequencing and disclosure of 7 PD relevant genes and secondary health-related genetic findings through genetic counseling to people with PD (PWP) globally. **Background:** The PD GENEration study, sponsored by the Parkinson's Foundation in partnership with the Global Parkinson's Genetics Program (GP2) (NCT04994015), is transitioning from CLIA testing of targeted exome to whole genome sequencing (WGS) and expanding to further include underrepresented populations in the Americas and Israel. **Methods:** This expansion involves collaboration with the Latin American Research consortium on the Genetics of Parkinson's Disease (LARGE-PD). To ensure wider accessibility, genetic counseling materials focused on WGS were developed in English and Spanish, empowering healthcare providers worldwide to deliver genetic results as part of standard of care. **Results:** The expansion of PD GENEration aims to yield an additional 8,400 participants in 2024, resulting in an overall cohort of 23,000+ PWP with genomic characterization. All clinical and genomic sequencing data will be made publicly available through the GP2 program. **Conclusion:** PD GENEration offers a flexible research study framework that can integrate globally, taking into consideration each country's infrastructure, cultural differences, and genetic counseling training needs. A decentralized study model and "train the trainer" methods allows PD GENEration to expand beyond the parameters of traditional genetic testing and genetic counseling.

Methods

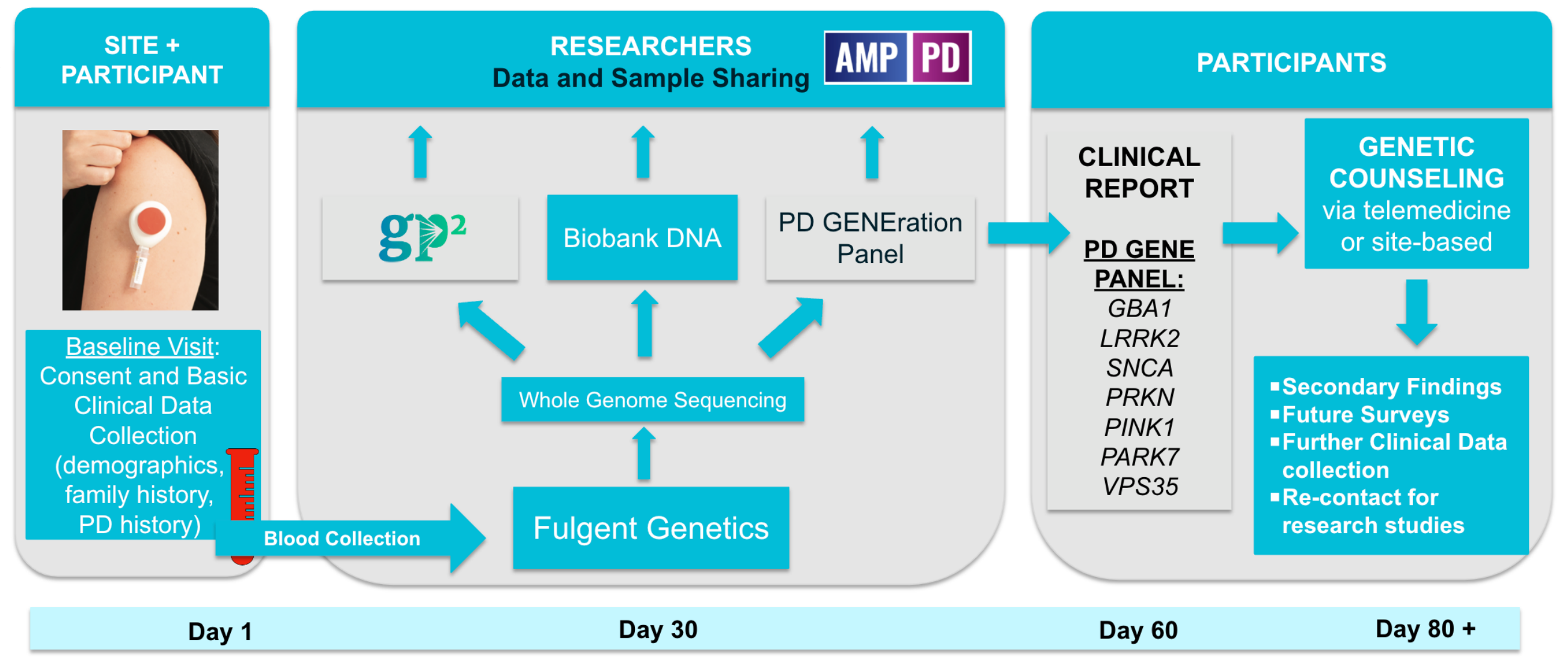
PD GENEration is a multi-center, observational study, offering genetic testing and counseling to those with PD in the United States, including Puerto Rico; Canada; the Dominican Republic; Israel; and in 5 Latin American Countries: Chile, Colombia, Mexico, Peru, Ecuador. DNA samples are analyzed by next-generation sequencing and deletion/duplication analysis (CLIA-certified; Fulgent Genetics). Variants classified as pathogenic/likely pathogenic and clinically actionable are disclosed.

Four phases of PD GENEration:

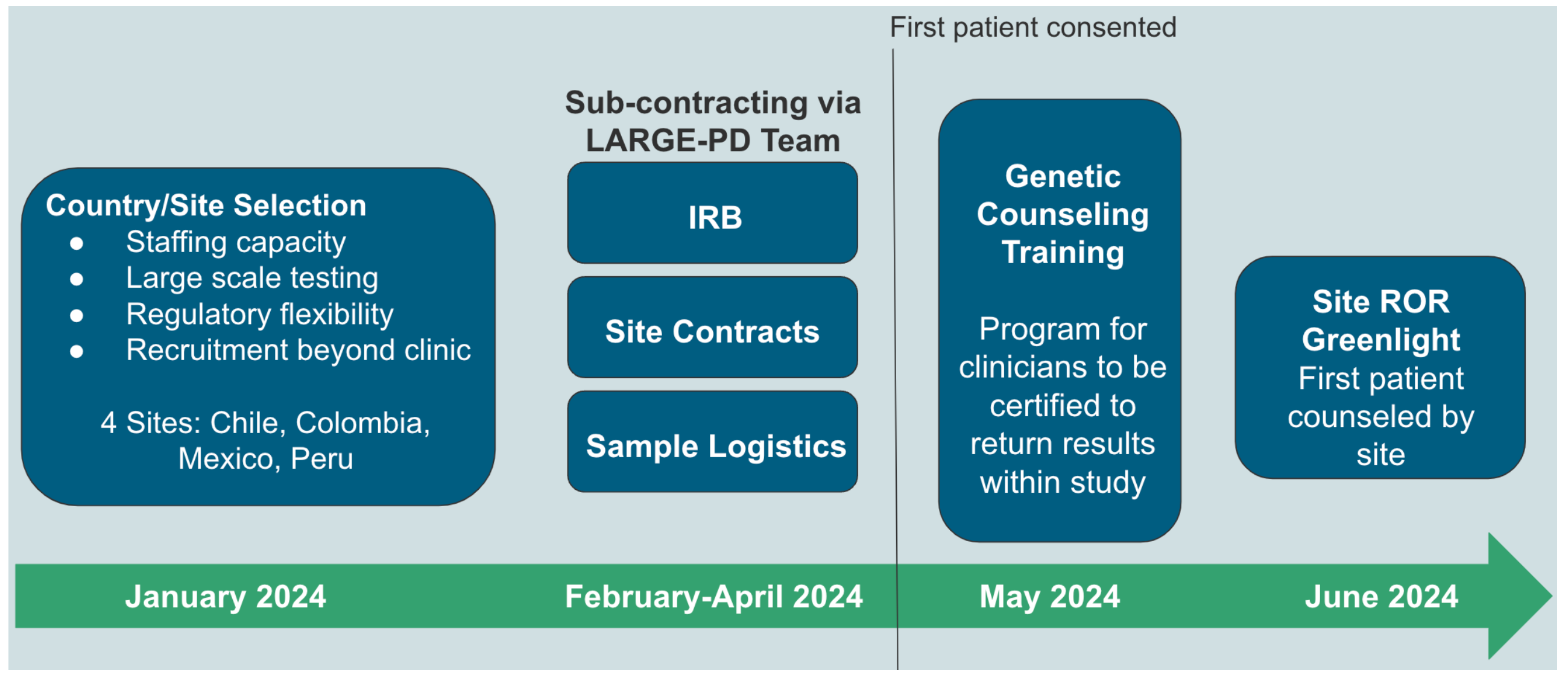
1) Pilot study- launched in Sep. 2019 and aimed at feasibility.
2) Clinical study- launched in Nov. 2020- continuation of the Pilot study at a larger scale, aimed at frequency and characterization of clinical phenotypes.
3) Registry study- launched in Jan. 2021 and aimed to make genetic counseling and testing accessible to 15,000 participants.
4) Registry study WGS- launched in Mar. 2024 and aims to offer whole genome sequencing (WGS) genetic testing and counseling to 8,400 participants with return of results in primary PD and secondary findings, shown in the table below.

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, VCP1, 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)

WGS Registry Study Pipeline For Participants and Researchers



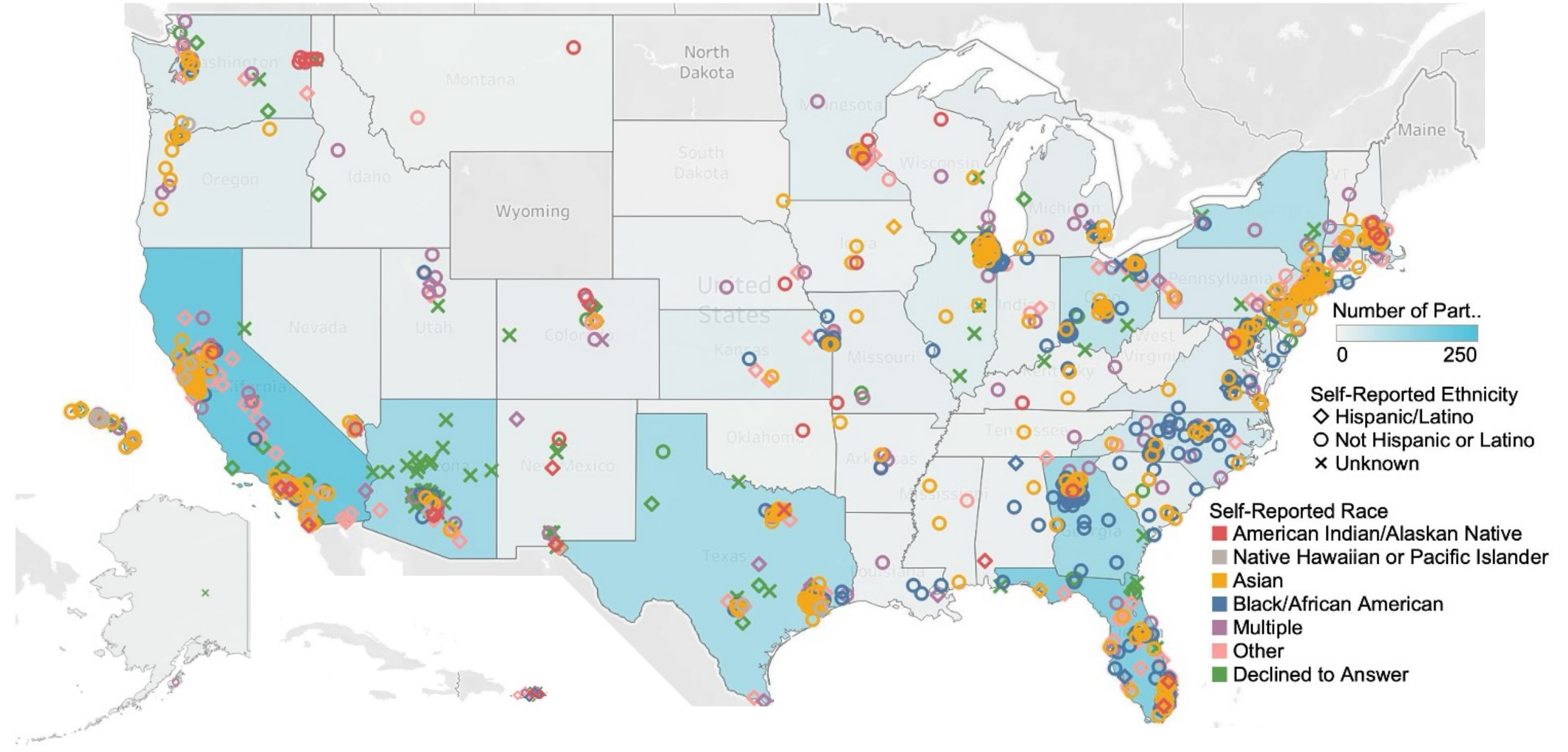
Timeline of Expansion to Latin America through LARGE-PD



Results

Demographics

Distribution of Enrollment of Underrepresented Populations



All results are as of August 26th, 2024.
PD GENEration has enrolled 18,003 participants.

