



**Ohio Senate**  
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**Committees:**  
Small Business & Economic Opportunity Committee  
(Chairman)  
Primary & Secondary Education Committee  
Transportation Committee  
Workforce & Higher Education Committee

**Michael A. Rulli**  
State Senator  
33<sup>rd</sup> Senate District

**SPONSOR TESTIMONY SENATE BILL 99**  
**Senator Michael A. Rulli**  
**6/16/21**

Chairman Huffman and members of the Health Committee, thank you for allowing me to provide sponsor testimony on Senate Bill 99. Senate Bill 99 would require the Ohio Department of Health to establish a Parkinson's Disease Registry for the collection and dissemination of Ohio-specific data related to Parkinson's disease.

This bill came into being after speaking with a constituent and friend who has been afflicted with Parkinson's. Ron Moore, a wonderful patriot and fighter, has dedicated his life to finding a cure for this debilitating disease. He contacted my office and asked that I work with the Michael J. Fox Foundation to craft this legislation.

Based on a 2019 study by The Michael J. Fox Foundation for Parkinson's Research, using 2017 data, it is estimated that there are approximately 37,000 people in Ohio living with Parkinson's disease.

Parkinson's is the fastest growing neurological disease in the world, and the number of people with Parkinson's Disease is expected to double by 2040. According to the Centers for Disease Control and Prevention (CDC), Parkinson's Disease is the nation's 14<sup>th</sup> leading cause of death.

The estimated annual economic burden of Parkinson's Disease exceeds \$52 billion, roughly half of which is borne by the federal government due to Medicare and Social Security, but the other half is borne by state and local governments, patients and caregivers. By 2037, the economic burden of Parkinson's Disease in the U.S. is expected to be around \$80 billion. The estimated overall current annual economic burden for Ohio is \$1.924 billion.

Based on the experiences of other states, an Ohio Parkinson's registry would power significant research into the prevalence and characteristics of Parkinson's throughout the state. Properly designed and executed, patient registries can provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness. Registry data can also inform policymakers on health care equity disparities and the influences of social determinants of health.

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.

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.

Thank you for the opportunity to appear today in support of this bill, I would be glad to answer any questions from the committee.