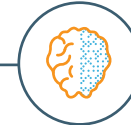




THE MICHAEL J. FOX FOUNDATION  
FOR PARKINSON'S RESEARCH

# The National Plan to End Parkinson's Act

An estimated more than 1 million people in the U.S. live with Parkinson's disease including over 110,000 military veterans. With the recent discovery of a Parkinson's biomarker, there is no better time for the federal government to invest in research for a cure.



With about **90,000 new diagnoses each year**, Parkinson's is the fastest growing and second most common neurological disease — and it costs the U.S. more than **\$52 billion annually**.

The National Plan to End Parkinson's Act (H.R.2365/S.1064) is bipartisan, no-cost legislation that will create an advisory council comprising members of federal agencies, patients, care partners, researchers, clinicians and other non-federal experts. The goal of the council is to ensure efficient and effective coordination among all federal entities with responsibility for diagnosing, treating, preventing and curing Parkinson's disease.

Each year, the advisory council will provide a report to Congress and the U.S. Secretary of Health and Human Services that contains evaluations of all federally funded programs related to Parkinson's. The report will also include recommendations to prevent and cure Parkinson's, improve health outcomes, limit exposures to environmental risk factors and reduce the financial impact of the disease on patients and the federal government.



The National Plan to End Parkinson's Act will, for the first time, unite the federal government on a mission to diagnose, treat, prevent and cure Parkinson's; alleviate financial and health burdens on American families and reduce government spending over time.



Please direct any questions or inquiries to Drew Hatter at [dhatter@michaeljfox.org](mailto:dhatter@michaeljfox.org).

# Faces of Parkinson's



## *Allie Signorelli, Virginia*

Allie lives in Arlington, Virginia, with her husband Mike and two kids. In December 2022, she was diagnosed with Parkinson's disease at age 47. What started as a twitch in her right big toe, gradually traveled up her ankle, then her leg and eventually to her right arm and hand. Visits to many doctors provided no answers. Many said it would be rare for a woman Allie's age to be diagnosed with Parkinson's, but a follow-up visit to a specialist and a DaTscan finally confirmed that Allie had young-onset Parkinson's disease. By sharing her story, Allie hopes that people will recognize that younger people and women are living with this disease, too. In fact, 40 percent of people with Parkinson's are women. An avid Parkinson's policy advocate, Allie is also a volunteer with the Michael J. Fox Foundation's landmark study, the Parkinson's Progression Markers Initiative.



## *Leonard Chandler, Alabama*

Leonard is a United States Air Force veteran who was diagnosed with Parkinson's disease in 2014. After his diagnosis, Leonard began participating in Parkinson's research. Leonard views research participation as an opportunity to contribute to the larger effort to eradicate Parkinson's. His diagnosis generated urgency to accomplish two goals: Start a project that would provide the stimuli to maintain his mental focus and clarity, and work on physical engagement to help slow the progression of the disease. Leonard is semiretired, having shifted his focus to the cattle industry where he is a producer of International Red Brangus beef cattle, further helping him accomplish his two goals.



## *Maria De Leon, Texas*

Maria was diagnosed with young-onset Parkinson's disease in 2008 followed by a Lupus diagnosis a few years later. She is a fellowship trained movement disorder specialist and an avid research advocate. Through her work with the Parkinson's Advocates in Research program, Maria aims to decrease the disparity in health care treatment among minorities. She also advocates for greater understanding of the gender differences in neurological diseases. Maria is the author of a book — *Parkinson's Diva* — about the unique perspective of being a woman with young-onset Parkinson's. Even as a Parkinson's specialist, Maria encountered a lot of resistance from colleagues before her diagnosis. She believes more work is needed to change misconceptions and ensure that everyone has access to adequate care and treatment.



## *George Manahan, West Virginia*

George is a small business owner trying to navigate the world of Parkinson's while providing jobs to 12 full time employees. When he was diagnosed in 2010, there were no services for people with Parkinson's in his area. George was determined to find other people in the community living with Parkinson's. He helped launch the first support group in Charleston, West Virginia, which expanded its services to include weekly exercise classes. George passionately engages in advocacy around policies that will make a difference for people living with Parkinson's, including the establishment of a new Parkinson's research registry in West Virginia. "I didn't know anyone else locally that had the disease," said George. "It was my hope that by telling my story, others would join me in this journey. Thankfully, they have."



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