

State Government Relations

2024 Legislative Priorities

At The Michael J. Fox Foundation (MJFF), we advocate because the government plays a pivotal role in accelerating research toward prevention and a cure, and ensuring quality of life for those already living with Parkinson's disease and their families.

Why We Advocate

Parkinson's disease occurs when brain cells that make dopamine, a chemical that coordinates movement, stop working or die. The experience of living with Parkinson's disease over the course of a lifetime is unique to each person. As symptoms and progression vary from person to person, neither a patient nor their doctor can predict which symptoms they will experience, when they may get them, or how severe they will be.

Currently, there is no cure for Parkinson's disease. There is no one exact cause of Parkinson's, and researchers believe it is likely caused by a combination of genetic and environmental factors. Known primarily as a "movement disorder," the most known traits of Parkinson's are tremor, slowness, walking and balance problems, as well as depression, memory problems, constipation, dementia and more. Parkinson's disease is a lifelong and progressive disease, which means that symptoms slowly worsen over time.

Funding Parkinson's Research

State governments must find new and innovative research to assist in finding treatments and cures for Parkinson's disease.

Establishing or increasing state funding for Parkinson's research will lead discoveries that will improve the lives of people living with Parkinson's disease today in partnership with the many clinical studies being done around the world in partnership with MJFF.

Since 2010, MJFF has been dedicated to building, strengthening and expanding the infrastructure for a longitudinal study known as Parkinson's Progression Markers Initiative (PPMI). With nearly \$450 million invested, PPMI has 50 clinical sites in 12 countries and over 2,000 participants. Public sector partnership and investment in PPMI is needed to accelerate research for earlier diagnosis, better treatments and, ultimately, a cure for Parkinson's disease.



An estimated more than *one million people* in the U.S. live with Parkinson's disease.

The annual economic burden of Parkinson's in the U.S. is an estimated *\$52 billion.*



Parkinson's is the *second-most common* and *fastest-growing* neurological disease.

MJFF has funded nearly *\$2 billion* in research programs to date.



Research Registries

A disease registry is a special database that contains information about people diagnosed with a specific type of disease. Registries can be used to closely monitor the health care process to detect potential problems and to ultimately achieve better results for patients.

Through state-level registries, designated agencies collect de-identified patient information with the goal of sharing the database with the CDC for use in research, planning for health care requirements and education of health care providers.

Passing legislation to create a statewide, population-based registry will be used to measure the incidence and prevalence of Parkinson's disease. The data collected will fuel further research that will discover improved treatments and therapeutics for Parkinson's disease.

Surprisingly, little is known about how Parkinson's disease is distributed among different population groups and whether the patterns of the disease are changing over time.

This legislation will:

- + Identify high-risk groups, support patient contact studies and serve as a valuable data resource to bolster continued research of Parkinson's disease.
- + Determine an accurate rate of incidence and prevalence of Parkinson's disease by state.
- + Help researchers study patterns of Parkinson's disease over time.
- + Improve our understanding of potential links, such as pesticide usage and military service, and the development of Parkinson's disease.

Status of State Legislation

- + To date, there are registries and/or recently enacted legislation to establish a registry in California, Maryland, Missouri, Nebraska, Nevada, Ohio, South Carolina, Utah, Washington and West Virginia.
- + In 2024, legislation has been introduced in Hawaii, Massachusetts, New Jersey and New York.

Biomarker Testing

Biomarker testing is the analysis of a person's tissue, blood, and other substances, known as biomarkers, that can provide information about cancer. Biomarker testing is a crucial step for accessing precision medicine, including targeted therapies that can lead to improved survivorship and better quality of life for cancer patients. While most current applications of biomarker testing are in oncology and autoimmune diseases, there is research underway to benefit patients in other areas, including neurological conditions such as Parkinson's disease.

Currently, insurance coverage for biomarker testing is failing to keep pace with innovation and advancement in treatment. We urge states to take legislative action to require health plans, including Medicaid, to cover biomarker testing so that more individuals have access to this important health care tool.

