

BLAAC PD Bulletin

Volume 4

A newsletter for study participants

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About BLAAC PD

Black and African American Connections to Parkinson's Disease (BLAAC PD) is a research study. It collects information on health, disease and genes. The study aims to learn more about gene changes that may cause Parkinson's in Black and African American people. BLAAC PD is happening at sites around the United States.

The study is part of the Global Parkinson's Genetics Program (GP2). GP2 is a research project working to transform understanding of Parkinson's genetics.

BLAAC PD by the Numbers



1,185
participants enrolled
(as of November 2025)



11
active sites



**Goal to enroll
at least
2,000 participants**

Reaching 1,000 Participants



Building the Largest Cohort of Black and African American Participants in Parkinson's Research

Your commitment and trust have helped us achieve an incredible milestone: **1,000+ participants enrolled in BLAAC PD!** Every person who joins brings us closer to breakthroughs in Parkinson's research and ensures diverse voices shape the future of care.

Since its launch in 2021, BLAAC PD has been an evolving collaboration:

- > Adding genetic data from individuals of African descent and those with blended African ancestry to the global map
- > Refining protocols based on discoveries like the novel *GBA1* variant
- > Testing new strategies to overcome systemic barriers to recruitment

This progress is part of a global effort through GP2, advancing genetic discovery and inclusion worldwide.

Naomi Louie, Senior Clinical Operations Specialist at the Michael J. Fox Foundation, shares how BLAAC PD grew in 2025 and is fostering diversity in research. Learn more about BLAAC PD and its role in shaping the future of Parkinson's research.



Visit bit.ly/3Nc3Wz0 or scan the QR code.

This timeline marks the milestones that helped BLAAC PD grow to over 1,000 participants

2021 – Launch

October 2021: BLAAC PD begins under GP2 to close gaps in Parkinson’s genetics research.

Four pilot sites: University of Chicago, Kaiser Mid-Atlantic, Rush University and University of Alabama at Birmingham lay the foundation for inclusive discovery.

2023 – Expansion & Breakthrough

February 2023: The study grows to six sites, adding Louisiana State University and University of Florida.

August 2023: Researchers identify a gene change in some people with Parkinson’s disease. This [change in the GBA1 gene](#) was found in people of African descent, with data from BLAAC PD participants contributing to the discovery. This finding helps researchers better understand genetic risk factors for Parkinson’s disease and may help guide future treatments, underscoring why diversity in research matters.

Late 2023 – Doubling Our Reach

December 2023: With 461 participants enrolled, the study sets a goal to expand to reach more people and communities. The number of study sites is doubled. Six new sites join to help meet recruitment targets: Medical University of South Carolina, Ochsner Health, University Hospitals Cleveland Medical Center, University of Maryland, UTHealth Houston, and Washington University in St. Louis.

2024 – Sharing & Improving

April 2024: A new demonstration project launches at three study sites to test recruitment strategies that aim to strengthen engagement. Lessons learned will help inform approaches across all BLAAC PD sites and may serve as a model for other Parkinson’s studies working to reach underrepresented communities.

October 2024: The BLAAC PD protocol – the roadmap of the study – publishes in a scientific journal, *BMC Neurology*. The publication outlines strategies to make participation easier and reduce barriers for volunteers.

December 2024: BLAAC PD introduces smell testing to learn more about the link between smell loss and Parkinson’s disease.

2025 – Refining & Reaching Milestones

February 2025: The study adds three more study assessments regarding cognition, sleep health and environmental exposures. This helps deepen understanding of Parkinson’s.

August 2025: BLAAC PD enrolls 1,000 participants, marking the study as the largest known cohort of Black and African American individuals with genetic data for Parkinson’s research.

Faces of BLAAC PD

Faces of BLAAC PD acknowledges the people behind the progress – participants and site leaders whose stories inspire trust, representation and a shared commitment to advancing Parkinson’s research.



When Toney Matthews of St. Louis was diagnosed with Parkinson’s disease (PD) in 2023, she was stunned. After years of unexplained symptoms and misdiagnoses, the news left her in shock and denial.



Visit bit.ly/4syLZLc or scan the QR code to learn more about Toney’s story.

“I was lost when I first began my PD journey,” Toney says. “The BLAAC PD study gave me courage to embrace PD, help myself, and devote myself to research that will help Black patients.”

Toney discovered BLAAC PD through a local event and soon enrolled in the study at Washington University in St. Louis. She appreciated the study team’s care and transparency: “They explained every step and made sure I was comfortable.”

Today, Toney serves on WashU’s BLAAC PD Community Advisory Board, helping others find answers and overcome fear. “There’s hesitation in our community, but research like this improves lives and moves us closer to a cure.”



When **Erin Foster**, PhD, OTD, OTR/L, FAOTA, began her career in occupational therapy, she was drawn to helping older adults live fuller lives. Over time, her curiosity about the brain led her to Parkinson’s research – and to a major gap she couldn’t ignore: how thinking and memory changes affect daily life.

“Standard tests tell us something, but they don’t show what happens when someone cooks a meal or pays bills,” Dr. Foster explains. “Real life is more complex.”

Today, Dr. Foster co-leads the BLAAC PD site at Washington University in St. Louis, where she and her team work to make research accessible and culturally respectful. “Representation matters,” she says.

“When communities are left out, we miss critical information about how Parkinson’s affects different groups and which treatments work best.”

Erin believes that when research reflects everyone affected by Parkinson’s, it moves us closer to better care and a cure for all.

Inspired by Toney’s journey? Share your story at michaeljfox.org/story and help others see the impact of research.

BLAAC PD in the Community



Black & African American
Connections to
Parkinson's Disease Study

BLAAC PD in the Community highlights how study sites are taking Parkinson's research beyond the clinic and into the community. In this bulletin, we spotlight Louisiana State University (LSU) Health Shreveport's outreach efforts, from community education and media engagement to building new care and research pathways for diverse populations.

1 Connecting with the Community at a Senior Day Expo

The LSU Shreveport BLAAC PD team connected with 2,500 attendees at a senior day expo, sharing resources and conversations about Parkinson's prevention.

2 Talking Parkinson's Disease, Early Care and Inclusive Research

Elizabeth Disbrow, PhD and Harlene Kaur, MD of the LSU Shreveport study team joined *The Best of Times Radio Hour*, a talk-show based out of Shreveport, Louisiana. They shared insights on Parkinson's disease, from early symptoms to the latest treatments. They emphasized the importance of timely evaluation, noting that "early diagnosis is key for symptom management and quality of life." The discussion also highlighted LSU Shreveport's commitment to research diversity through BLAAC PD and its role in advancing genetic studies for underrepresented communities. When asked why they do the work they do, Dr. Disbrow shared, "Finding a cure for



Parkinson's disease is going to require data from everyone."

Visit bit.ly/4jvdLnE or scan the QR code to listen to the podcast

3 New Patient Clinic with Care Navigation

LSU Shreveport is building a multidisciplinary clinic designed to support patients from diagnosis onward. The clinic offers personalized care navigation, connecting individuals to medical and non-medical resources, including specialists, therapy options and assistance with paperwork. As Dr. Disbrow explained, "We're building a one-stop shop for care and resources — medical and non-medical." This model ensures patients receive comprehensive guidance and reduces barriers to quality care.



GP2 is a resource of the Aligning Science Across Parkinson's initiative and implemented by The Michael J. Fox Foundation for Parkinson's Research.

blaacpd.org