

BLAAC PD Bulletin

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.

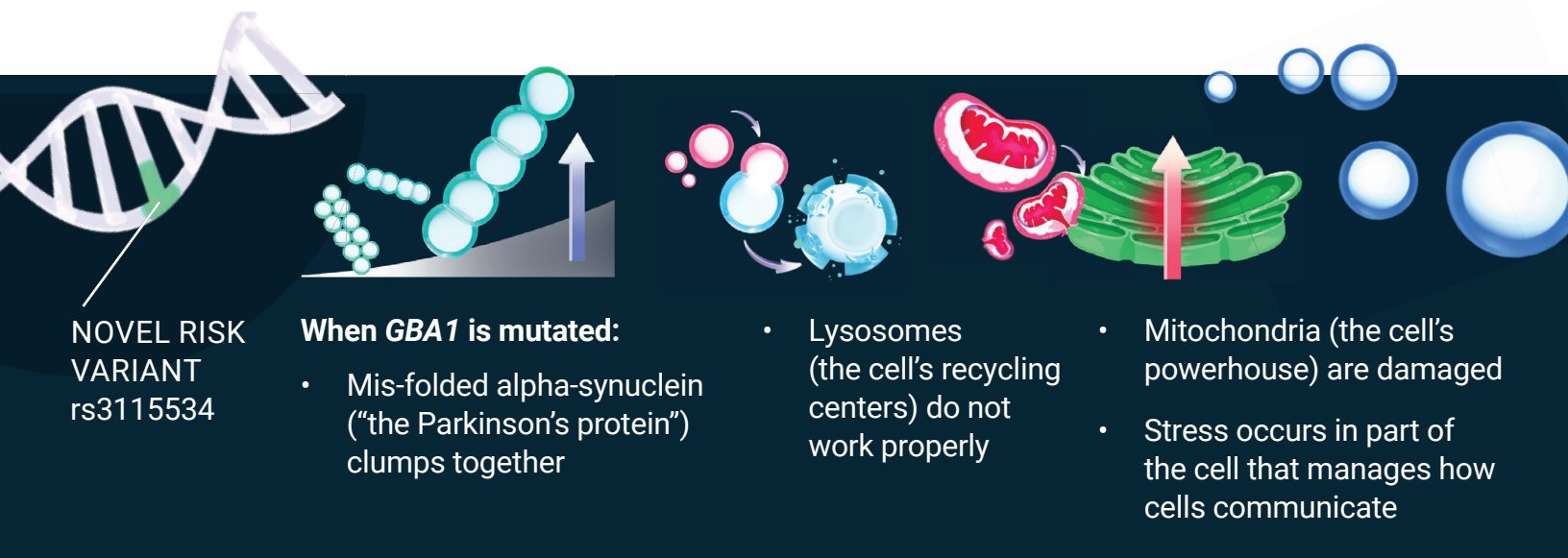


Thanks to You, New Parkinson's Genetic Risk Factor Discovered in African Populations

Editor's Note: In August 2023, GP2 scientists published this finding in The Lancet Neurology. Read the paper at bit.ly/gba1.

The GP2 study — that BLAAC PD contributes to — found a gene change in some people with Parkinson's disease. The change is in the *GBA1* gene.

But what is the *GBA1* gene? The *GBA1* gene tells the body how to make a protein called GCase. The GCase protein plays a role in the cell's "recycling center." This part of a cell removes damaged or faulty cell parts. Changes in the *GBA1* gene can reduce GCase activity, which means the cell's recycling center doesn't work correctly. Without that function, damaged or faulty cell parts can build up, harming the cell. Scientists believe this build-up may lead to the cell death that causes Parkinson's symptoms in people with a *GBA1* change, but more research is needed.



This change in the *GBA1* gene was found in people with African ancestry. The finding is from genetic information shared by BLAAC PD participants like you and from another study in Nigeria, primarily. (While having this variant may increase risk of Parkinson's, it does not guarantee disease.)

Thanks to your contributions, we are starting to understand causes of Parkinson's in people of African descent.

As scientists learn more about this gene change, there may be other findings. Some gene changes may be linked to faster or slower progression or to certain symptoms. That information could help doctors monitor disease more closely. It may help you make lifestyle choices as well. You may decide to exercise more or change your diet.

This finding also shows the importance of partnering with people of many backgrounds.

Most genetics studies have been in people of European descent. This finding shows scientists have more to learn by working with diverse groups.

