



The Black Church Joins the Fight Against Parkinson's Disease and is Working Toward a Cure



BlackParkD News

Parkinson's disease (PD) is the world's fastest growing progressive neurodegenerative brain disease. An estimated one million people in the U.S. are living with PD.



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President of National Black
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**Ministers are not Doctors.*



Dr. Elena Rios
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The National Black Church Initiative, a Coalition of 150,000 Black Churches, is Joining with The Michael J. Fox Foundation in Raising Awareness of Parkinson's Disease and Research

This is part of the NBCI National Black Health Agenda

The National Black Church Initiative (NBCI), a coalition of 150,000 African American churches and 27.7 million members, is launching a new program supported by [The Michael J. Fox Foundation for Parkinson's Research \(MJFF\)](http://www.michaeljfox.org/) - www.michaeljfox.org/ to raise awareness of Parkinson's disease and research opportunities in the African American community. The pilot program, launching in Houston, Texas and St. Louis, Missouri, will engage NBCI members in educational programming and connect congregants to Parkinson's care and research resources.

MJFF, the largest nonprofit funder of Parkinson's research, runs many programs to broaden our understanding of the disease. Notably, the Foundation supports the [Global Parkinson's Genetics Program](https://gp2.org/) - <https://gp2.org/>, a resource of the [Aligning Science Across Parkinson's initiative](http://parkinsonsroadmap.org/) - parkinsonsroadmap.org/. This program collects data and samples from more than 220 studies in over 60 locations on six continents to uncover more about genetic drivers of Parkinson's disease. [The Black and African American Connections to Parkinson's Disease](http://www.blaacpd.org/DJYD/) - www.blaacpd.org/DJYD/ study is one contributing study. It is recruiting at 11 U.S. sites, including in Houston and St. Louis.

"The Michael J. Fox Foundation is committed to driving cures for all people with Parkinson's disease," says Alyssa O'Grady, MJFF Head of Clinical Research. "We are grateful for this partnership with the National Black Church Initiative to educate, engage and empower the African American Parkinson's community toward better care and research participation. Momentum is building toward new treatments; only with partners from all backgrounds will we fully realize a future without this disease."

African Americans and Parkinson's Disease

Currently, about one million people in the US have Parkinson's disease (PD). The prevalence of PD in the Black and African American community is not exactly known. This is partly due to limited inclusion of Black and African American people in research studies. Approximately 6% of all PD clinical trial participants are "non-White".

African Americans are about half as likely to be diagnosed with PD as their White counterparts. When diagnosed, they are often at a later stage in their disease than their White counterparts. Appropriate and representative participation in research will improve understanding of how PD impacts the Black and African American community.



What is Parkinson's Disease

Parkinson's disease (PD) is a progressive movement disorder of the nervous system. It causes nerve cells (neurons) in parts of the brain to weaken, become damaged, and die. This leads to symptoms like movement problems, tremor, stiffness, and impaired balance. As symptoms progress, people with PD may have difficulty walking, talking, or completing simple tasks.

Who is at risk for Parkinson's Disease

Although the cause of most Parkinson's disease cases is unknown, researchers believe it is caused by multiple factors. Some of these risk factors include:

- **Aging.** The greatest risk factor for PD is aging, and researchers expect the number of people with PD to double by 2040 due to an aging population.
- **Environment.** Factors like head injury, pesticide exposure or stressors of military service (like traumatic brain injury or exposure burn pits) are associated with an increased risk of developing PD
- **Genetics.** Researchers estimate about 30% of PD risk is explained by genetics. Several genes increase the risk of Parkinson's disease (PD) but don't guarantee the disease.
 - o In 2023, [researchers found a GBA gene variant - tinyurl.com/yj78bdy3](https://www.tinyurl.com/yj78bdy3) that raises PD risk in people of African ancestry.

The Michael J. Fox Foundation and Aligning Science Across Parkinson's (ASAP) is working on the Global Parkinson's Genetics Program (GP2) and its study, [Black and African American Connections to Parkinson's Disease - www.blaacpd.org/DJYD/](https://www.blaacpd.org/DJYD/) (BLAAC PD). BLAAC PD is currently enrolling Black and African American individuals with or without PD nationwide. Visit www.blaacpd.org to learn more and join!

Symptoms of Parkinson's disease (PD)

Symptoms of PD look different in different people. If you think you might have symptoms of PD, it's important to visit a neurologist or movement disorder specialist.

Some symptoms of PD are **motor symptoms**, like:

- **Stiffness**, or rigidity – where someone may experience muscle stiffness
- **Slowness**, or bradykinesia – where someone may experience decreased spontaneous and voluntary movement. This could look like slower walking, less arm swinging while walking, or decreased blinking or facial expressions
- **Resting tremor** – where someone may experience a rhythmic, involuntary shaking that occurs in a finger, hand or limb when relaxed and disappears during voluntary movement.

Other symptoms are non-motor symptoms, sometimes called the “invisible” symptoms of PD:

- **Non-movement symptoms**
 - o Constipation
 - o Low blood pressure
 - o Sexual, sweating, and urine problems
- **Mood and thinking changes**
 - o Apathy (lack of interest)
 - o Cognitive (memory or thinking) problems
 - o Mood disturbances

Disparities in Parkinson's Disease

- African Americans with neurological diagnoses are less likely to see neurologists. Newly diagnosed African Americans with PD are less likely to receive physical therapy or medications at their first appointment.
- African Americans with Parkinson's Disease have higher rates of dementia diagnosis and lower rates of survival
- African Americans are less likely to receive deep brain stimulation

PD in The News

Parkinson's research advocate Richard Huckabee, age 65, shared his story with the leading scientific outlet [STAT - tinyurl.com/46w-bx9mb](https://www.tinyurl.com/46w-bx9mb) about the challenges he faced in his nearly decade-long journey to receive a diagnosis and access care. As a Black man, Richard experienced ongoing disparities when, alongside his wife Angela, they sought answers from multiple physicians: “We don't fit the profile. Some of the doctors said I'm taking it too serious. Some of them said, 'There's nothing wrong with you.'” [Read the full article here - tinyurl.com/46wbx9mb](https://www.tinyurl.com/46wbx9mb).