69 years average age at enrollment

60 years average age at onset

62 years average age at diagnosis

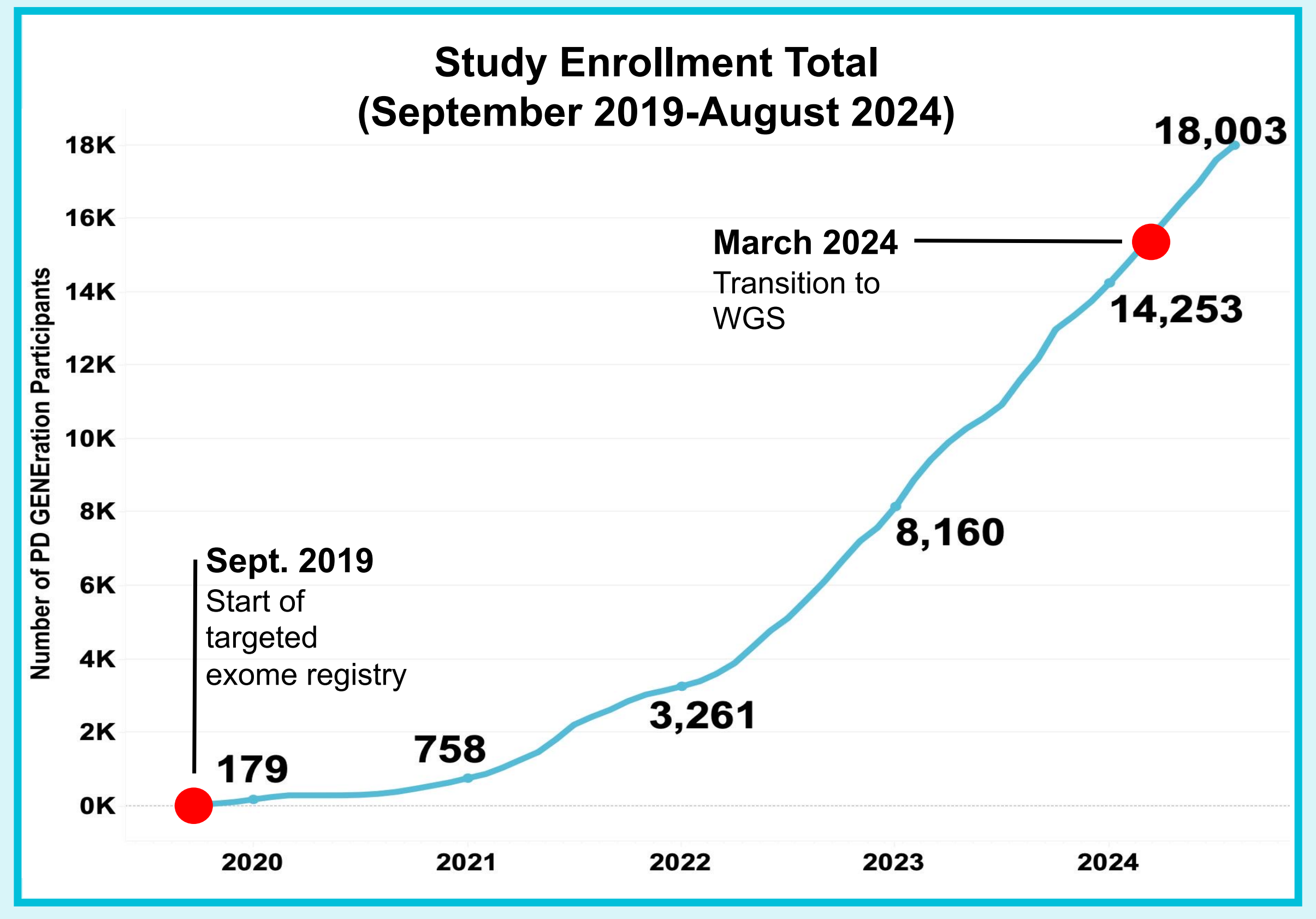
57% : 43% genetic sex ratio of male : female

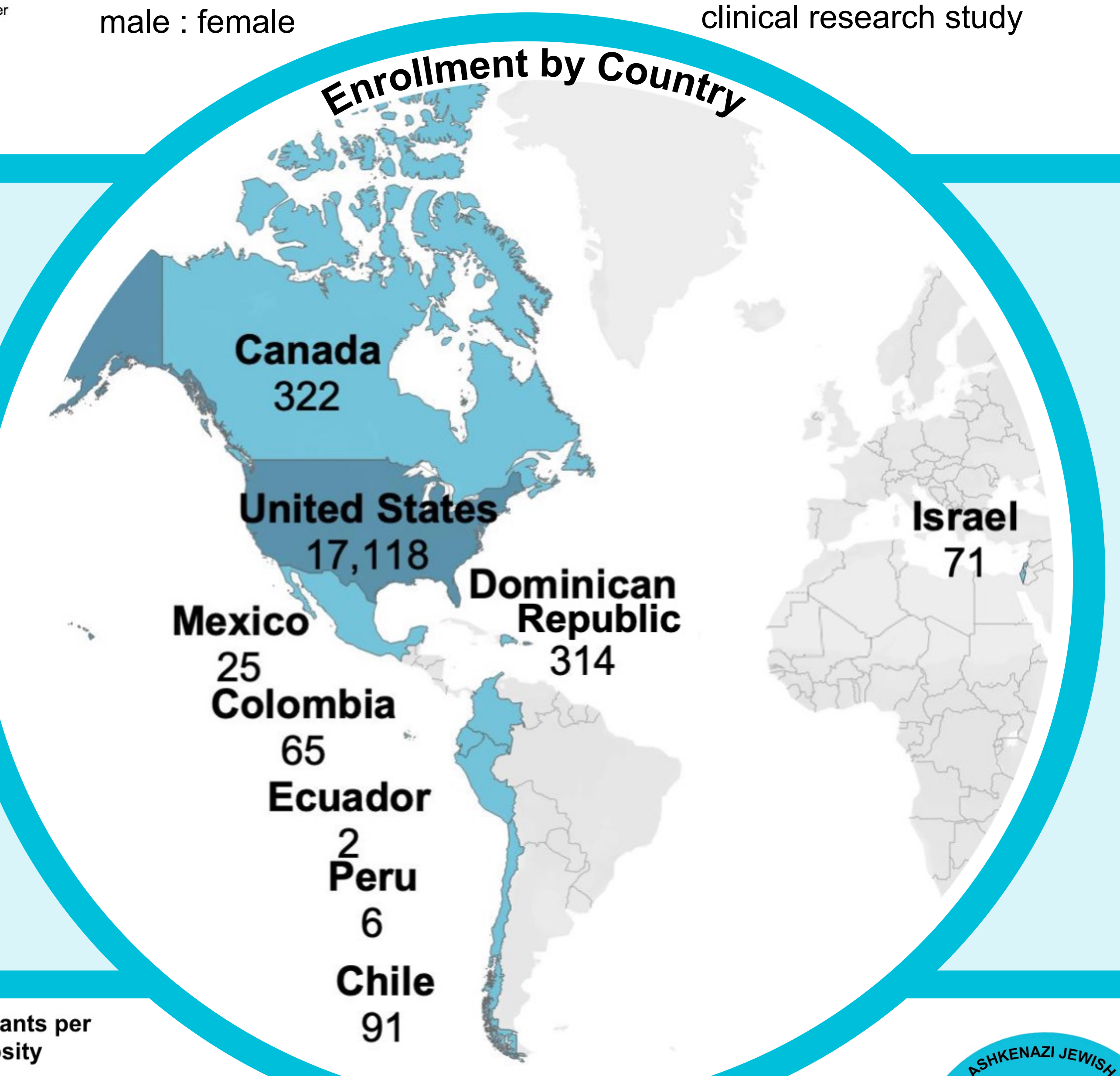
37% diagnosed in the past 3 years

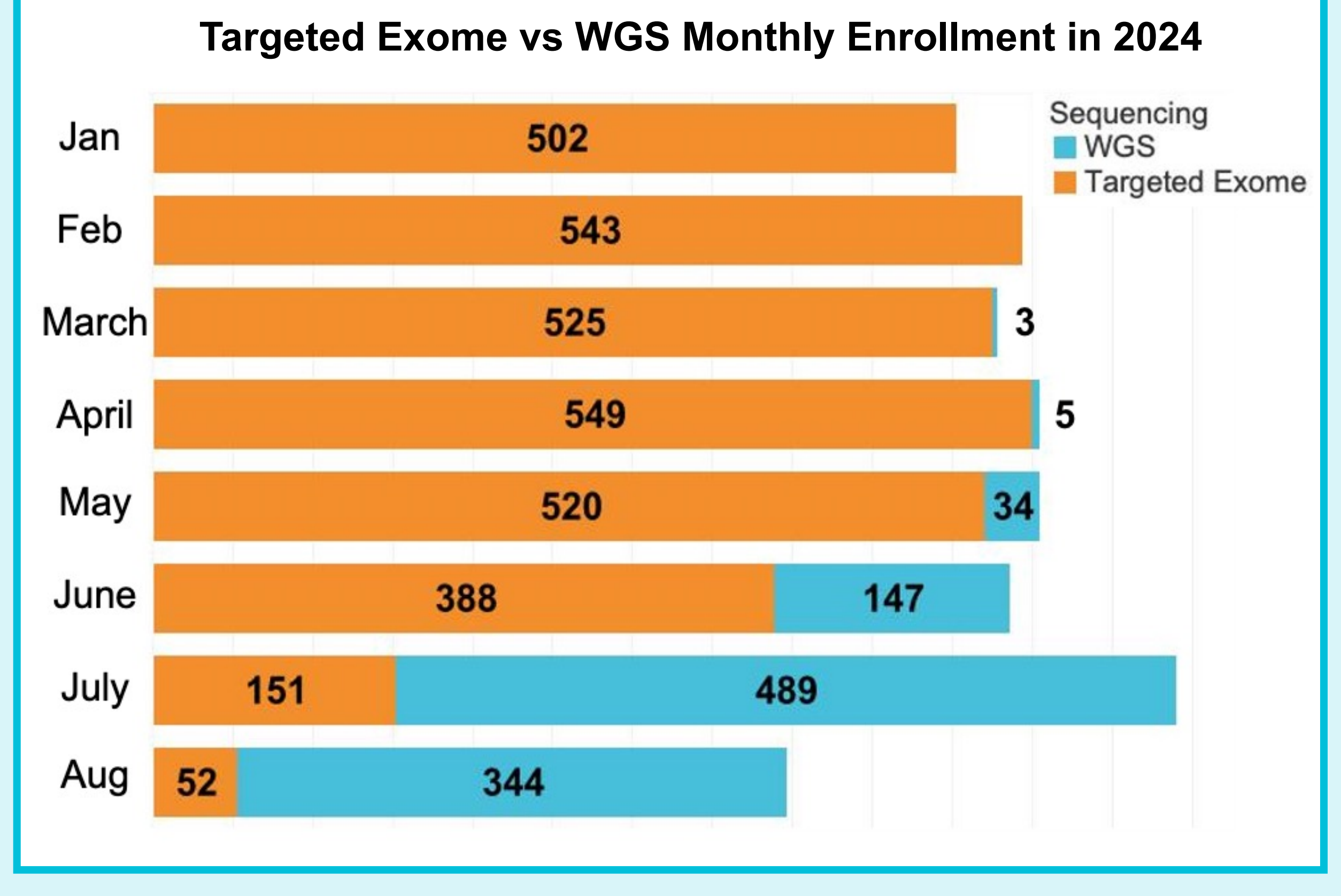
77% never participated in a clinical research study

Participant Racial and Ethnic Demographics			
Self-Reported Race	US	Outside US	Total
White	14,963 (87.4%)	391 (43.6%)	15,354 (85.2%)
Other (i.e. Indian, Middle Eastern)	326 (1.9%)	356 (39.7%)	682 (3.8%)
Unknown/Declined to Answer	520 (3.0%)	82 (9.1%)	602 (3.3%)
Asian	503 (2.9%)	46 (5.1%)	549 (3.0%)
Black/African American	505 (3.0%)	13 (1.5%)	518 (2.9%)
Multiple	243 (1.4%)	7 (0.8%)	250 (1.4%)
American Indian/Alaskan Native	41 (0.2%)	1 (0.1%)	42 (0.2%)
Native Hawaiian/Pacific Islander	17 (0.1%)		17 (0.1%)
Self-Reported Ethnicity	US	Outside US	Total
Not Hispanic or Latino	15,163 (88.6%)	286 (32.0%)	15,449 (85.8%)
Hispanic or Latino	1,376 (8.0%)	505 (56.3%)	1,881 (10.4%)
Unknown/Declined to Answer	580 (3.4%)	105 (11.7%)	685 (3.8%)

