



THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

**Testimony in Support of SB584
Public Health – Parkinson’s Disease Registry – Established**

Madame Chair, Madame Vice Chair, and Fellow Members of the Senate Finance Committee:

SB584 establishes a voluntary Parkinson's Disease Registry database which will feed deidentified patient information upon diagnosis to the state Department of Health (DoH), and further to the Center for Disease Control for use in research, for planning for health care requirements, and for education of health care providers.

Background

Parkinson’s disease (PD) 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, nor is there a cure. Common symptoms include tremors, muscle rigidity, slowness of movement, impaired balance, and a shuffling gait. More than one million Americans, including 110,000 military veterans live with PD.

Beyond its impact on the people living with PD and their loved ones, the disease is costly to our society with an economic burden of \$52 billion each year. The amount spent on research of the disease pales in comparison to the amount spent to care for people with Parkinson’s with the federal government spending \$28 billion every year on care and only \$180 million on research.

Solution

The registry created by SB584 will expand our understanding of PD to ultimately improve the lives of those affected. The registry will help:

- Identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage PD.
- Researchers study patterns of PD over time.
- Determine if certain regions of the state that use more pesticides have higher incidents of Parkinson’s.

- 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.

Six states have already created a state PD registry include California, Washington, and West Virginia.

Amendment & Reprint

I am offering an amendment to the bill that will drastically reduce the fiscal impact of the bill as outlined in the Fiscal Note. Over the interim, the DoH, Chesapeake Regional Information System for our Patients (CRISP), and other stakeholders met pursuant to the bill passed on this topic in the last Legislative Session, SB740. Representatives from CRISP offered to integrate data collection on PD into their existing system, which means the DoH will not need to create a new database to implement the registry. A final report that reflects this arrangement is expected to be published by DoH imminently. The amendment and the accompanied reprint that I am offering reflects this agreement. Because the DoH would not need to collect the data for the registry, no additional staff would need to be hired and no major infrastructure would need to be established to create the registry. CRISP has agreed to take on these responsibilities at no significant cost to the state. Upon adoption of the amendment, I expect a revised Fiscal Note to show a drastically reduced fiscal impact than the original one based on the existing text of the bill.

For these reasons, I respectfully request a favorable report with amendments on Senate Bill 584.