

THE NIH SAYS PARKINSON'S DISEASE IS A PROGRESSIVE MOVEMENT DISORDER OF THE NERVOUS SYSTEM. THERE ARE 1,000,000 PEOPLE LIVING WITH PARKINSON DISEASE.

PRESENTLY, THERE IS NO CURE.

THIS IS A PART OF NBCI NATIONAL BLACK AGENDA



Rev. Anthony Evans
President of National Black Church Initiative
**Ministers are not Doctors.*



Dr. Elena Rios
President & CEO of the National Hispanic Medical Association, (NHMA)



Dr. Virginia A. Caine, M.D.
President of the National Medical Association
Member of the Regenstrief Institute Board of Directors



Dr. Joseph Webster, MD
Internist and Gastroenterologist
Institute for African American Health, Inc.
Tallahassee, Florida

African Americans and Parkinson Disease Statistics

Incidence: The 4-year incidence of PD is 23 per 100,000 person-years for African Americans, compared to 54 per 100,000 person-years for whites. Three hundred nineteen incident PD cases were identified. The 4-year incidence of PD was 54 per 100,000 person-years for whites, 23 per 100,000 person-years for African-Americans and 40 per 100,000 person-years for Latinos. This translates to a 4-year cumulative risk of PD that was 0.18%.

Treatment: African Americans are less likely to receive medication or physical therapy than white patients.

Diagnosis: Black patients are 30% less likely to see a neurologist than white patients, even after adjusting for insurance status.

Survival: African Americans have the lowest rates of survival among racial groups studied, as well as the highest rates of dementia.

Cognitive abnormalities: African Americans with Parkinsonism may have more cognitive abnormalities than white patients with Parkinsonism.

Other factors that may affect the prevalence of PD in African Americans include:

Poverty: In one study, 37.6% of Black/African Americans below the poverty level were diagnosed with PD.

Location: Prevalence and incidence of PD are greater in urban counties than in rural ones.

Reverend Jesse Jackson Diagnosed with Parkinson's Disease

Rev. Jesse Jackson's announcement today that he has been living with Parkinson's Disease since 2015 further proves that receiving a diagnosis of Parkinson's is not a death sentence.

There are many ways that people living with Parkinson's can control the symptoms of the disease with exercise and physical therapy to help maintain mobility and balance.

"We have over the years advised people in the public spotlight and those who have rigorous travel schedules to carefully plan the timing of Parkinson's medication dosages," said Michael Okun, M.D., National Medical Director of the Parkinson's Foundation. "Exercise, planning and regular follow-up with a Parkinson's disease specialist is the secret to remaining active and maintaining a high quality of life with Parkinson's."



NBCI encourages people living with Parkinson's and their families to seek expert care from a neurologist. With support and expert care, Parkinson's can be managed. In addition to exploring the website michaeljfox.org

What is Parkinson's disease?

Parkinson's disease 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, leading to symptoms that include problems with movement, tremor, stiffness, and impaired balance. As symptoms progress, people with Parkinson's disease (PD) may have difficulty walking, talking, or completing other simple tasks.

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

This is a 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) 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, a resource of the Aligning Science Across Parkinson's initiative. 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 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."

Who is Most Likely to Get Parkinson's Disease?

Risk factors for PD include:

- **Age.** The average age of onset is in a person's early to mid-60s, and the incidence rises significantly with older age. However, a small percent of people with PD have "early-onset" Parkinson's disease, which begins before the age of 50.
- **Biological sex.** PD affects more men than women.
- **Heredity.** People with one or more close relatives who have PD have an increased risk of developing the disease themselves.
- **Environmental exposure.** Studies show an increased risk of PD in people who live in rural areas where exposure to pesticides is common. Exposure to certain toxins has caused parkinsonian symptoms in rare circumstances (such as exposure to MPTP, an illicit drug—or exposure to the metal manganese in welders).



While the exact cause of PD is unknown, some cases are hereditary and can be traced to specific genetic mutations. . Most cases are sporadic, meaning they arise with no known cause. Researchers think that PD likely results from a combination of genetics and exposure to one or more (mostly unknown) environmental factors that trigger the disease.

Several genetic mutations are associated with PD, including the alpha-synuclein gene, and many more genes have been linked to the disorder. The same genes and proteins that are altered in inherited cases may also be altered in sporadic cases by environmental toxins or other factors, including inflammation.

- **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 had lowest rates of survival and highest rates of dementia diagnosis.**
- **African Americans with neurological diagnoses are less likely to see neurologists, more likely to have more hospital stays and more emergency room visits.**



Symptoms of Parkinson’s disease

PD affects different people in different ways. The rate of progression and the particular symptoms differ among individuals. PD symptoms typically begin on one side of the body. However, the disease eventually affects both sides, although symptoms are often less severe on one side than on the other. The four primary symptoms of PD are:

1. **Tremor (shaking)** often begins in a person’s hand, although sometimes the person’s foot or jaw is affected first. The particular tremor associated with PD has a rhythmic back-and-forth motion. Often, the tremor will cause the person to rub their thumb and forefinger together, which may appear as “pill rolling.” It is most obvious when the hand is at rest or when a person is under stress. This tremor usually disappears during sleep and may improve when the person makes a purposeful, intended movement.
2. **Rigidity (muscle stiffness)**, or resistance to movement, affects most people with PD. The muscles stay tense and tight so the person aches or feels stiff. If another person tries to move the individual’s arm, it will move only in short, jerky movements (known as “cogwheel” rigidity).
3. **Bradykinesia** is a slowing down of spontaneous and some automatic movement. It can make simple tasks more difficult, and activities the person could once perform quickly and easily—such as washing or dressing—may take much longer. The person’s face may be less expressive (known as “masked face”).
4. **Postural instability**, such as balance problems and changes in posture, can increase the risk of falls.