Enrollment



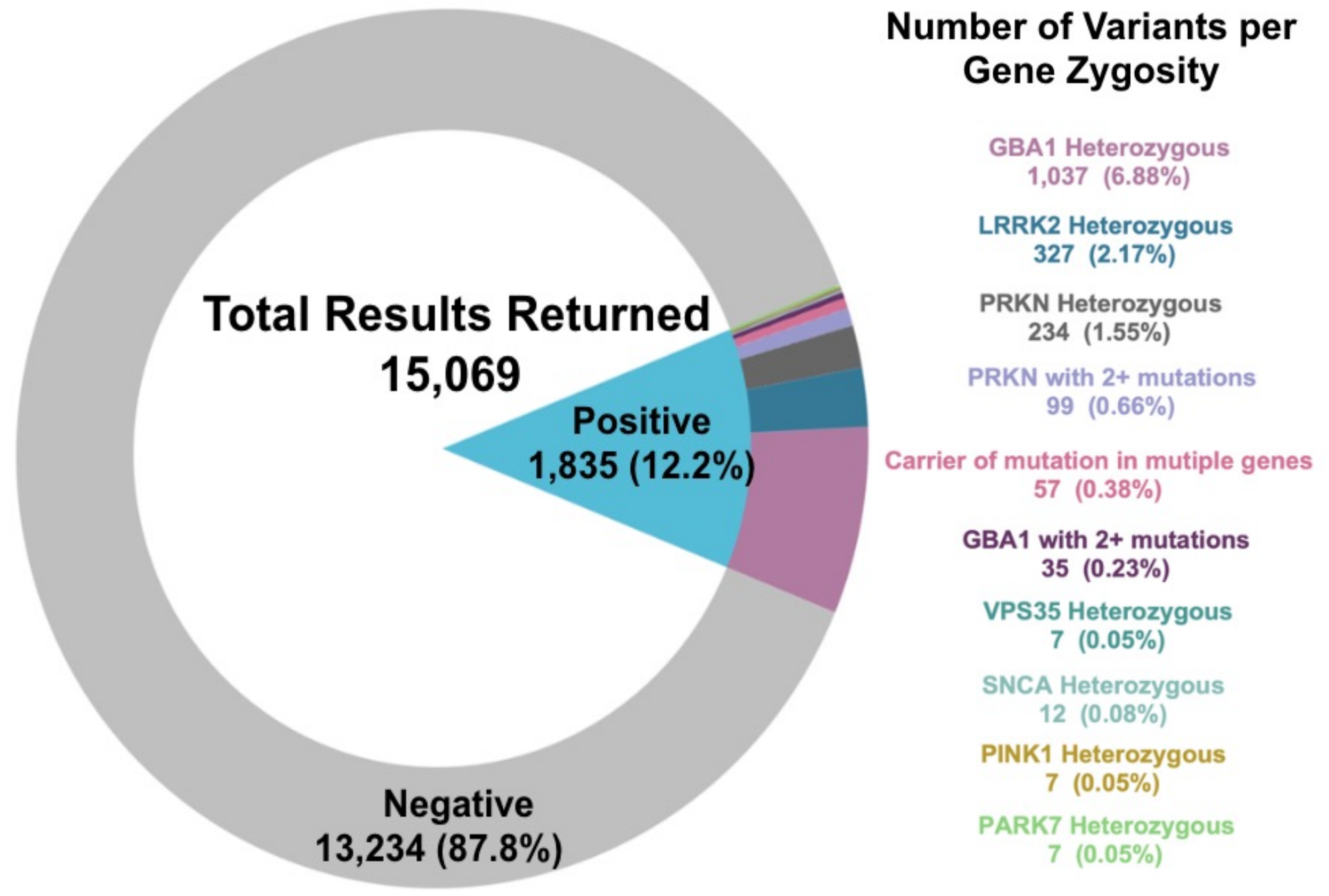




Genetics

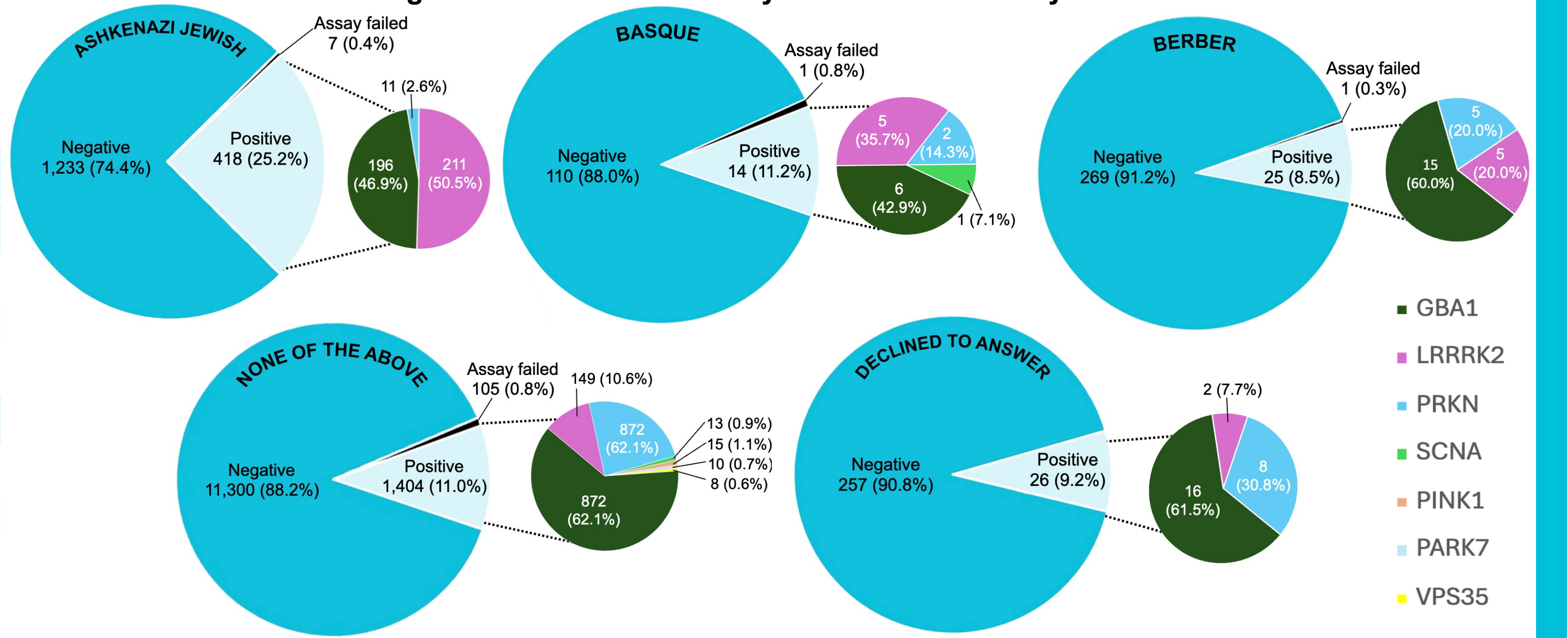
1,033 participants consented into WGS phase of study

994 participants consented to receive secondary health findings



Higher Genetic Risk vs Genetic Positivity Rate (7-gene panel)		
Diagnosis Age	Positive	Negative
50 years old or younger	391 (18.8%)	1,685 (81.2%)
More than 50 years old	1,406 (11.7%)	10,620 (88.3%)
Unknown Age	90 (9.4%)	864 (90.6%)
Family History	Positive	Negative
Positive first degree	418 (12.9%)	2,828 (87.1%)
No first degree	1,353 (11.9%)	10,044 (88.1%)
Declined to answer	5 (8.0%)	57 (92.0%)

Higher Genetic Risk Ancestry vs Genetic Positivity Rate



Conclusion

PD GENEration offers a flexible research study framework that can integrate internationally, taking into consideration each country's infrastructure, cultural differences, and genetic counseling training needs. A decentralized study model and "train the trainer" methods allows PD GENEration to expand beyond the parameters of traditional genetic testing and genetic counseling.

More about PD GENEration

Parkinson's Foundation

Parkinson.org

Engagement of the Black and African American Community in Parkinson's Genetic Research

MOREHOUSE SCHOOL OF MEDICINE

Evelyn Stevens[1], Amasi Kumeh[1], Sherline Sauveur[2], David Oguoma-Richards[2], Richard Huckabee[3], Angela Huckabee[3], Denise Coley[3], Bernard Coley[3], Michael Fitts[3], Phil Gee[3], Evelyn Lewis[3], Lisa Seghetti[3], Tammyjo Best[4] Kimberly Gamble[5], Karen Williams[6], Lance Wilson[7], Reversa Joseph[8], Hiral Shah[9], Casey Gallagher[1], Christiana Evers[1], James C. Beck[1], Anna Naito[1], Chantale Branson[2]

1) Parkinson's Foundation; 2) Morehouse School of Medicine; 3) Parkinson's Foundation Research Advocate/Volunteer; 4) Emory University; 5) Atrium Health; 6) Northwestern University; 7) Jefferson Health; 8) Chalmers P Wylie Veterans Outpatient Clinic; 9) Columbia University

Background

- Advancements in understanding the biological pathways of Parkinson's disease (PD) have largely been focused on people of European ancestry. [1,2]
- There is a critical need to understand genetic differences across populations, including people with African ancestry. Black and African American people with PD face health disparities that may be exacerbated by the paucity of representation in Parkinson's genetic research.[1,2]
- PD GENEration is a multi-center, observational, registry based clinical trial offering clinical genetic testing, counseling and return of genetic test results at no cost to individuals with PD and aims to expand participation in the Black community to improve representation and advance health equity.

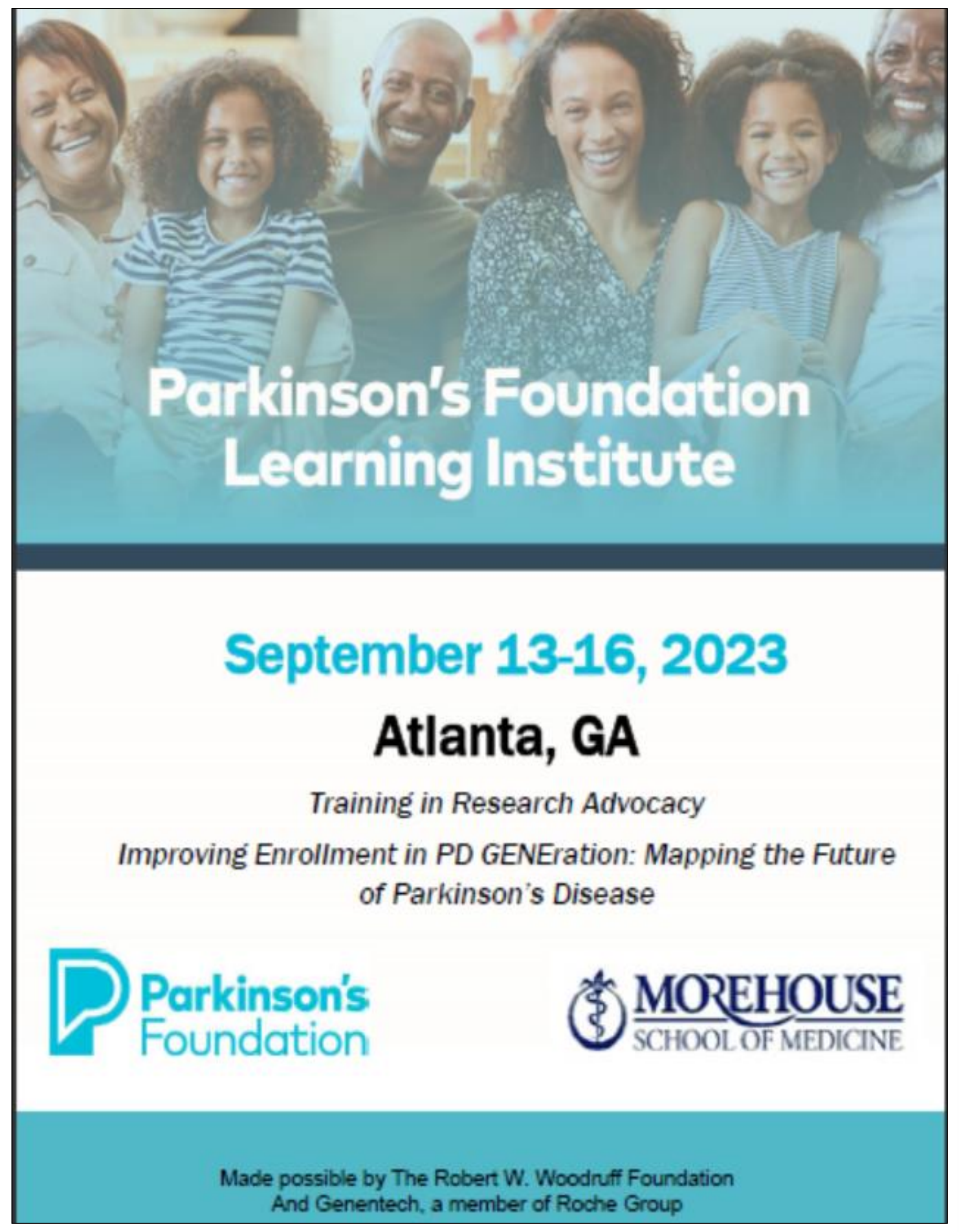
Methodology

Guided by best practices in diversity, equity and inclusion and patient engagement,[3,4] the Parkinson's Foundation partnered with Morehouse School of Medicine (MSM), a historically Black institution of medicine to:

1) improve inclusion in PD GENEration,
2) prioritize PD awareness, education and resources; and
3) tailor an in-person, research advocacy training program – the Learning Institute – to understand research and lived experiences of the Black and African American community affected by Parkinson's disease.

We have more posters for you to visit:

Abstract Title: Engage, Educate and Empower: Parkinson's Research Advocates from the Black and African American Community
Abstract Number: 1862



Parkinson's Foundation Learning Institute

September 13-16, 2023

Atlanta, GA

Training in Research Advocacy

Improving Enrollment in PD GENEration: Mapping the Future of Parkinson's Disease

Parkinson's Foundation — MOREHOUSE SCHOOL OF MEDICINE

Made possible by The Robert W. Woodruff Foundation
And Genentech, a member of Roche Group

PD GENEration

MAPPING THE FUTURE OF PARKINSON'S DISEASE

Neuro Talk: PD GENEration and the Black Community

Attendees (n=59) included members of the planning committee, faculty speakers and participants being trained as research advocates. 90% identify as Black or African American.

Planning Committee/Faculty	Research Advocates
• 5 people with Parkinson's, 4 care partners **All are current Research Advocates, attended a prior Learning Institute*	• 17 care partners, 16 people with Parkinson's
• 3 Movement Disorder Specialists	• 73% receive care from a Movement Disorder Specialist
• 3 Patient/Research Coordinators	• 73% female
• 1 Social Worker	• Average age = 58 years old (range 30-79yrs old)
• 7 Parkinson's Foundation Staff **Includes executive leadership, patient engagement team, research team*	• Average years of diagnosis = 8 years (range 2-23 years)
	• 90% live in suburban/urban area (recruited from Atlanta, Chicago, Charlotte)
	• 71% have never been invited to take part in a clinical trial

Results

From November 2021 - March 2024, in partnership with Morehouse School of Medicine

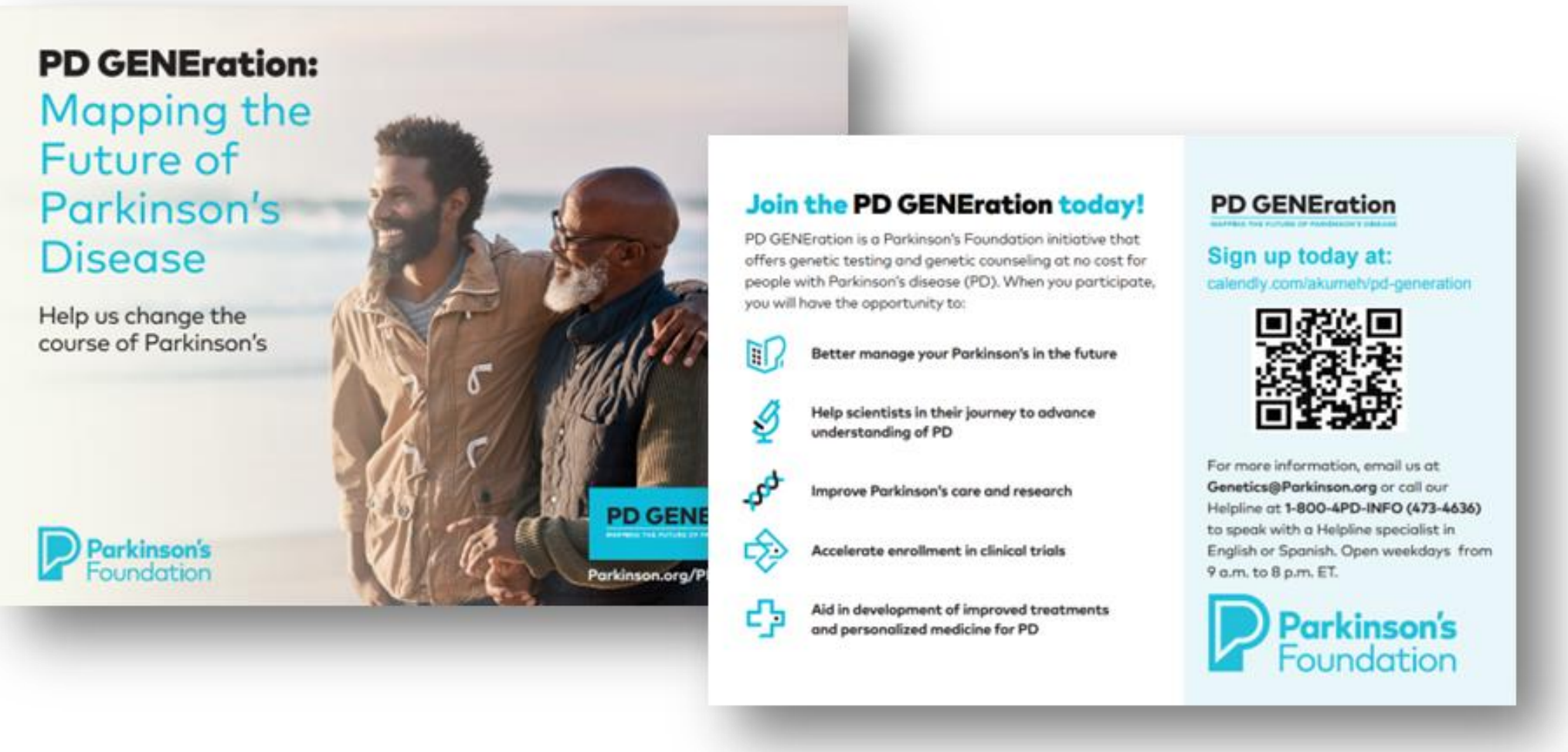
Black / African American Participants

157
Participants

364 Black/African American participants enrolled overall
2.4% of overall cohort

11%
Genetic Positivity Rate
(of the overall cohort)

77%
Never Participated in Research
(of the overall cohort)



PD GENEration: Mapping the Future of Parkinson's Disease

Help us change the course of Parkinson's

Parkinson's Foundation

Join the **PD GENEration** today!

