

19th House District

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134th General Assembly Committees

Higher Education and Career Readiness
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Representative Mary Lightbody 19th House District

Testimony to the House Health Committee House Bill January 25, 2022 Mary Lightbody, Ph.D.

Chairman Lipps, Vice Chair Holmes, Ranking Member Russo, and members of the House Health Committee, thank you for allowing me to testify in support of House Bill 476.

Approximately 37,000 Ohioans are living with Parkinson's disease according to a 2019 study by The Michael J. Fox Foundation for Parkinson's Research.¹ It is the fastest growing neurological disease in the world, expected to double by 2040.² According to the Centers for Disease Control and Prevention complications from Parkinson's is the nation's 14th leading cause of death.³

Parkinson's disease is a chronic and progressive neurological disorder resulting from a deficiency of the neurotransmitter dopamine as the consequence of specific degenerative changes in the area of the brain called the basal ganglia. Parkinson's disease can be characterized by tremor at rest, slow movements, muscle rigidity, stooped posture, and unsteady or shuffling gait. "Parkinsonism" means a condition related to Parkinson's disease that can cause a combination of the movement abnormalities seen in the disease, including tremor at rest, slow movement, muscle rigidity, impaired speech, or muscle stiffness, which often overlaps with and can evolve from what appears to be Parkinson's disease.

I have witnessed the impact that Parkinson's can have on someone's life. My grandmother had the disease, so I know from personal experience how debilitating and painful the disease can be. She passed away when I was twelve, and I remember feeling helpless because the medical options available at the time were so very limited.

This legislation 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 and Parkinsonisms; require cases of Parkinson's disease and Parkinsonisms to be reported to the Registry by certified nurse practitioners, clinical nurse specialists, physicians, and physician assistants or by the employers of those health care providers; create the Parkinson's Disease Registry Advisory Committee to

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<https://www.michaeljfox.org/sites/default/files/media/document/2019%20Parkinson%27s%20Economic%20Burden%20Study%20-%20FINAL.pdf>

² <https://pubmed.ncbi.nlm.nih.gov/30584159/>

³ <https://www.parkinson.org/understanding-parkinsons/what-is-parkinsons#:~:text=While%20Parkinson's%20itself%20is%20not,death%20in%20the%20United%20States.>

assist the Department in developing and implementing the Registry; and move the designated “Parkinson’s Disease Awareness Month” from September to April.

Data collection is an essential component in furthering our understanding causes and risk factors of Parkinson’s disease in order to better prevent and treat it. A state registry would provide information regarding the prevalence of Parkinson’s and any demographic and geographic patterns in the state of Ohio. 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.

All patient information collected pursuant to the bill is confidential. The data must be coded in a manner which removes any identifying information. The language regarding confidentiality precludes an insurance company from accessing this data and using it to adjust insurance costs or coverage.

Thank you for the opportunity to testify in support of this important piece of legislation. Along with Representative Bird, I would be happy to answer any questions the committee members may have.

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