



March 16, 2022

The Honorable Shane Pendergrass, Chairwoman
House Health & Government Operations Committee
241 House Office Building
Annapolis, MD 21401

RE: HB 1412 – Maryland Parkinson's Disease Registry (SUPPORT)

Dear Chairwoman Pendergrass and members of the committee,

The Michael J. Fox Foundation for Parkinson's Research was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson's Disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with PD today. **We offer our full support for HB 1412 which would establish a Parkinson's Disease Registry in Maryland.**

A Maryland Parkinson's Disease registry, along with those already established in California, Nebraska, Utah, Massachusetts, and most recently passed in West Virginia could truly power significant progress toward new treatments, and ultimately a cure for Parkinson's patients. The registry would provide data on the incidence of the disease and its various patterns in the state, including potential geographic clusters and environmental exposures. Patient registries can provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness. Registry data can also inform policymakers about health care equity disparities and the influences of social determinants of health.

Parkinson's disease is the second most common and fastest growing neurological disease in the world and the number of people with PD is expected to double by 2040. According to the Centers for Disease Control and Prevention, PD is the nation's 14th leading cause of death. The annual cost of Parkinson's nationally is at least \$58 billion and that will rise to nearly \$80 billion by 2037.¹

The direct and indirect costs to care for the over 19,000 people living with PD in Maryland is \$950 million per year – finding new treatments and ultimately a cure would save tens of millions of dollars each year.

Establishing a state research collection registry will feed into the Center for Disease Control's National Neurological Conditions Surveillance System which tracks the incidence and prevalence of many neurologic disorders, including Parkinson's.

Researchers around the globe will be able to take state-based data to:

- 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 a higher incidence 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.
- Privacy of individual patients is protected rigorously within registries, compliant with the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state privacy laws.

When properly designed, a Parkinson's registry can expand in the future to collect data on other neurological diseases. Given the known, and unknown, neurological impact of COVID-19, a state registry could provide data critical for treatments of future coronaviruses.

The registry data would also provide insight into Parkinson's 'clusters' in the state and would enable greater scientific understanding of exposure of firefighters and other first responders to chemicals, toxins, heavy metals, and other possible environmental factors that may be Parkinson's triggers.

On behalf of the foundation and the patients we support, we urge a **favorable vote on HB 1412**. Thank you for your time and consideration, please don't hesitate to contact me at jworcester@michaeljfox.org or 202-638-4101, ext. 441.

Sincerely,

A handwritten signature in cursive script that reads "Julia Pitcher Worcester".

Julia Worcester, JD
Director of State Government Relations
The Michael J. Fox Foundation for Parkinson's Research