PD GENEration is a Parkinson's Foundation initiative that offers genetic testing and genetic counseling at no cost for people with Parkinson's disease (PD). When you participate, you will have the opportunity to:

- Better manage your Parkinson's in the future
- Help scientists in their journey to advance understanding of PD
- Improve Parkinson's care and research
- Accelerate enrollment in clinical trials
- Aid in development of improved treatments and personalized medicine for PD

PD GENEration

Sign up today at:
calendly.com/akumeh/pd-generation

For more information, email us at **Genetics@Parkinson.org** or call our Helpline at **1-800-4PD-INFO (473-4636)** to speak with a Helpline specialist in English or Spanish. Open weekdays from 9 a.m. to 8 p.m. ET.

Parkinson's Foundation

Why our Research Advocates Enrolled in PD GENEration:

When asked what factored into their decision to enroll:

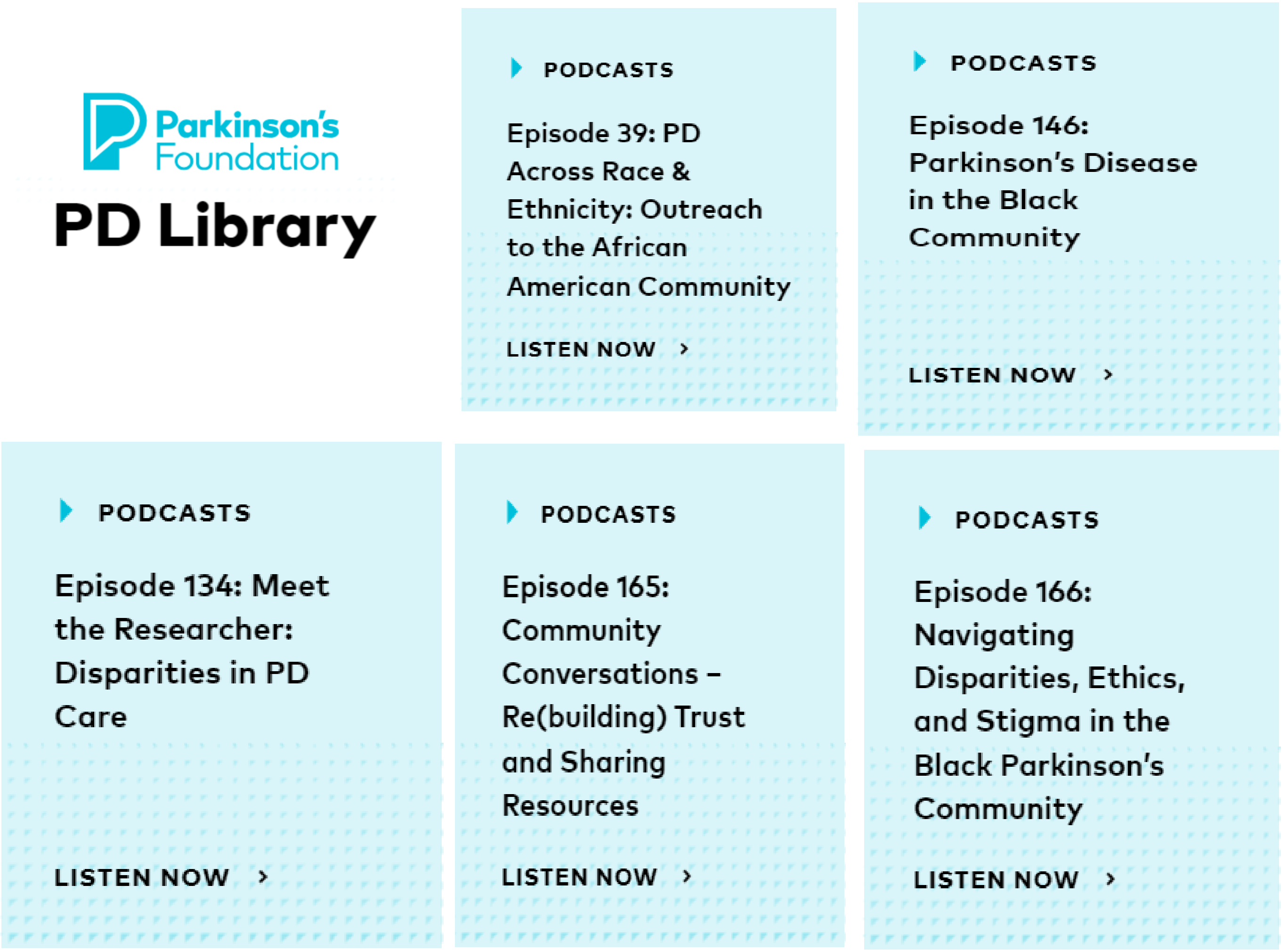
- Determining genetic risk of Parkinson's
- Information for my family members
- Better treatments for the future
- Receiving consistent information, was explained well

Results (continued)

14 community education events were held, including the Learning Institute in September 2023.

Tailored and targeted media was utilized to expand reach, engage the community, and raise awareness on Parkinson's disease and PD GENEration. This included **2 webinars, 5 podcasts and 6 blog/news articles**.

All research advocates with PD enrolled in PD GENEration and received a toolkit to support their advocacy efforts in their own communities



Parkinson's Foundation

PD Library

PODCASTS
Episode 39: PD Across Race & Ethnicity: Outreach to the African American Community
LISTEN NOW ›

PODCASTS
Episode 146: Parkinson's Disease in the Black Community
LISTEN NOW ›

PODCASTS
Episode 134: Meet the Researcher: Disparities in PD Care
LISTEN NOW ›

PODCASTS
Episode 165: Community Conversations – Re(building) Trust and Sharing Resources
LISTEN NOW ›

PODCASTS
Episode 166: Navigating Disparities, Ethics, and Stigma in the Black Parkinson's Community
LISTEN NOW ›

Conclusions: Looking Ahead

- Establishing partnerships with trusted sources of the Black community is critical to providing equitable access to PD education and resources, including PD GENEration.
- Media can be a successful engagement strategy for raising awareness.
- Focusing on diversity and inclusion in PD GENEration will accelerate breakthroughs towards a cure for PD.

References

1) Bailey M. et al (2020). Parkinson's Disease in African Americans: A Review of the Current Literature. *J Parkinsons Dis*. 10(3):831-841.; 2) Schneider MG . et al (2009) Minority enrollment in Parkinson's disease clinical trials. *Parkinsonism Relat Disord* 15, 258–262; 3) Vaswani PA, et al (2020). Overcoming Barriers to Parkinson Disease Trial Participation: Increasing Diversity and Novel Designs for Recruitment and Retention. Neurotherapeutics, 17(4):1724-1735. 4) Feeney M, et al (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. Health Expect.(4):722-730. 5) Ladson-Billings, G. (1995) Toward a theory of culturally relevant pedagogy. *American Education Research Journal*, 32(3), 465-491

Benefits of Parkinson’s Team Training Are Maintained Long-Term

Kelly E. Lyons[1], Elizabeth Pollard[2], Denise Beran[2], Christine Hunter[3] ,Heather Cianci[4], Elaine Book[5]
[1] University of Kansas Medical Center, [2] Parkinson’s Foundation; [3]Deceased; [4] University of Pennsylvania; [5] University of British Columbia

Objective

To determine if the improvements in confidence to provide and coordinate patient care and understanding of individual and other team member roles among interprofessional healthcare teams reported after Parkinson’s Foundation (PF) Team Training (TT) are maintained long-term.

Background

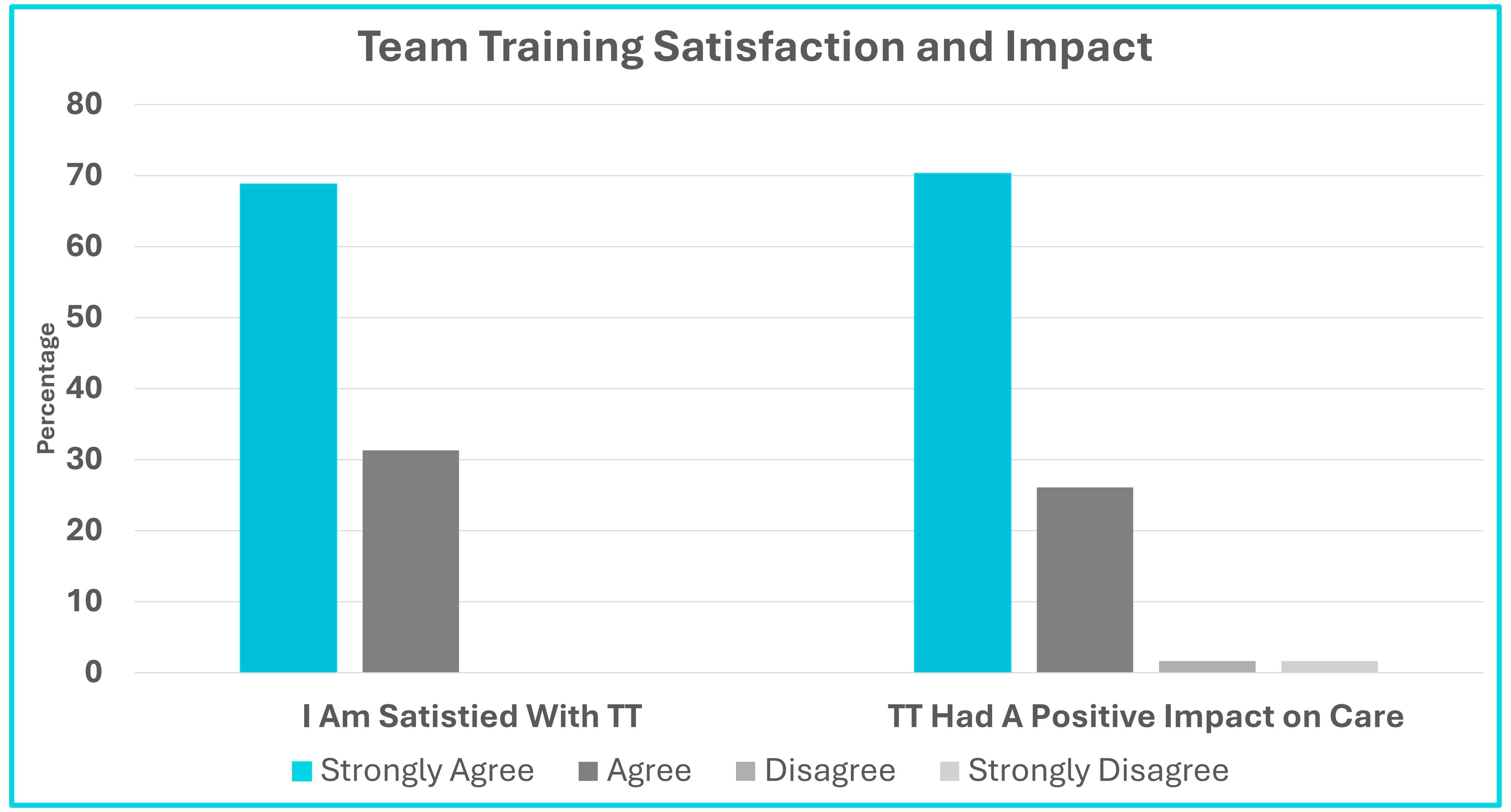
PF TT offers training to interprofessional healthcare teams to better coordinate and improve care. Significant improvements were previously reported 6 months after TT in confidence in providing care and improving quality of life in persons with Parkinson’s disease (PD) and care partners, as well as in understanding individual and other team member roles.

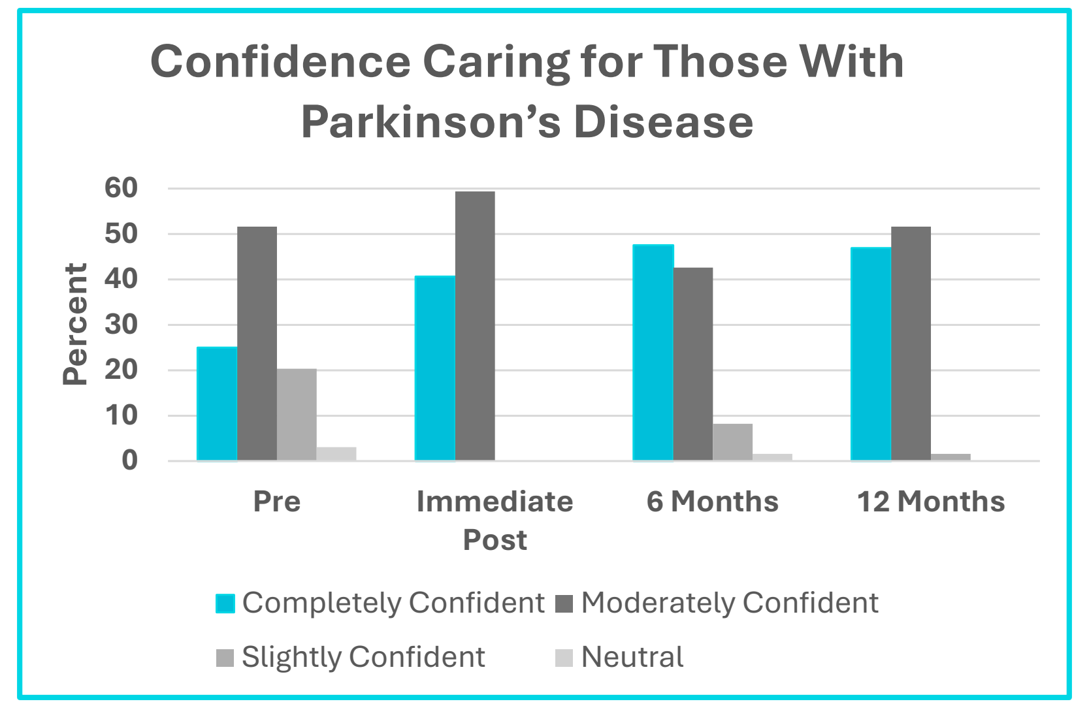
Methods

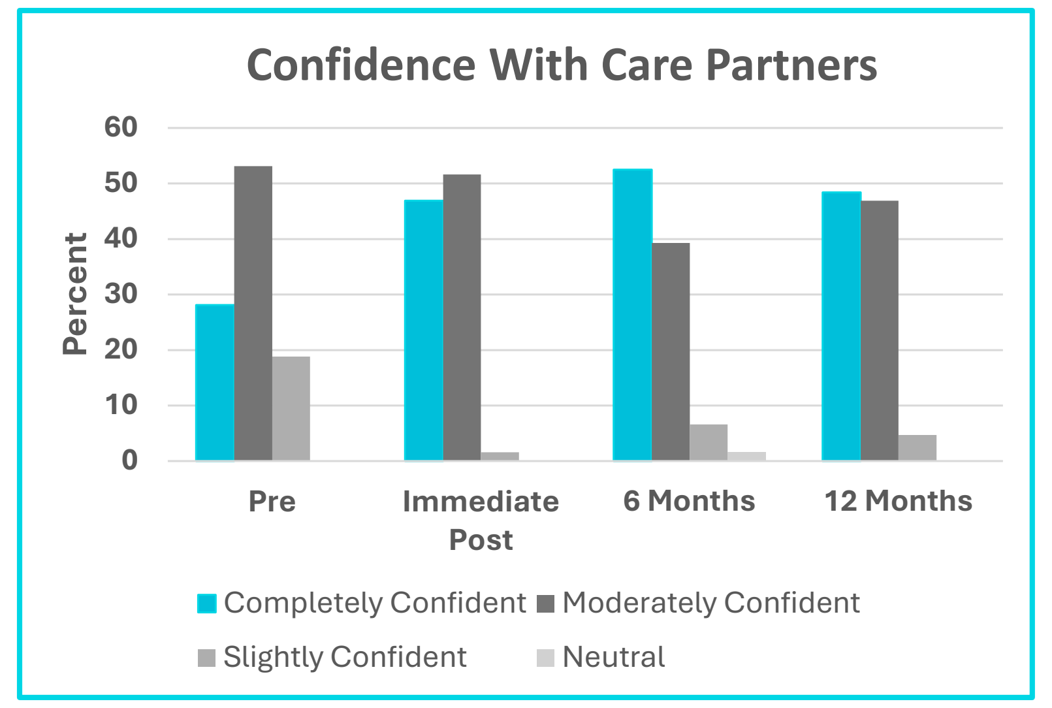
Healthcare professionals, including physicians, nurse practitioners, physician assistants, nurses, occupational, physical, and speech therapists, dieticians, psychologists, social workers, pharmacists, and other team members that attended PF TT in October 2022 completed 4 surveys to assess learning and TT impact. The surveys were completed prior to and immediately after, 6 months after, and 1 year after TT. For each survey, the attendees rated their confidence or knowledge in a scale of 1 to 7 in which a response of 1 represented the highest level of confidence or knowledge and 7 represented the lowest level.