Legislative action on biomarker testing access coincided with **the Foundation's groundbreaking news, announced in April 2023, that researchers have discovered a new biomarker tool that can reveal a key pathology of the Parkinson's: abnormal alpha-synuclein — known as the "Parkinson's protein" — in brain and body cells.**

Steady and critical advances in the pursuit of a reliable and accurate biomarker test have been the hallmark of PPMI, which was built for this purpose. The discovery enabled by the new test is the latest, and most significant, finding to date from the study.

You can read more about this extraordinary scientific breakthrough, and the accompanying study posted in *The Lancet Neurology*, [here](#).

Status of State Legislation

- + In 2023, legislation to expand access to biomarker testing, or to study the benefits of doing so, was enacted in Arizona, California, Georgia, Kentucky, Louisiana, Maryland, Nevada, New Hampshire, New Mexico, New York, Oklahoma and Texas.
- + In 2024, legislation has been introduced, or is expected to be introduced imminently, in Connecticut, Florida, Hawaii, Indiana, Iowa, Maine, Massachusetts, Ohio, Pennsylvania, Vermont and West Virginia.



Genetic Testing Protections

The Genetic Information Nondiscrimination Act (GINA) is a federal law that prohibits health insurers from using information learned through genetic testing, such as a gene mutation linked to neurological disorders, to deny coverage or engage in price discrimination. These protections, however, do not extend to life insurance, long-term care insurance and disability insurance coverage. This needs to change.

No one should have to fear that accessing genetic testing may be weaponized against them in the future. We believe that more people should have access to genetic testing and that no one should face discrimination in pursuit of their health care needs. State legislatures should pass legislation that prohibits discrimination based on genetic predisposition for life insurance, long-term care insurance, and disability insurance coverage. These laws should address the refusal to issue or renew a policy, charging any increased rate, or restricting any length of coverage, and requiring genetic testing before approving coverage.

Environmental Transparency

A small minority of Parkinson's disease can be predominantly linked to genetics, leaving the etiology of the majority of cases including an environmental risk component. A large body of literature suggests that environmental risks (including, but not limited to pollutants, pathogens and diet) could play a role in the development of Parkinson's disease. There is still more research required to understand the magnitude and mechanisms of environmental risks and the development of Parkinson's disease.

To contribute to this work, our state team is focused on increasing environmental transparency, such as requiring states to develop and publicly share on a state website where toxic chemicals have been approved for use. We believe that state governments have a duty to provide public health information and we will continue to push for further transparency on behalf of our patient community.

Access to Care

Prescription Drug Affordability

- + **People with Parkinson's disease need to be able to afford their medications, and they need quick access to those treatments to manage Parkinson's symptoms.** As health care costs increase, we know people with Parkinson's disease feel the financial strain when costs of prescriptions also go up.
- + We urge states to pass legislation that allows people with Parkinson's disease to evenly spread out their medication costs over a whole year, instead of being hit with one big payment.

Social Determinants of Health

- + **Economic and social conditions have a powerful impact on our health and wellness.** Stable housing, reliable transportation and access to healthy foods are all factors that can make a difference in the prevention and management of many health conditions like diabetes, asthma and heart disease. Known as social determinants of health, a focus on these non-medical factors can improve health outcomes and wellbeing.

Mental Health

- + **Access to behavioral health care is essential for people with Parkinson's disease because the disease makes them prone to adverse mental health conditions.** We urge states to pass legislation to expand the behavioral health workforce and remove barriers to accessing behavioral health services via telehealth so that people with Parkinson's disease can access behavioral health care when and where they need it.



The Michael J. Fox Foundation for Parkinson's Research has a single, urgent goal: Eliminate Parkinson's in our lifetime. We have funded nearly \$2 billion in research since our founding over 20 years ago. MJFF advocates at the federal and state level for funding and policies that accelerate the search for a cure and improve quality of life for people with Parkinson's as well as their families and caregivers. MJFF is here until Parkinson's isn't.

Stay in touch with us by visiting the [State Action Center](#) or emailing policy@michaeljfox.org.