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THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

March 10, 2022

Testimony in Favor of SB740
Public Health - Parkinson's Disease Registry - Established

Chairwoman Kelley, Vice-Chair Feldman, and members of the Finance Committee,

I respectfully request a favorable report of Senate Bill 740 to establish a comprehensive statewide Parkinson's Disease registry that will allow Maryland to more effectively monitor the prevalence of this disease while also supporting the national effort to find a cure.

Parkinson's Disease is a chronic neurodegenerative disease [or chronic motor system disorder] that gradually worsens over time. There is no treatment to slow, stop, or reverse the progression of Parkinson's Disease, nor is there a cure¹.

Senate Bill 740 will establish a statewide Parkinson's Disease registry within the Maryland Department of Health (MDH) that will disseminate relevant population data from patients living with the disease to the Centers for Disease Control and Prevention (CDC) national research database. This MDH registry will ultimately provide researchers across the country with the best possible chance to use this data and prevalence patterns towards finding a cure for this progressive, chronic disease.

As of 2022, more than 1 million Americans, including 110,000 military veterans, live with Parkinson's Disease. Approximately 60,000 Americans are diagnosed with Parkinson's Disease each year². The federal government spends approximately \$28 billion annually to care for People with Parkinson's Disease, and only \$180 million researching the disease. It is estimated that more than 1.6 million Americans will live with Parkinson's Disease by 2037, at an estimated cost of well over \$79 billion. With this continued and unabated instance of Parkinson's Disease across the United States (U.S.), it is paramount that states such as Maryland take a proactive stance in monitoring, researching and combating this disease.

Creation of a state registry database will feed unidentified patient information upon diagnosis, to the Maryland 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.

This legislation will:

1. Establish a Parkinson's Disease Registry in the Maryland Department of Health;
2. Require the Maryland Department of Health to establish a Parkinson's Disease Registry Advisory Committee;
3. Authorize the Maryland Department of Health to share certain information in the Registry with certain entities under certain conditions (i.e., the CDC); and
4. Ensure and provide for the confidentiality of information collected under this Act

¹ The Michael J. Fox Foundation. (2022). "Parkinson's 101". <https://www.michaeljfox.org/parkinsons-101>

² Parkinson's Foundation. (2022). "Statistics". <https://www.parkinson.org/Understanding-Parkinsons/Statistics>.

As of this testimony, five states - including Massachusetts, California, Utah, Nebraska, and neighboring West Virginia - have established a comprehensive Parkinson's registry to compile data, monitor trends, and track the prevalence of this progressive, chronic disease. Five additional states - Hawaii, Colorado, Michigan, Ohio, and South Carolina - are contemplating similar legislation.

Little is known about how Parkinson's Disease is distributed among different population groups and whether these patterns of disease prevalence are changing over time. Maryland's large and diverse population makes it an ideal candidate for joining the collective of states establishing Parkinson's Disease registries in an effort to provide valuable information about this disease.

I respectfully request a favorable report of Senate Bill 740.