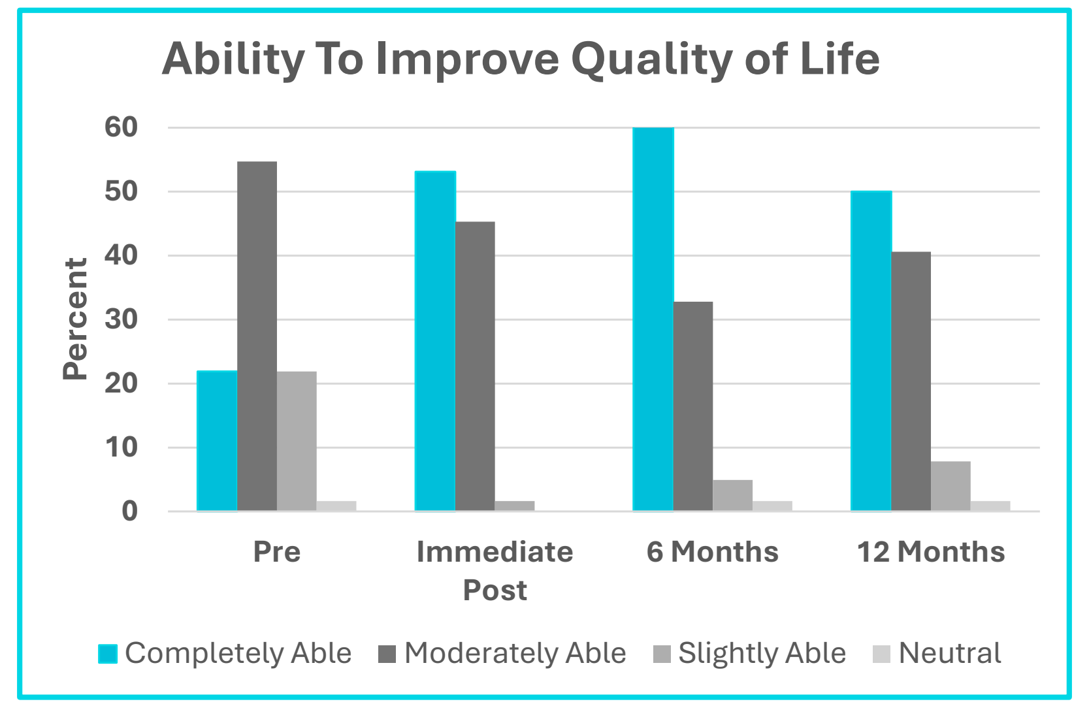
Results

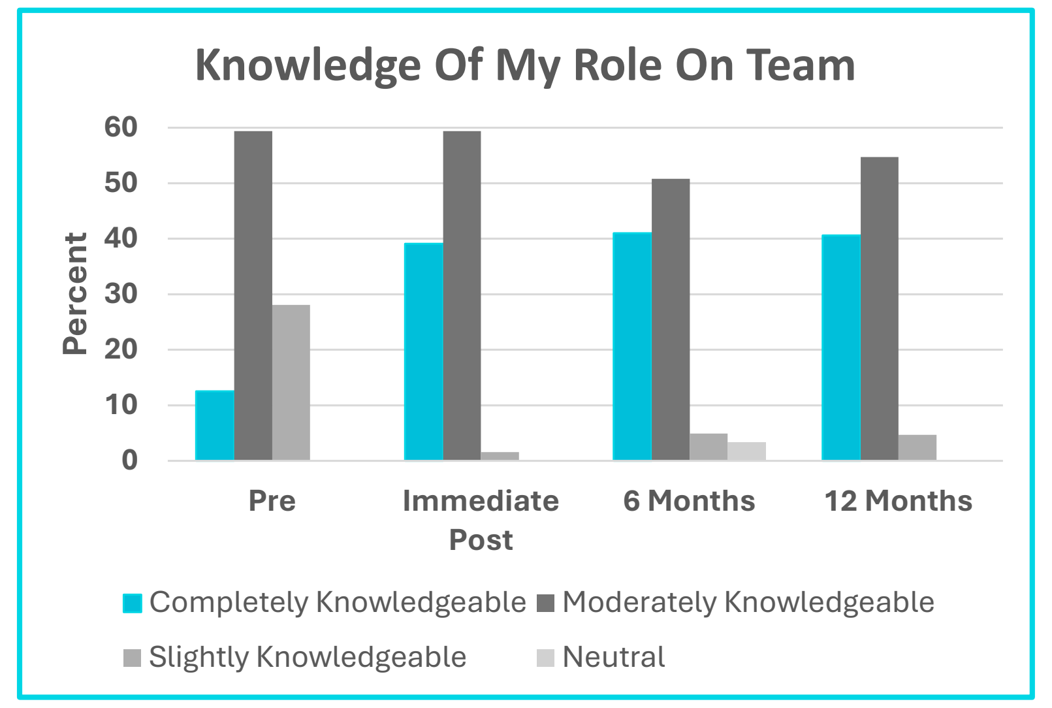
A total of 64 healthcare professionals from both new and established PD interprofessional care programs completed surveys before and 1 year after TT. There were significant improvements in the percentage of those that felt completely confident in various measures of providing care and team coordination that were reported immediately after TT and maintained throughout the 6 month and 1-year surveys ($p \leq 0.005$). Improvements were seen in confidence to provide care to persons with PD (88%), confidence in working with a care partner of someone with PD (72%), ability to directly improve the quality of life for a person with PD (128%), knowledge about the individual’s role in the interprofessional care team (225%) and understanding of the role of each team member and how they can assist in the care of persons with PD (95%).

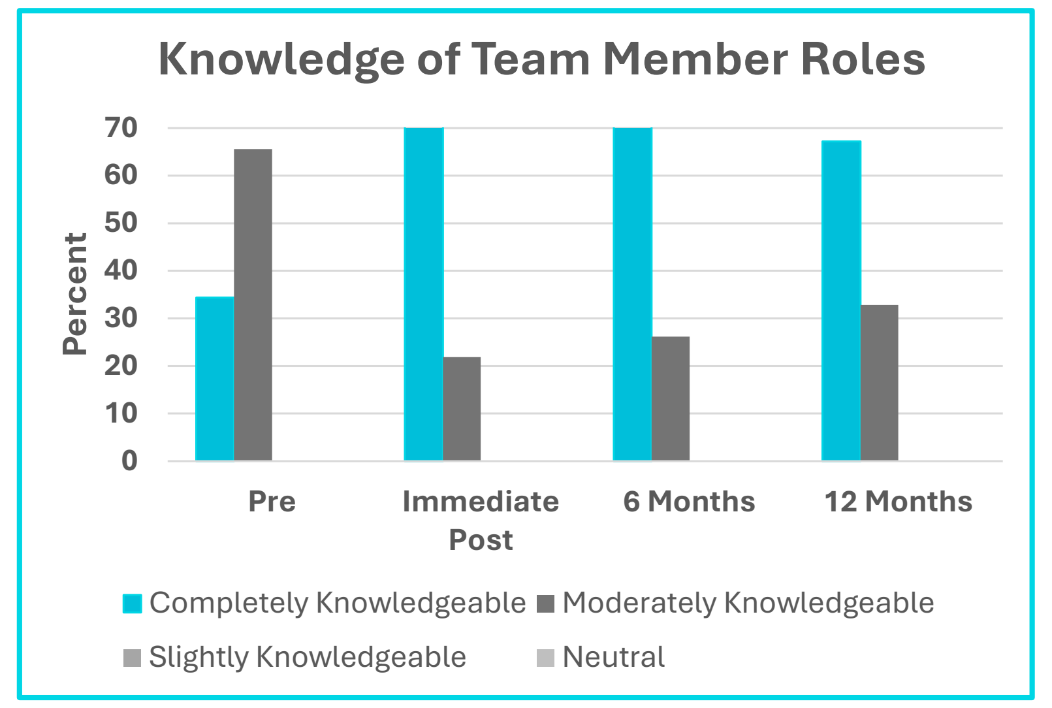












Conclusions

Parkinson’s Foundation Team Training resulted in significant and sustained improvements in healthcare professional confidence in caring for and working with persons with PD and their care partners, as well as in the understanding of individual and team member roles in the care of persons with PD.

Abstract 1861

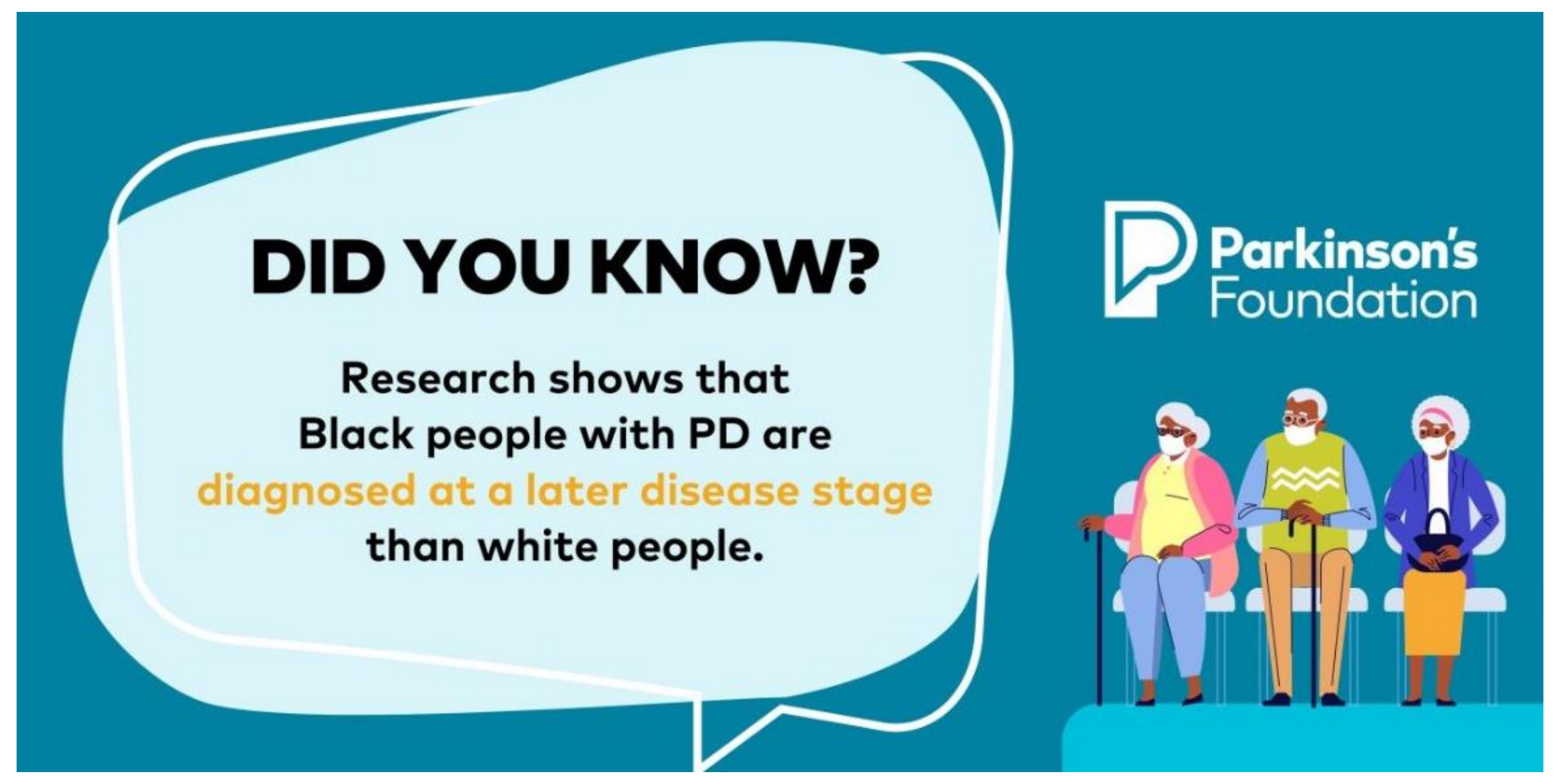
Parkinson's Foundation
Parkinson.org

Engage, Educate and Empower: Parkinson's Research Advocates from the Black and African American Community

<u>Reversa Joseph</u>[1], Kimberly Gamble[2], Tammyjo Best[3], Karen Williams[4], Lance Wilson[5], Denise Coley[6], Bernard Coley[6], Michael Fitts[6], Phil Gee[6], Richard Huckabee[6], Angela Huckabee[6], Evelyn Lewis[6], Lisa Seghetti[6], Chantale Branson[7], Hiral Shah[8], Amasi Kumeh[9], Casey Gallagher[9], Christiana Evers[9], Evelyn Stevens[9]

1 Chalmers P Wylie Veterans Outpatient Clinic; 2 Atrium Health; 3 Emory University; 4 Northwestern University; 5 Jefferson Health; 6 Parkinson's Foundation Research Advocate/Volunteer; 7 Morehouse School of Medicine; 8 Columbia University; 9 Parkinson's Foundation

