

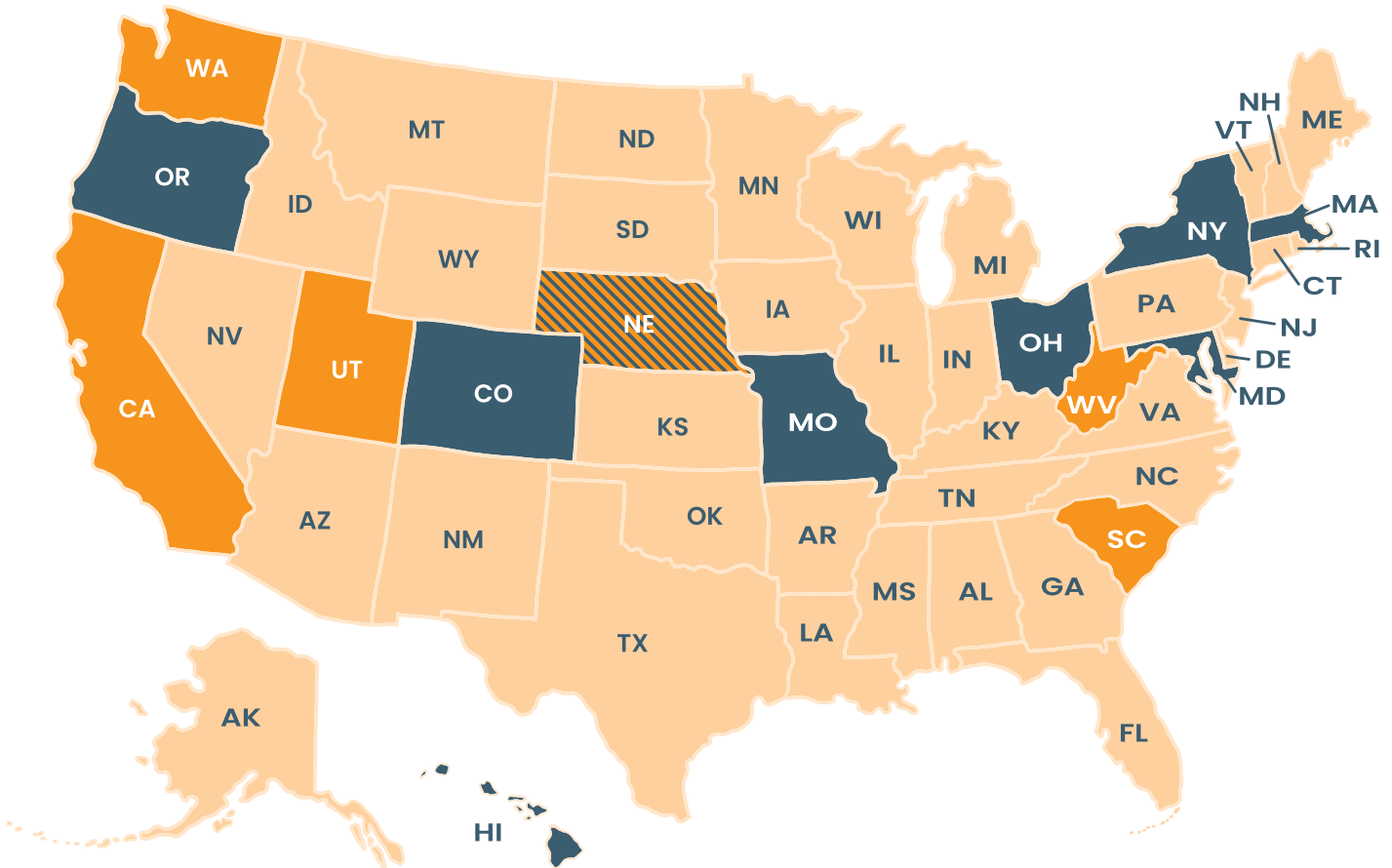


# Parkinson's Research Registries

-  States with registries
-  Targeted states for 2023



## Current Registries

### California

Established in 2017. Expanded in 2021 to include other neurodegenerative diseases.

### Nebraska

Established in 1996, but still a paper/manual registry. Legislation expected in 2023 to increase state funding to modernize the existing registry.

### South Carolina

Passed registry legislation in 2022 and will be housed within the Medical University of South Carolina (MUSC). Establishing Advisory Committee members now, and plans for infrastructure coming within the next year.

### Utah

Established in 2015 and housed within the University of Utah Department of Neurology.

### Washington

Voluntary registry exists, but information pertaining to metrics or if information is reported to CDC is not clear.

### West Virginia

Passed registry legislation in 2022 and will be housed within WVU Rockefeller Neuroscience Institute. Establishing Advisory Committee members now, and plans for infrastructure coming within the next year.

## 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 healthcare process to detect potential problems and to, ultimately, achieve better results for patients. For example, patient engagement has often been a struggle for providers.

Creation of a state registry database will feed deidentified patient information upon diagnosis, to the state department of health, and further to the CDC for use in research, for planning for health care requirements, and for education of health care providers.

Passage of this legislation to create a statewide population-based registry will be used to measure the incidence and prevalence of Parkinson's disease.

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

**This legislation will expand our understanding of Parkinson's disease to ultimately improve the lives of those affected.**

- + The data will help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson's disease.
- + To determine incidence and prevalence of Parkinson's disease more accurately by state.
- + The data will help researchers study patterns of Parkinson's disease over time.
- + Help determine if certain regions of the state that use more pesticides have higher incidents of Parkinson's. Studies have shown a correlation between higher pesticide use and increases in Parkinson's cases.
- + Improve our understanding of the link between Parkinson's and military service since a larger portion of the veteran's community has Parkinson's compared to the general population.

## Why We Advocate

**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 and their families.** Parkinson's occurs when brain cells that make dopamine—a chemical that coordinates movement—stop working or die. Currently, there is no treatment to prevent, slow, stop, or reverse disease progression, nor is there a cure. There is no one exact cause of Parkinson's, and researchers believe it is likely caused by a combination of genetic factors 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 constipation, depression, memory problems, dementia, and more. Parkinson's symptoms worsen over time.



**1 million+**

people in the U.S. live with Parkinson's, including more than 100,000 veterans



**\$52 billion**

is spent by the U.S. every year on Parkinson's; half is paid for by the federal government



**\$80 billion**

is what the annual cost will grow to by 2037, with more than \$40 billion shouldered by the federal government



**Fastest-growing**

Parkinson's is the fastest -growing brain disease (second most common after Alzheimer's)



**90,000+**

people are diagnosed with Parkinson's each year



The Michael J. Fox Foundation for Parkinson's Research The Michael J. Fox Foundation for Parkinson's Research (MJFF) has a single, urgent goal: Eliminate Parkinson's in our lifetime. We have funded over \$1.5 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](mailto:policy@michaeljfox.org).