Black & African American Connections to Parkinson's Disease Study

BLAAC PD Bulletin

A newsletter for study participants

asap Aligning Science Across Parkinson's

gp2 Global Parkinson's Genetics Program

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

About BLAAC PD

Black and African American Connections to Parkinson's Disease (BLAAC PD) is a research study. 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 the understanding of Parkinson's genetics.

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Genetic Link Found Between REM Sleep Behavior Disorder and Parkinson's Disease in Nigeria

GP2 collects data from studies at 60 locations across the globe. One of those studies is in Nigeria. GP2 researchers used study data to see if the *GBA1* variant was associated with REM sleep behavior disorder (RBD). They looked at data from participants with and without Parkinson's disease in Nigeria. This genetic variant is a small change in the DNA that can influence how certain proteins function in the body. To learn more about the *GBA1* variant in people of African ancestry, read BLAAC PD's last newsletter available at **bit.ly/blaac-pd-participants**.

What is RBD?
RBD is a condition where individuals act out their dreams during the REM (rapid eye movement) stage of sleep. This can sometimes lead to injury as people might kick, punch or jump out of bed while still asleep.

What were the key findings?

- People with Parkinson's disease of Nigerian origin who have the *GBA1* variant are more likely to experience RBD.
- The connection between this genetic variant and RBD remained strong even after accounting for factors like age and sex. This indicates that the variant could play a role in the development of RBD in people with Parkinson's disease.
- Understanding this risk may help doctors in the future better identify and manage RBD in people with this risk variant.

Why is this important?
This discovery highlights the importance of studying genetic factors in Parkinson's disease within diverse populations. By focusing on gene changes that may cause Parkinson's in Black and African American individuals, we aim to improve identification and treatment of the disease in our communities.

For more information, read the full article (**bit.ly/gba-rbd-paper**).

New Addition to Study Visits: The Smell Test

Our sense of smell plays an important role in monitoring brain health as we age. Research, primarily in people of European descent, shows that ongoing smell loss as we age can be a sign of early cell damage associated with brain disease, including Parkinson's. Testing for smell loss may help diagnose and treat brain disease earlier in the future.

BLAAC PD aims to learn if these trends carry in Black and African American people.

7 IN 10

People living with smell loss don't know it until they are tested

Parkinson's disease
Alzheimer's disease
Huntington's disease
Multiple Sclerosis

100%

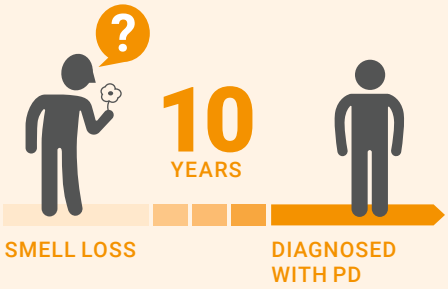
of major brain disorders are associated with smell loss