Background



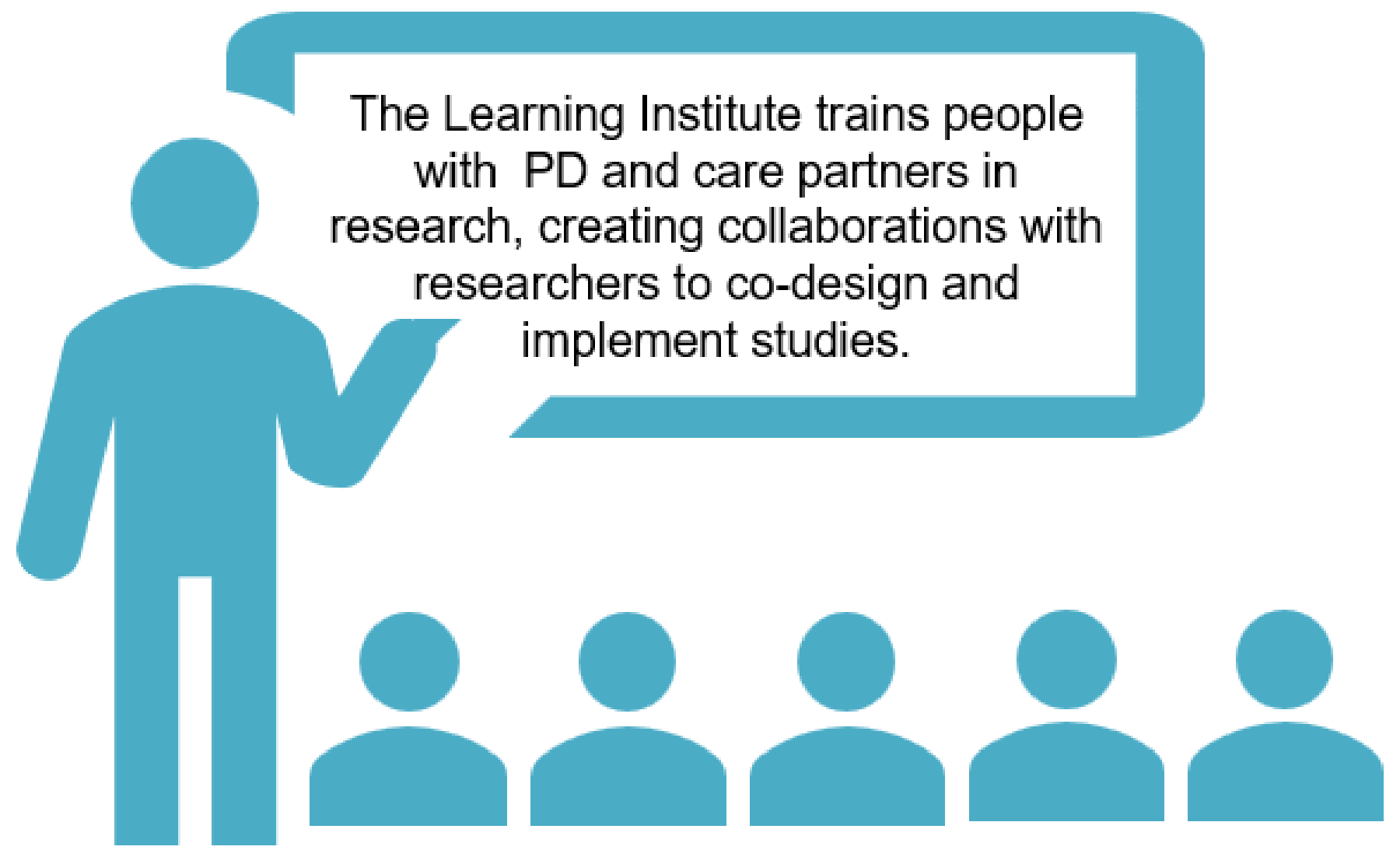
DID YOU KNOW?

Research shows that Black people with PD are diagnosed at a later disease stage than white people.

- Black and African American people with Parkinson's disease (PD) face significant disparities in care, including delays in diagnosis and treatment, limited access to care, and historical exclusion from research.[1,2]
- To address these challenges, the **Parkinson's Foundation Research Advocacy Training** program, the **Learning Institute**, was tailored to engage, educate, and empower the Black community in Parkinson's research.

Methodology

- The Parkinson's Foundation Learning Institute was established in 2008 and has trained over 400 volunteers in research and patient engagement (research advocacy), creating a national network of research advocates around the U.S. that are actively changing the face of Parkinson's disease research.[3]



The Learning Institute trains people with PD and care partners in research, creating collaborations with researchers to co-design and implement studies.

Scan QR code for more information on our Research Advocates program

- Black and African American people living with Parkinson's, care partners, clinicians, social workers, nurses and researchers were invited to join a coalition as key partners of planning and implementation

The first goal of the coalition was to ***redesign and execute the Parkinson's Foundation Learning Institute*** in a <u>culturally responsive</u> way for Black and African American communities and improve enrollment in **PD GENEration: Mapping the Future of Parkinson's Disease,** our groundbreaking initiative offering genetic testing, counseling and return of results at no cost to people living with Parkinson's

Results

- The Learning Institute was held in September 2023. 33 people from the Black community were trained in research advocacy (16 people with Parkinson's, 17 care partners; Average age=58 years; Average years of diagnosis=8 years).
- Community awareness and education was rated as the most interesting area for research advocacy (56%), followed by Collaborations with Industry (25%). ***See Figure 1***
- 79% of Research Advocates indicated feeling prepared to begin research advocacy and 83% indicated feeling excited about the work they can do as a Research Advocate. ***See Table 1***

FIGURE 1:
MOST INTERESTED AREA OF RESEARCH ADVOCACY

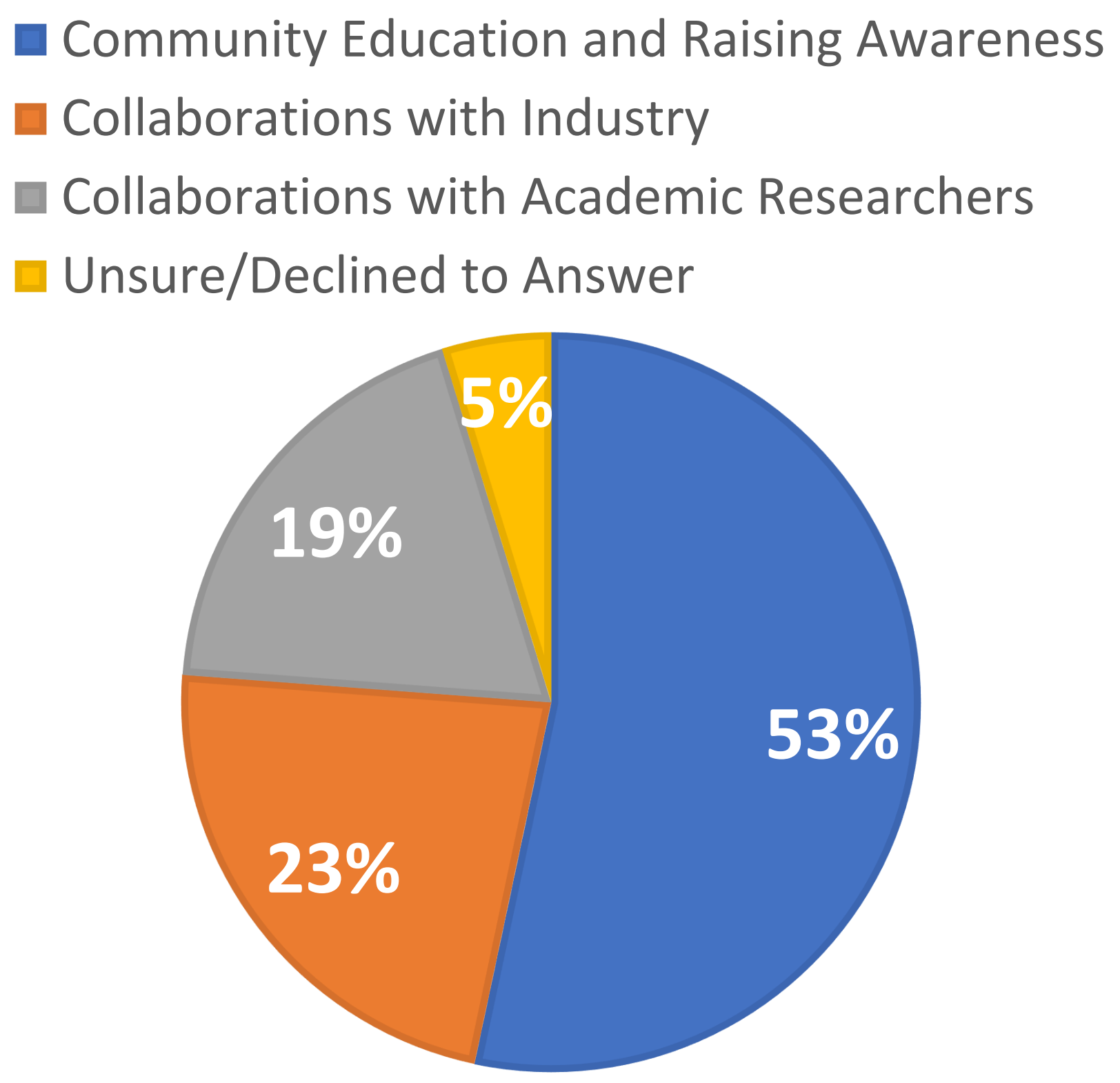


Table 1: Attitudes Post Learning Institute

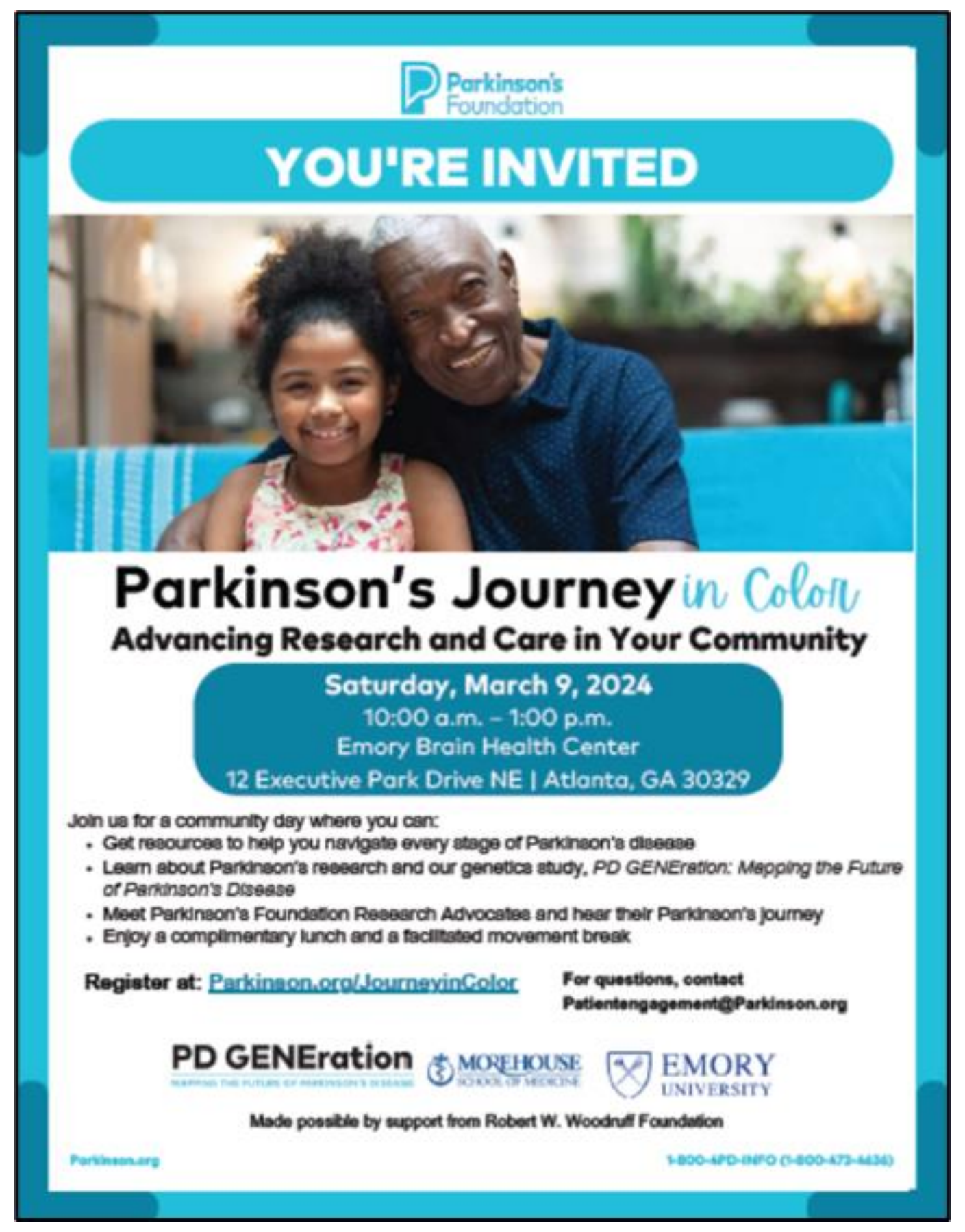
After attending the Learning Institute….	Moderate/Very
How prepared do you feel about getting involved in Parkinson's advocacy?	79%
How much has your perspective changed regarding the role people with Parkinson's and care partners can play in the research process?	91%
How excited are you about the work you can do as a Research Advocate?	83%

We have more posters for you to visit:
Abstract Title: Engagement of the Black and African American Community in Parkinson's Genetic Research
Abstract Number: 1654

From September 2023 through April 2024:

17 meetings on continued education and engagement were held by the Parkinson's Foundation patient engagement team. All research advocates have been engaged in at least one meeting.

17 advocacy tasks were completed by 26 Research Advocates. Of those tasks 16 were community engagements (e.g., presentation at local churches and health fairs, panelists at a Parkinson's Foundation community-based program), and one was a partnership with a professional coalition to inform Parkinson's care.



Parkinson's Foundation

YOU'RE INVITED

Parkinson's Journey *in Color*
Advancing Research and Care in Your Community

Saturday, March 9, 2024
10:00 a.m. – 1:00 p.m.
Emory Brain Health Center
12 Executive Park Drive NE | Atlanta, GA 30329

Join us for a community day where you can:
- Get resources to help you navigate every stage of Parkinson's disease
- Learn about Parkinson's research and our genetics study, *PD GENEration: Mapping the Future of Parkinson's Disease*
- Meet Parkinson's Foundation Research Advocates and hear their Parkinson's journey
- Enjoy a complimentary lunch and a facilitated movement break

Register at: <u>Parkinson.org/JourneyinColor</u>

For questions, contact
Patientengagement@Parkinson.org

PD GENEration
MOREHOUSE SCHOOL OF MEDICINE
EMORY UNIVERSITY

Made possible by support from Robert W. Woodruff Foundation

Parkinson.org
1-800-4PD-INFO (1-800-473-4636)

Conclusions: Looking Ahead

- Engagement of the Black Parkinson's community as Research Advocates is important to advancing health equity.
- Continued awareness, education and skill-building on research and patient engagement is needed as research advocates form partnerships with researchers and scientists developing treatments.
- The Parkinson's Foundation Learning Institute is a model to provide tailored training, shift perspectives, and generate excitement to help bridge the gaps in Parkinson's research and care.