People with PD often develop a “parkinsonian gait.” This includes a tendency to lean forward, taking small, quick steps as if hurrying (called festination), and reduced swinging in one or both arms. They may have trouble initiating movement (called “start hesitation”) and stop suddenly as they walk, freezing in place. In addition to the characteristic symptoms noted above, people with PD may experience other problems related to the disease. These may include:

- **Mental and emotional health problems**, including depression or anxiety, may occur during the early stage of the disease, even before the onset of movement issues.
- **Difficulty with swallowing and chewing.** Problems with swallowing and chewing may occur in later stages of the disease. Food and saliva may collect in the mouth and back of the throat, resulting in choking or drooling. It can be difficult for people in the later stages of PD to get enough nutrients.
- **Speech changes.** Most individuals with PD have speech difficulties, which may include speaking quietly or in a monotone. Some people may hesitate before speaking. They may also slur or speak too quickly.
- **Urinary problems or constipation.** In PD, the autonomic nervous system, which controls movements and functions we don’t have to think about, doesn’t function normally. This can cause bladder and bowel problems.
- **Skin problems.** People with Parkinson’s may have increased facial oils, particularly on the forehead and at the sides of the nose. The scalp may become oily, too, resulting in dandruff. In other cases, the skin can become very dry, or the person may experience excessive sweating.
- **Sleep problems.** Common sleep problems in PD include difficulty staying asleep at night, restless sleep, nightmares and emotional dreams, and drowsiness or suddenly falling asleep during the day. Another common problem is REM sleep behavior disorder, in which people act out their dreams. This may result in injury to themselves or their bed partners. Medications used to treat PD may contribute to some sleep issues.
- **Dementia or other cognitive problems.** Some people with PD develop memory problems and slowed thinking. Cognitive problems become more severe in the late stages of PD, and some people are diagnosed with Parkinson’s disease dementia. Memory, visuospatial skills, attention, language, reasoning, or other mental and cognitive skills may be affected.
- **Orthostatic hypotension.** Orthostatic hypotension is a sudden drop in blood pressure when a person stands up from a lying down or seated position. This may cause dizziness, lightheadedness, and, in extreme cases, loss of balance or fainting.
- **Muscle cramps and dystonia.** The rigidity and lack of normal movement associated with PD often causes muscle cramps, especially in the legs and toes. PD can also be associated with dystonia—sustained muscle contractions that cause forced or twisted positions.
- **Pain.** People with PD may have aches and pains in their muscles and joints because of the rigidity and abnormal postures with the disease.
- **Fatigue and loss of energy.** Many people with PD often have fatigue, especially late in the day. Fatigue may be associated with depression or sleep disorders, but it may also result from motor control issues such as trouble initiating or carrying out movement, tremors or stiffness.
- **Sexual dysfunction.** Because it affects nerve signals from the brain, PD can cause sexual dysfunction. PD-related depression or use of certain medications may also cause decreased sex drive and other problems.

PD is the most common form of parkinsonism, which describes disorders that produce features and symptoms that closely resemble Parkinson’s disease. Many disorders can cause symptoms similar to those of PD, including [multiple system atrophy](#), [Lewy body dementia](#), [progressive supranuclear palsy](#), and [corticobasal degeneration](#). These disorders are sometimes referred to as “Parkinson’s-plus syndrome” or “atypical Parkinsonism” because they have the symptoms of PD plus additional features. These disorders often do not respond to levodopa treatment like PD does.

Black Adults Face Delays in Parkinson’s Diagnosis and Treatment

One man living with the disorder offers advice on how to overcome disparities

Richard Huckabee first noticed something was off in 2004. That’s when the public speaking pro suddenly found himself struggling to talk. “My voice was so raspy and so strained,” says Huckabee. In meetings, he says, his voice would “freeze” and “crack.” He went to the doctor, but they couldn’t find anything wrong.

As the years went on, other concerning symptoms emerged. Huckabee’s body would seize up, and his movements became slower. “My left side would hardly move,” he recalls.



Richard Huckabee and his wife

He endured nearly a decade of doctor’s appointments, emergency room visits and medical tests, and still didn’t have an answer for what was causing these concerning and disruptive symptoms. Huckabee was told it might be Lyme disease, or perhaps stress. Finally, he was referred to a neurologist, and after about 10 minutes, he had a diagnosis: Parkinson’s disease — a chronic neurodegenerative disorder that affects movement.

“I was devastated. Nine years in and out of hospitals, doctor’s offices, emergency rooms, and it took a neurologist 10 minutes to diagnose me with Parkinson’s disease,” says Huckabee, who is African American and lives in the Cleveland area. “I was happy to know what I had, but also devastated to know what I had, and that it took so long.”

Huckabee’s experience is not unique. Research shows that Black adults with Parkinson’s disease are less likely to receive a diagnosis than their white peers, and if they do get one, they’re more likely to get it later in the disease process. A study published in the journal *Parkinsonism & Related Disorders* found that Black patients were four years older than white patients at the time of their Parkinson’s diagnosis.

Huckabee was diagnosed with Parkinson’s disease in 2013, nine years after symptoms first began. Research shows Black adults in the U.S. are more likely to receive a Parkinson’s diagnosis later than their white counterparts.