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Sponsor Testimony
House Bill 476
Before the House Committee on Health

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Chair Lipps, Vice-Chair Holmes, Ranking Member Russo, and members of the House Health Committee, thank you for the opportunity to provide sponsor testimony for House Bill 476, to establish an Ohio Parkinson's Disease Registry.

HB 476 establishes a state-run Parkinson's Disease Registry within the Department of Health for collection of data on the disease and Parkinsonisms, including geographical "clusters" and other demographic factors – these patterns may help researchers to better understand the environmental factors which contribute to the prevalence of the disease. The bill also moves Parkinson's Disease Awareness Month from September to bring it in line with the nationally-recognized month of April.

There are multiple reasons to favorably consider this bill:

- An Ohio Parkinson's registry would power significant research into the prevalence and characteristics of Parkinson's throughout the state. For the first time, we would create the base of data on the incidence of this debilitating disease and its various patterns in our state.
- Parkinson's Disease is the fastest growing neurological disease in the world, and the number of people with the disease is expected to double by 2040. According to the Centers for Disease Control and Prevention, it is the nation's 14th leading cause of death.
- A 2019 study by The Michael J. Fox Foundation for Parkinson's Research found that there are an estimated 37,000 people in Ohio living with Parkinson's Disease.
- The estimated annual economic burden of Parkinson's exceeds \$58 billion, roughly half of which is borne by the federal government due to Medicare and Social Security. The other half is borne by state and local governments, patients, and caregivers. Currently the estimated annual economic burden for Ohio is more than \$2.1 billion. By 2037, the economic burden of Parkinson's Disease in the U.S. is expected to be around \$80 billion.

This bill will provide greater opportunities to research, study, and further understand Parkinson's Disease as we seek to combat it, all while protecting the medical privacy rights of individual patients. Thank you Chair Lipps and members of the committee for the opportunity to speak to this important bill before you today. I'd now like to turn our testimony over to my joint sponsor, Representative Lightbody, and then we will be happy to answer your questions.