There are treatments currently in testing to correct *GBA1* and GCase function in Parkinson's disease. The scientists who found the gene change in people of African descent are talking to the researchers testing these treatments. They may decide to open their trials to test for this new *GBA1* gene change.

Right now, your doctor cannot tell you if you have this variant. There are tests that share information on other changes in the *GBA1* gene. (Not all genetic tests look for all variants.)

Scientists can now learn more about this newly discovered *GBA1* variant. Soon it may be added to those existing *GBA1* tests.

In the future, you may be able to help test new treatments.

Thank you for playing a critical role toward better understanding of Parkinson's genetics. By learning how Parkinson's starts in people from all backgrounds, we get closer to stopping it.

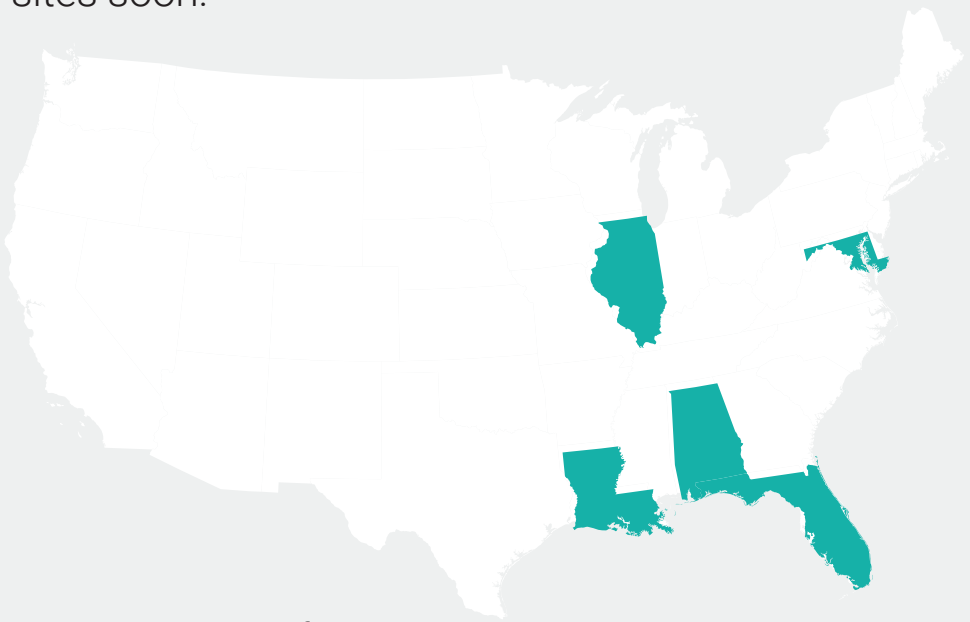
Learn more about this finding and Parkinson's genetics at michaelfox.org.

BLAAC PD on the Map

Six sites across the United States are collecting valuable data and samples from volunteers like you. And BLAAC PD is expanding! The study will add more sites soon.

BLAAC PD Site Locations:

- Alabama – *Birmingham*
- Florida – *Gainesville*
- Illinois – *Chicago (2 sites)*
- Louisiana – *Shreveport*
- Maryland – *Largo*



BLAAC PD is part of GP2. GP2 is gathering genetic information from groups with different backgrounds. Learn more at gp2.org.

Spreading the Word about Parkinson's

By Jaronda Little, age 52, fine arts school
outreach officer, Birmingham, Alabama



Editor's Note: Since Jaronda's enrollment in BLAAC PD, the study has changed its eligibility criteria. Parents, siblings or children of people with Parkinson's are no longer eligible for BLAAC PD. This helps scientists more accurately understand gene changes in Black and African American people with and without Parkinson's.

I'd never even heard of Parkinson's disease until my mother was diagnosed in 2006.

I saw firsthand what Parkinson's can do to a person. I enrolled in BLAAC PD because there's still no treatment that can stop progression of the disease, and there's so much to learn. Anything I can do to help researchers find out why it exists, how to treat it, or even how to prevent it, I'll do. After I gave blood, I went through my contacts and emailed everyone — 30 people at a time — asking them to participate.

I know it's not a guarantee that just because my mother had Parkinson's, I'll get it. But I am passionate about helping researchers find a cure, not just for myself but because I don't want anyone to experience Parkinson's the way my mom did. I hope treatments can be found so others will have a better quality of life.

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