References

1) Bailey M. et al (2020). Parkinson's Disease in African Americans: A Review of the Current Literature. J Parkinsons Dis. 10(3):831-841.; 2) Schneider MG . et al (2009) Minority enrollment in Parkinson's disease clinical trials. *Parkinsonism Relat Disord* 15, 258–262; 3) Feeney M, et al (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. Health Expect.(4):722-730. 5) Ladson-Billings, G. (1995) Toward a theory of culturally relevant pedagogy. *American Education Research Journal*, 32(3), 465-491

Hospital Care Learning Collaborative:
Sharing Strategies to address the Parkinson's Foundation Inpatient Clinical Care Standards

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Sheera Rosenfeld, Vice President, Chief Strategic Initiatives Officer , Parkinson's Foundation; **Katherine Amodeo, MD,** Movement Disorders Specialist Westchester Medical Center, MidHudson Regional Hospital;
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Parkinson's Foundation

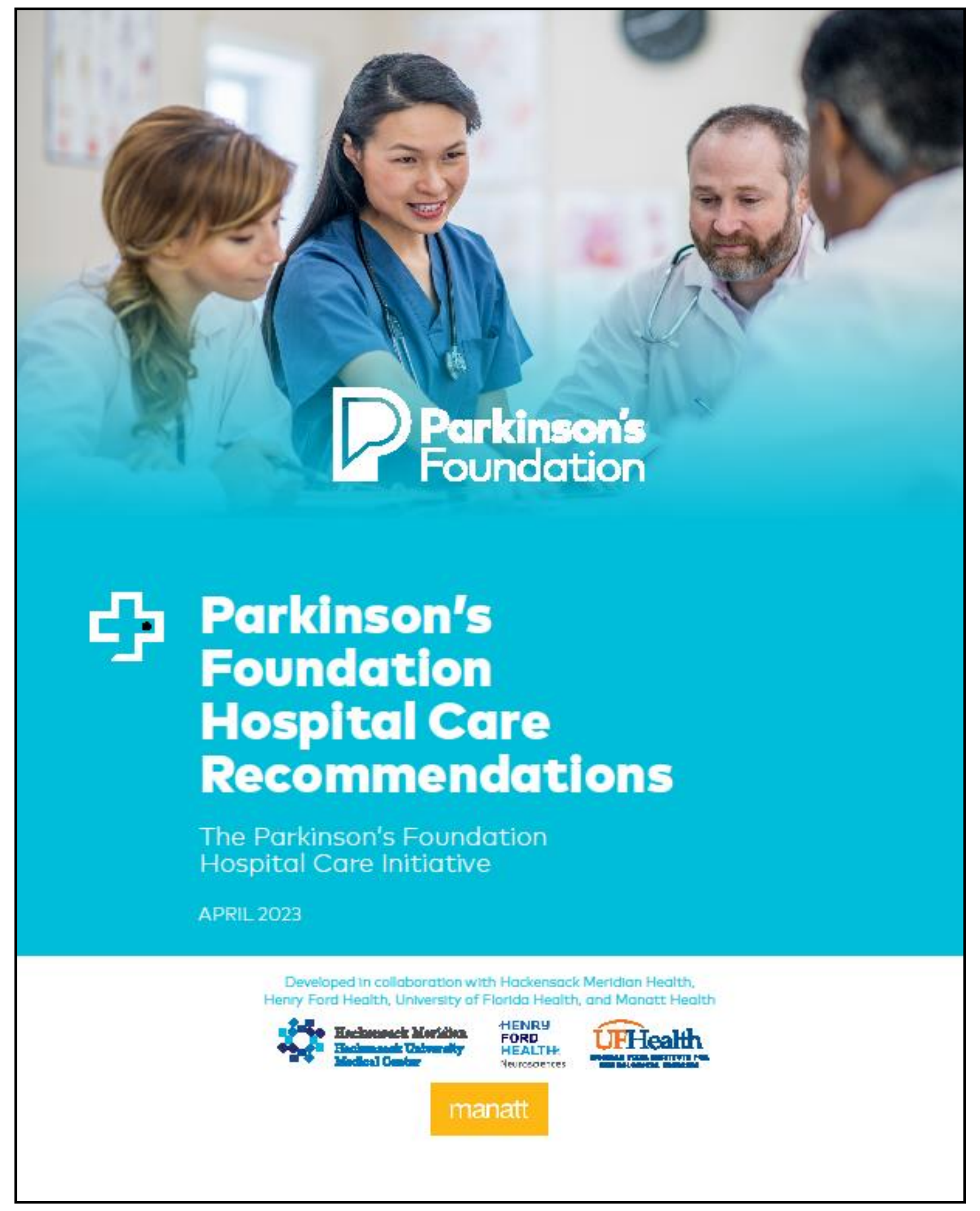
Parkinson.org

Background

The Parkinson's Foundation is committed to leading the national effort to improve hospital care and drive systemic change.

In April 2023, in partnership with *Hackensack Meridian Health, Henry Ford Health, and University of Florida Health Norman Fixel Institute for Neurological Diseases*, the Foundation released the Parkinson's Foundation Hospital Care Recommendations to address major gaps in hospital safety for people with Parkinson's disease (PD).

The Recommendations introduce five clinical care standards in areas frequently associated with preventable harm: medication management, mobility, and swallowing function.



Parkinson's Foundation

Parkinson's Foundation Hospital Care Recommendations

The Parkinson's Foundation Hospital Care Initiative

APRIL 2023

Developed in collaboration with Hackensack Meridian Health, Henry Ford Health, University of Florida Health, and Manatt Health

Objectives

The Parkinson's Foundation made another significant step toward its vision to eliminate preventable harm and promote higher reliability in care with the launch of its Hospital Care Learning Collaborative, a peer-learning group for professionals from twenty leading healthcare systems who are independently working to implement quality improvement projects focused on improving hospital safety for people with PD.

Methods

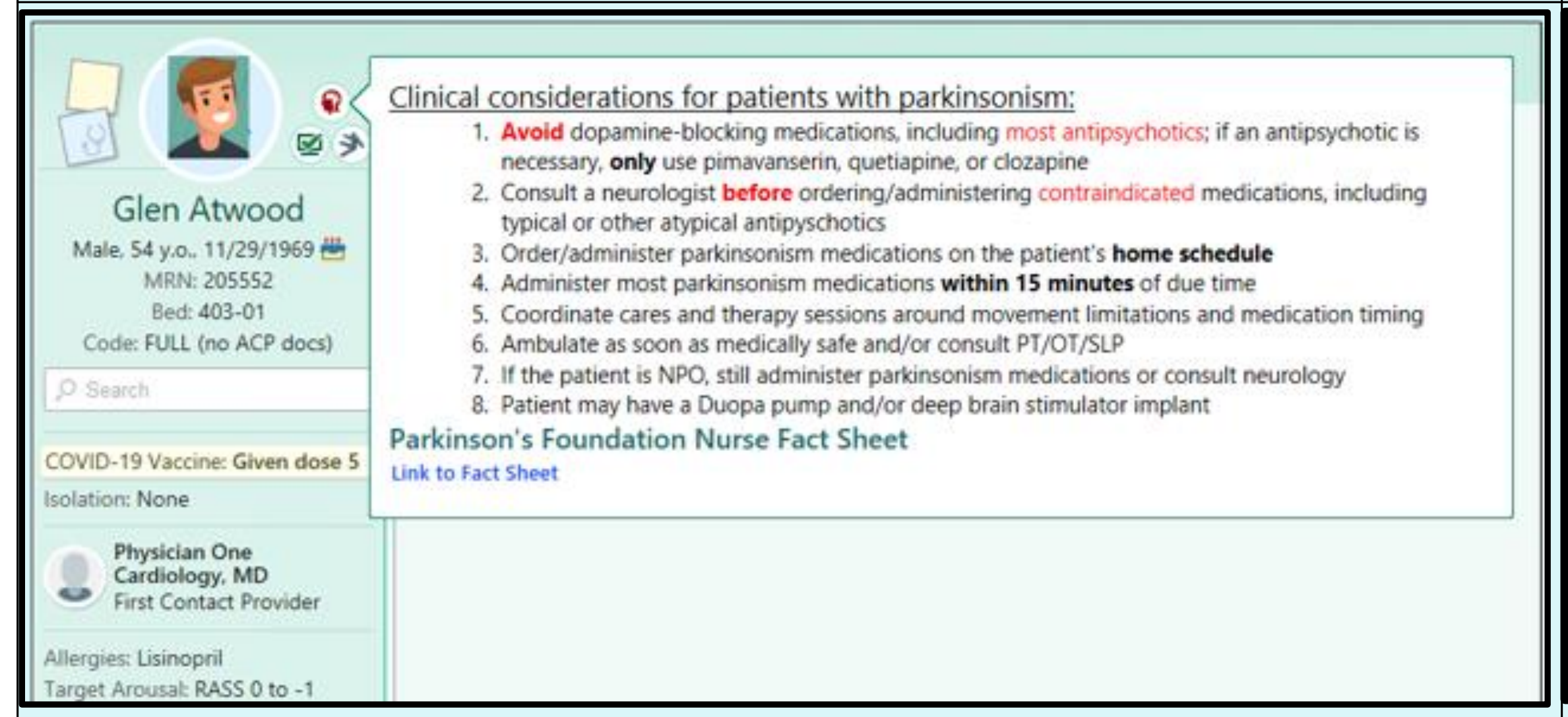
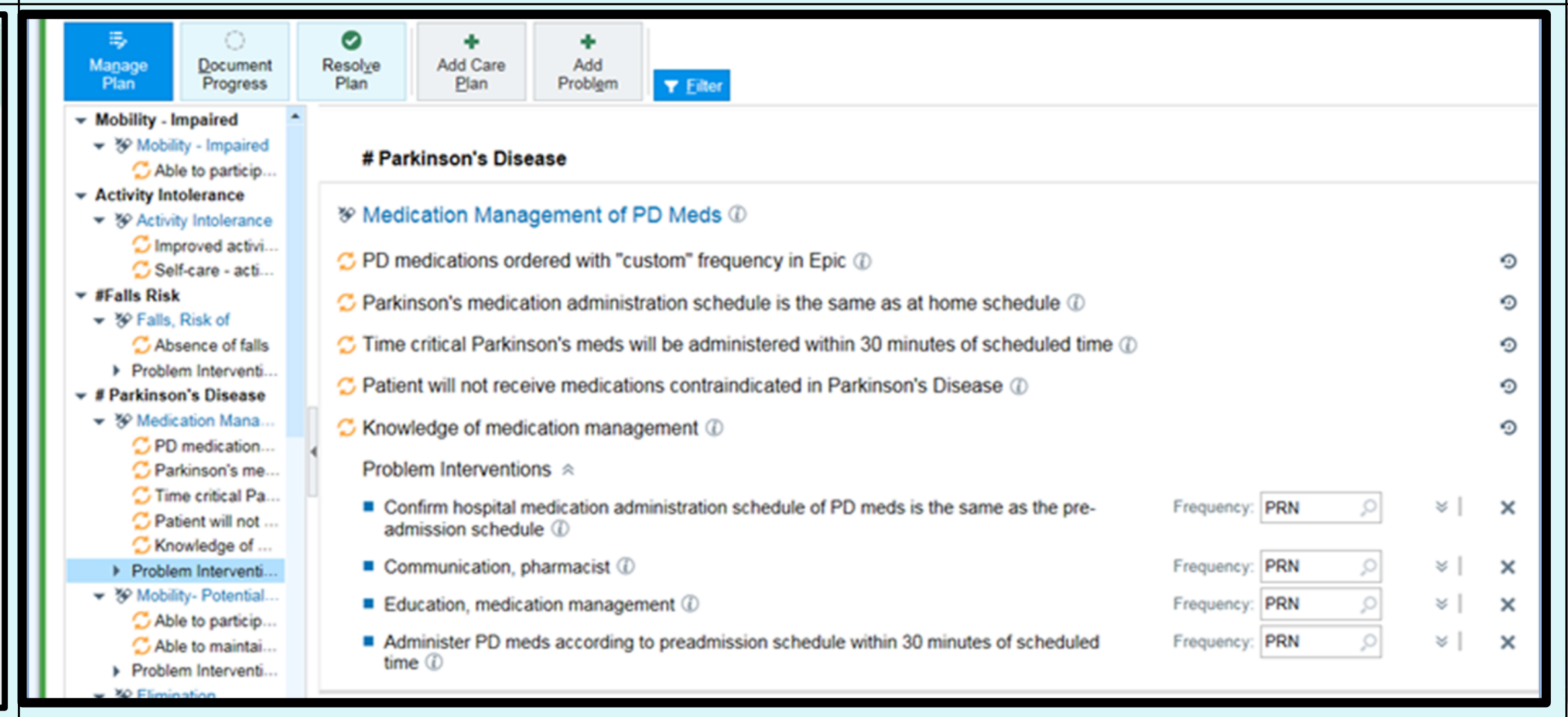
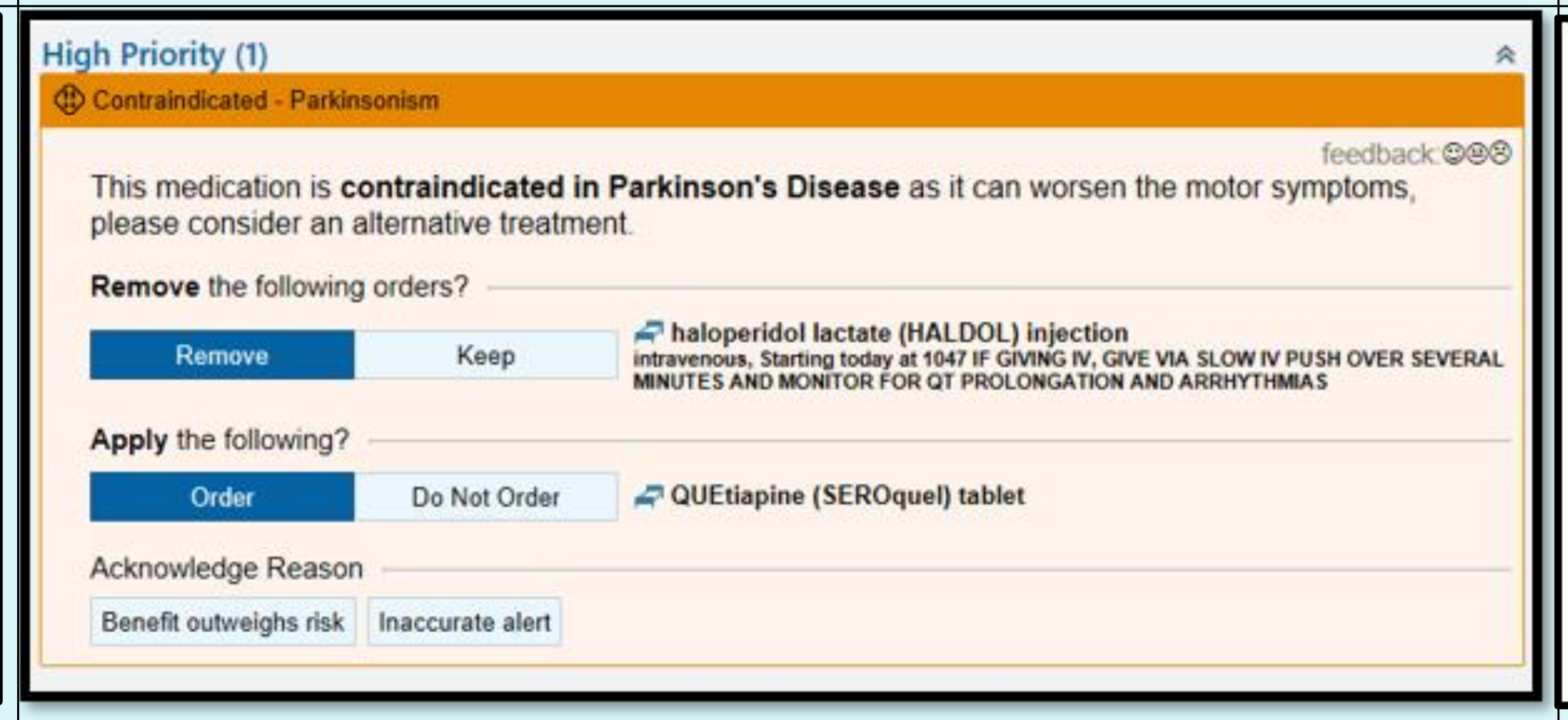
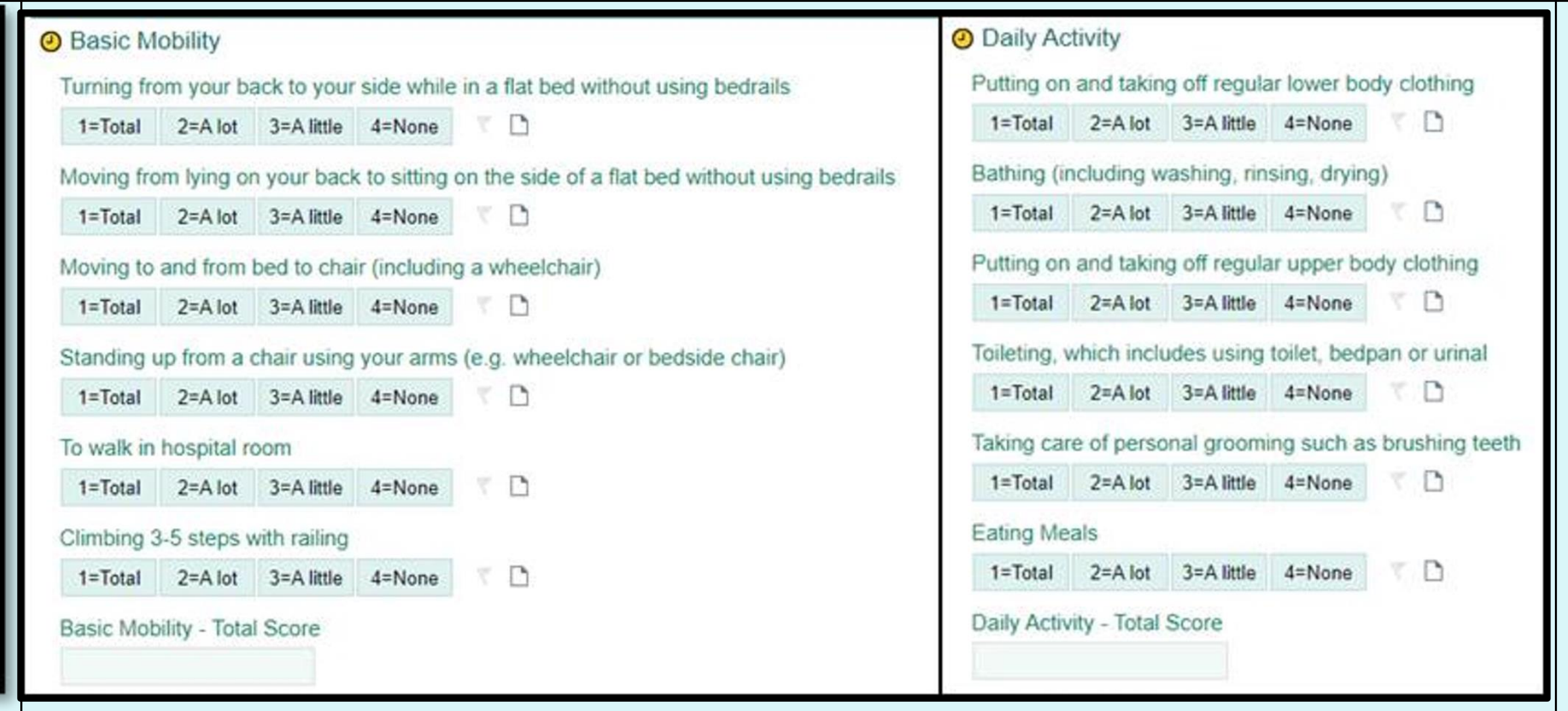
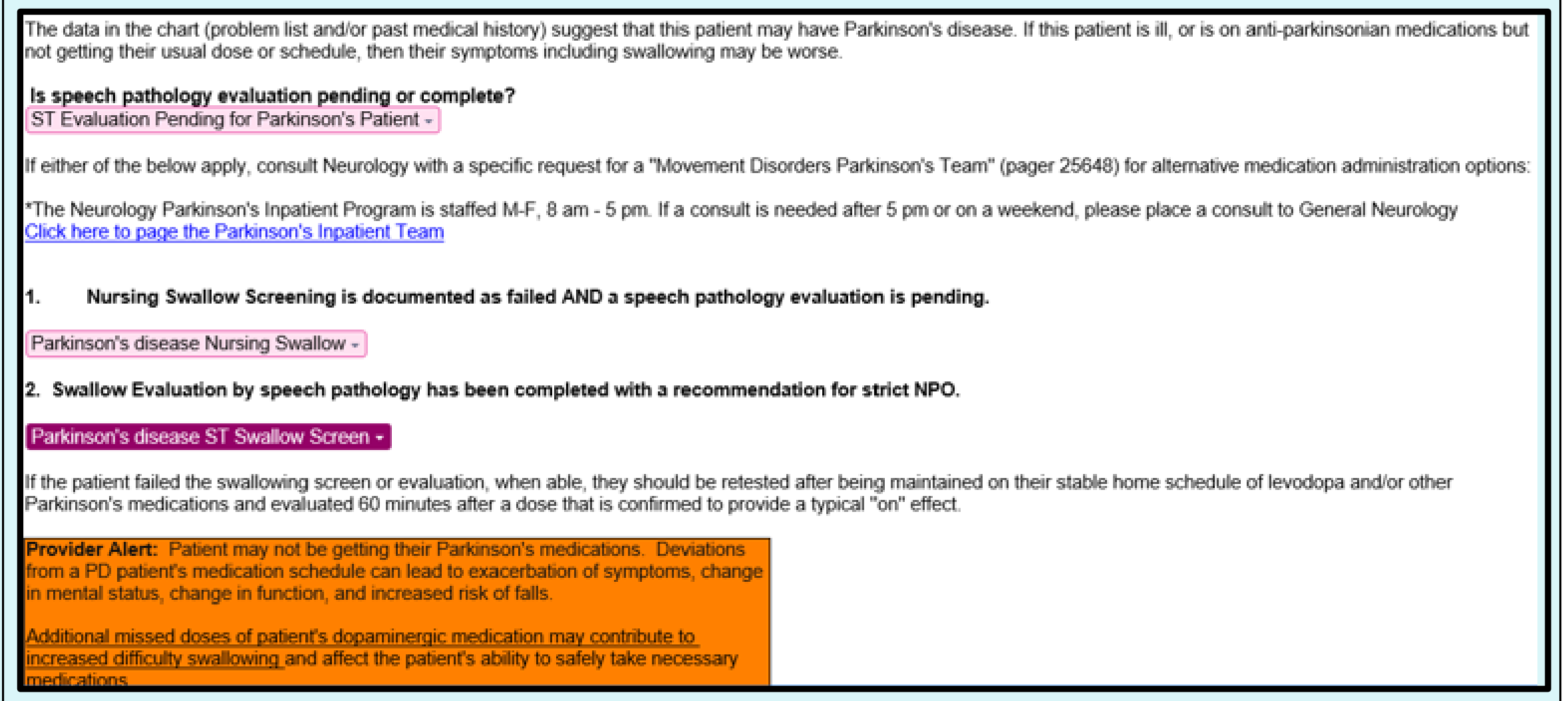
For one year, participants met bi-monthly to share strategies to address one of the five hospital care standards.

