

# **SB 740 - LOS for PD Registry NPAM.pdf**

Uploaded by: Beverly Lang

Position: FAV



*Advocating for Maryland NPs since 1992*

The Honorable Delores Kelley, Chairwoman  
Senate Finance Committee  
3 East Miller Senate Office Building  
Annapolis, MD 21401

**Bill: SB 740 – Maryland Parkinson’s Disease Registry (SUPPORT)**

Dear Chair Kelley and Members of the Committee:

On behalf of the Nurse Practitioner Association of Maryland, Inc., (NPAM), the only professional association advocating solely for the over 8,011 certified Nurse Practitioners (NPs) licensed in Maryland, and the over 800 active members of NPAM, we are requesting your support for **SB 740 – Maryland Parkinson’s Disease Registry** which would establish a Maryland Parkinson’s Disease registry. Maryland would join those states with existing registries including California, Nebraska, Utah, Massachusetts, and, most recently, West Virginia.

PD 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 Michael J. Fox Foundation for Parkinson’s Research, of the 6,030,517 people living in Maryland, 18,949 have PD.

This data would track the incidence of Parkinson’s Disease (PD) disease and its various patterns in the state, including potential geographic clusters and environmental exposures, would provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness, and could inform policymakers about health care disparities and the influences of social determinants of health. Establishing this registry will ensure that researchers have access to information as they explore treatments and a cure for PD.

Thank you for your support of **SB 740 – Maryland Parkinson’s Disease Registry**.  
Please contact Beverly Lang, NPAM Executive Director should you have any questions.

The Nurse Practitioner Association of Maryland, Inc.  
5372 Iron Pen Place, Columbia, MD 21044  
Office: 443-367-0277 Fax: 410-772-7915 [NPAM@npedu.com](mailto:NPAM@npedu.com)  
[www.NPAMonline.org](http://www.NPAMonline.org)

Kindest Regards,

**Beverly Lang MScN, RN, ANP-BC, FAANP**

Executive Director,

Nurse Practitioner Association of Maryland, Inc

5372 Iron Pen Place

Columbia, MD 21044

443-367-0277

Fax: 410-772-7915

[NPAMexdir@npedu.com](mailto:NPAMexdir@npedu.com)

The Nurse Practitioner Association of Maryland, Inc.  
5372 Iron Pen Place, Columbia, MD 21044  
Office: 443-367-0277 Fax: 410-772-7915 [NPAM@npedu.com](mailto:NPAM@npedu.com)  
[www.NPAMonline.org](http://www.NPAMonline.org)

# **MD SB 740 - PD Registry - Letter of Support.pdf**

Uploaded by: Julia Worcester

Position: FAV



March 10, 2022

The Honorable Delores Kelley, Chairwoman  
Senate Finance Committee  
3 East Miller Senate Office Building  
Annapolis, MD 21401

**RE: SB 740 – Maryland Parkinson's Disease Registry (SUPPORT)**

Dear Chairwoman Kelley 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 SB 740 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 14<sup>th</sup> 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.<sup>1</sup>

**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 SB 740**. Thank you for your time and consideration, please don't hesitate to contact me at [jworcester@michaeljfox.org](mailto:jworcester@michaeljfox.org) or 202-638-4101, ext. 441.

Sincerely,

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

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

# **SB740\_fav\_MovementDisorderEd.pdf**

Uploaded by: Larry Zarzecki

Position: FAV

**TESTIMONY IN SUPPORT OF SB 740 PARKINSON'S DISEASE REGISTRY**

**LARRY ZARZECKI**

**MARCH 10, 2022**

Thank you, Chair Kelley and members of the Senate Finance Committee, for the opportunity to testify in support of SB 740 that will create a Parkinson's Disease Registry in Maryland. I thank Senators Elfreth, Beidle, Feldman, and Klausmeier for sponsoring and cosponsoring of this bill, including those of you on this committee.

I am a retired law enforcement officer, and I was diagnosed with Parkinson's disease in 2009. I experienced a "freezing" episode which is a sudden paralysis, that caused me to fall and suffer a closed head injury and shattered my spine. Through intensive rehabilitation I had to learn to take care of myself. I have used my challenges and experiences to inspire and support others with Parkinson's, spinal cord injury, traumatic brain injury, multiple sclerosis, and other movement disorders.