1 IN 2

People over age 60 may be living with smell loss

96%

of newly diagnosed people with Parkinson´s have lost some ability to smell



Smell loss may precede a Parkinson's diagnosis by up to 10 years

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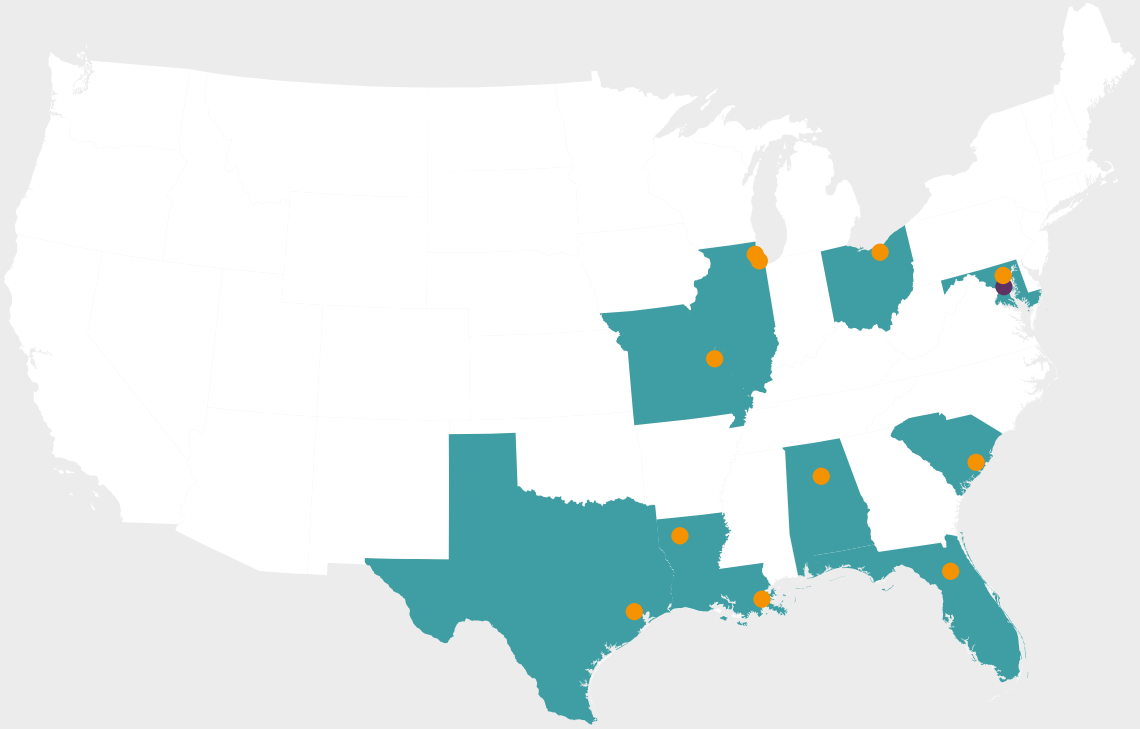
BLAAC PD on the Map

BLAAC PD is adding more sites in the U.S. to partner with more study volunteers. Data from this study joins the Global Parkinson's Genetics Program, learning more about drivers of disease with cohorts in 60 countries.

Currently, there are 11 sites across the United States collecting valuable data and samples from volunteers like you:



BLAAC PD Site Locations:

Alabama — *Birmingham*
Florida — *Gainesville*
Illinois — *Chicago (2 sites)*
Louisiana — *Shreveport and New Orleans (2 sites)*
Maryland — *Baltimore and Largo (inactive)*
Missouri — *St. Louis*
Ohio — *Cleveland*
South Carolina — *Charleston*
Texas — *Houston*

Better Brain Health

BLAAC PD partner The Michael J. Fox Foundation offers free educational resources. These materials help people and families navigate Parkinson's and boost brain health.

Better Brain Health is a guide that offers practical tips for boosting brain health and limiting risk. It also highlights the latest advances in brain research and the critical role we all play in moving research forward.

From the guide, here we share four tenets for a healthy brain:

1. **What's good for your body is good for your brain.**
Exercise and a balanced diet are good for your brain. Simple activities like walking and eating fruits and vegetables can boost brain health.

2. **Change is a normal part of getting older; disease is not.**
Aging brings changes, but diseases like Parkinson's or Alzheimer's are not normal. Learn the signs and talk to your doctor about any changes.

3. **Connection keeps your brain healthy.**
Positive relationships and social interactions are crucial for brain health. Stay in touch with friends and family, but limit time on social media.

4. **The answers to better brain health and care are in you.**
You are already helping researchers by sharing your experience in BLAAC PD. Participation in research can lead to better treatments and understanding of brain health.

Learn about this and more in the full ***Better Brain Health* guide** (michaeljfox.org/brainhealth).

Making an Impact on the Parkinson's Community

Dominique "Dom" Thomas, BLAAC PD coordinator at Ochsner Health in New Orleans, is on a mission. She aims to reach more people with Parkinson's in Louisiana and connect them with support and research opportunities.

Dom recognizes the challenges and opportunities of engaging Black and African American people in research.

Dominique Thomas, third from left, with other members of the Ochsner team.

"Themes of racial disparities between Black and African Americans and research studies have had a tremendous effect on the community," says Dom. "It's important to demystify research and have honest conversations with patients and families. I often talk with them about the impact they can have in the search for new treatments."

BLAAC PD wants to hear from participants like you! The study aims to share stories and connect participants with opportunities such as taking part in a focus group.
*Please **fill out a form** (michaeljfox.org/shareyourstory) or email patientengagement@michaeljfox.org to learn more.*

Dom has worked with the Parkinson's community in the New Orleans area since 2012. Recently, she planned a symposium that reached over 250 people and families with Parkinson's.

"We become family," Dom says. "You build relationships and get to know participants and what's happening in their lives."

Thank you, Dom, for all you do for BLAAC PD and the Parkinson's community!

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

Learn more about GP2 at gp2.org.
Learn more about BLAAC PD at blaacpd.org

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