Results

Care Standards and associated strategies reviewed within the Learning Collaborative are outlined in the chart below.

Conclusion

Find the complete Recommendations along with information and tools for providers and hospital systems at: Parkinson.org/HospitalCare. Want to learn more or get involved? Email: ABrooks@Parkinson.org

Customize All Medication Orders	Prevent Medication Delays	Avoid Contraindicated Medications	Prioritize Regular Movement	Address Risk of Dysphagia/Aspiration
Allan Wu, MD shared a framework to work with IT to request EHR optimizations, including the ability to customize PD medication orders.	*Hooman Azmi, MD, FAANS* shared how quality improvement programs led by multidisciplinary teams have advanced safer care including sustained improvements in timely medication administration.	*Ryan Schell, PharmD, MMHC* shared a nuanced alert for contraindicated medications that offers alternative prescriptions as approved by the Pharmaceutical & Therapeutics committee.	*Peter Pronovost, MD, PhD, FCCM* reviewed ways to tap into existing ambulation and mobility goals to improve PD mobilization practices.	*Benjamin Walter, MD, MBA* reviewed strategies to mitigate medication delays in the event of safety concerns due to dysphagia, including the administration of crushed medication and use of an automated trigger for SLP evaluation
 Glen Atwood Male, 54 y.o., 11/29/1969 MRN: 205552 Bed: 403-01 Code: FULL (no ACP docs) COVID-19 Vaccine: Given dose 5 Isolation: None Physician One Cardiology, MD First Contact Provider Allergies: Lisinopril Target Arousal: RASS 0 to -1 Clinical considerations for patients with parkinsonism: 1. **Avoid** dopamine-blocking medications, including most antipsychotics; if an antipsychotic is necessary, **only** use pimavanserin, quetiapine, or clozapine 2. Consult a neurologist **before** ordering/administering contraindicated medications, including typical or other atypical antipyschotics 3. Order/administer parkinsonism medications on the patient's **home schedule** 4. Administer most parkinsonism medications **within 15 minutes** of due time 5. Coordinate cares and therapy sessions around movement limitations and medication timing 6. Ambulate as soon as medically safe and/or consult PT/OT/SLP 7. If the patient is NPO, still administer parkinsonism medications or consult neurology 8. Patient may have a Duopa pump and/or deep brain stimulator implant Parkinson's Foundation Nurse Fact Sheet Link to Fact Sheet	 Manage Plan · Document Progress · Resolve Plan · Add Care Plan · Add Problem · Filter Mobility - Impaired Mobility - Impaired Able to particip... Activity Intolerance Activity Intolerance Improved activi... Self-care - acti... #Falls Risk Falls, Risk of Absence of falls Problem Interventi... # Parkinson's Disease Medication Mana... PD medication... Parkinson's me... Time critical Pa... Patient will not ... Knowledge of ... Problem Interventi... Mobility- Potential... Able to particip... Able to maintai... Problem Interventi... # Parkinson's Disease Medication Management of PD Meds PD medications ordered with "custom" frequency in Epic Parkinson's medication administration schedule is the same as at home schedule Time critical Parkinson's meds will be administered within 30 minutes of scheduled time Patient will not receive medications contraindicated in Parkinson's Disease Knowledge of medication management Problem Interventions Confirm hospital medication administration schedule of PD meds is the same as the pre-admission schedule — Frequency: PRN Communication, pharmacist — Frequency: PRN Education, medication management — Frequency: PRN Administer PD meds according to preadmission schedule within 30 minutes of scheduled time — Frequency: PRN	 High Priority (1) Contraindicated - Parkinsonism feedback This medication is **contraindicated in Parkinson's Disease** as it can worsen the motor symptoms, please consider an alternative treatment. **Remove** the following orders? Remove · Keep **haloperidol lactate (HALDOL) injection** intravenous, Starting today at 1047 IF GIVING IV, GIVE VIA SLOW IV PUSH OVER SEVERAL MINUTES AND MONITOR FOR QT PROLONGATION AND ARRHYTHMIAS **Apply** the following? Order · Do Not Order **QUEtiapine (SEROquel) tablet** Acknowledge Reason Benefit outweighs risk · Inaccurate alert	 Basic Mobility Turning from your back to your side while in a flat bed without using bedrails: 1=Total · 2=A lot · 3=A little · 4=None Moving from lying on your back to sitting on the side of a flat bed without using bedrails: 1=Total · 2=A lot · 3=A little · 4=None Moving to and from bed to chair (including a wheelchair): 1=Total · 2=A lot · 3=A little · 4=None Standing up from a chair using your arms (e.g. wheelchair or bedside chair): 1=Total · 2=A lot · 3=A little · 4=None To walk in hospital room: 1=Total · 2=A lot · 3=A little · 4=None Climbing 3-5 steps with railing: 1=Total · 2=A lot · 3=A little · 4=None Basic Mobility - Total Score Daily Activity Putting on and taking off regular lower body clothing: 1=Total · 2=A lot · 3=A little · 4=None Bathing (including washing, rinsing, drying): 1=Total · 2=A lot · 3=A little · 4=None Putting on and taking off regular upper body clothing: 1=Total · 2=A lot · 3=A little · 4=None Toileting, which includes using toilet, bedpan or urinal: 1=Total · 2=A lot · 3=A little · 4=None Taking care of personal grooming such as brushing teeth: 1=Total · 2=A lot · 3=A little · 4=None Eating Meals: 1=Total · 2=A lot · 3=A little · 4=None Daily Activity - Total Score	 The data in the chart (problem list and/or past medical history) suggest that this patient may have Parkinson's disease. If this patient is ill, or is on anti-parkinsonian medications but not getting their usual dose or schedule, then their symptoms including swallowing may be worse. **Is speech pathology evaluation pending or complete?** ST Evaluation Pending for Parkinson's Patient If either of the below apply, consult Neurology with a specific request for a "Movement Disorders Parkinson's Team" (pager 25648) for alternative medication administration options: *The Neurology Parkinson's Inpatient Program is staffed M-F, 8 am - 5 pm. If a consult is needed after 5 pm or on a weekend, please place a consult to General Neurology Click here to page the Parkinson's Inpatient Team **1. Nursing Swallow Screening is documented as failed AND a speech pathology evaluation is pending.** Parkinson's disease Nursing Swallow **2. Swallow Evaluation by speech pathology has been completed with a recommendation for strict NPO.** Parkinson's disease ST Swallow Screen If the patient failed the swallowing screen or evaluation, when able, they should be retested after being maintained on their stable home schedule of levodopa and/or other Parkinson's medications and evaluated 60 minutes after a dose that is confirmed to provide a typical "on" effect. **Provider Alert:** Patient may not be getting their Parkinson's medications. Deviations from a PD patient's medication schedule can lead to exacerbation of symptoms, change in mental status, change in function, and increased risk of falls. Additional missed doses of patient's dopaminergic medication may contribute to increased difficulty swallowing and affect the patient's ability to safely take necessary medications
Epic Turbocharger	*Nursing Careplan*	*Best Practice Advisory Alert*	*Nursing Admission Navigator*	*Dynamic Note Template*