I tell you this story because Parkinson's disease is a neurodegenerative disease which there is no cure but can be managed. A registry will be beneficial in estimating future health care costs and medications. On the Average, according to medical statistics, people with Parkinson's disease spend an average of four days longer than usual during a hospital stay.

A Parkinson's disease registry will be helpful in estimating cases of different types of Dementia including but not limited to Alzheimer's, multiple system atrophy (MSA), muscular, muscular/skeletal, brain and mental health issues.

Passage of this bill also makes economic sense as it will be a helpful tool in projecting future health care costs as Parkinson's attacks the entire body, due to the life span or the lack of the body's ability to produce dopamine.

A registry for Maryland would help us better understand the depth and scope of the disease. Thank you for allowing me to testify, I ask you for a favorable report on SB 740. If you would like to follow up with me, I can be reached at [larryzarzecki@yahoo.com](mailto:larryzarzecki@yahoo.com) or by calling me at 410-916-1638.



# **SB740\_Elfreth\_FAV.pdf**

Uploaded by: Sarah Elfreth

Position: FAV

**SENATOR SARAH ELFRETH**  
*Legislative District 30*  
Anne Arundel County

Budget and Taxation Committee

*Subcommittees*

Education, Business and Administration

Chair, Pensions

*Senate Chair*

Joint Committee on Administrative,  
Executive, and Legislative Review

Joint Committee on the Chesapeake and  
Atlantic Coastal Bays Critical Area



James Senate Office Building  
11 Bladen Street, Room 103  
Annapolis, Maryland 21401  
410-841-3578 · 301-858-3578  
800-492-7122 Ext. 3578  
Fax 410-841-3156 · 301-858-3156  
Sarah.Elfreth@senate.state.md.us

**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 cure<sup>1</sup>.

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 year<sup>2</sup>. 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

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

<sup>2</sup> 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.

# **SB 740 Public Health – Parkinson’s Disease Registr**

Uploaded by: Tammy Bresnahan

Position: FAV



One Park Place | Suite 475 | Annapolis, MD 21401-3475  
1-866-542-8163 | Fax: 410-837-0269  
aarp.org/md | md@aarp.org | twitter: @aarpmd  
facebook.com/aarpmd

**SB 740 Public Health – Parkinson’s Disease Registry – Established**  
**Senate Finance Committee**  
**FAVORABLE**  
**March 10, 2022**

Good afternoon Chair Kelley and members of the Senate Finance Committee. I am Tammy Bresnahan. I am the Director of Advocacy for AARP Maryland. As you know, AARP Maryland is one of the largest membership-based organizations in the country. AARP Maryland support SB 740. We thank Senator Elfreth for sponsoring this important bill.

AARP is a nonpartisan, nonprofit, nationwide organization that fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse.

SB 740 establishes a Parkinson’s Disease Registry and a Parkinson’s Disease Registry Advisory Committee to establish a system for the collection and dissemination of information determining the incidence and prevalence of “Parkinson’s Disease. An individual with Parkinson’s may opt out of participating in the registry. A nurse practitioner, physician, or physician assistant who diagnoses patients with Parkinson’s disease and related to Parkinson Disease must report each case to the registry. The registry will be housed at the Maryland Department of Health.

Parkinson's disease is a chronic motor system disorder that normally affects patients over the age of 50. However, young-onset Parkinson's disease occurs in those aged 21-45. Common symptoms include tremors, muscle rigidity, slowness of movement, impaired balance and a shuffling gait.

The registry is a database that can be utilized for research on Parkinson's, for planning for health care requirements and for education of health care providers. This bill if passed will create a Parkinson Disease registry that will collect information about the disease and will be used by researchers. If enacted, researchers could use that data to identify patterns, look at trends across a population diverse in race, ethnicity, socioeconomic status and history of exposure to occupational and environmental toxins to help Marylanders who have Parkinson Disease.

For these reasons we respectfully ask the Committee for a favorable report. For follow up or questions, please contact me at [tbresnahan@aarp.org](mailto:tbresnahan@aarp.org) or by calling 410-302-8451.

