

May 5, 2016

Representative Anne Gonzales
Chair, House Health and Aging Committee
77 S. High Street, 13th Floor
Columbus, OH 43215

Chair Gonzales,

Thank you for the opportunity to provide written testimony on House Bill 499. Legislation that creates a Parkinson's and movement disorder registry within the Ohio Department of Health. The Ohio Hospital Association represents approximately 220 hospitals throughout the state of Ohio and exists to collaborate with member hospitals and health systems to ensure a healthy Ohio.

OHA truly appreciates the work of Representatives Grossman and Schuring to advance discussions on Parkinson's Disease. We would also like to thank Franklin County Auditor Clarence Mingo and his staff for meeting with us to discuss the complexities of this disease and the goals of this legislation. We look forward to continuing to work with all of the interested parties.

Parkinson's disease is a progressive, neurodegenerative disorder that affects movement, muscle control, and balance as well as numerous other functions. It is part of a group of conditions known as motor systems disorders. As most of you are aware, the hallmark symptoms of Parkinson's disease (PD) are asymmetric tremors at rest, rigidity, and slowness in movement. It is always chronic and progressive, meaning that the symptoms always exist and always worsen over time. The rate of progression varies from person to person, as does the intensity of the symptoms. Parkinson's disease itself is not a fatal disease and many people live into their older years. There is currently no cure for Parkinson's disease. There is significant research being conducted to try and treat and hopefully find a cure for Parkinson's Disease.

There are a number of concerns regarding the creation of a registry within the Ohio Department of Health for Parkinson's Disease and other movement disorders.

The most significant issue with this legislation is that there is not a need, at this time, to create a new registry in state government. The Ohio Hospital Association currently receives data from our hospital members, through the ICD 10 system, that can be used to identify the number of patients treated in a hospital with Parkinson's disease. We also currently have access to information regarding the regions of the state and even some demographic information regarding these patients. While we must always take into account the protections provided by HIPAA, OHA is currently working with Battelle, in Columbus, to utilize census track information to further mine data that can be utilized to identify possible "hot spots" and even possible socio-economic variables. While we are still working on this project with our private sector partners, We do not feel that the creation of a duplicative database in the state would provide additional value.

Another important concern with the creation of a state run database is the issue of accuracy of the data and the potential for false positives being included in the registry. Such errors of inclusion

would dilute its utility in identifying risk factor (e.g., environmental, genetic, social and/or other) for Parkinson's disease; not to mention other potential consequences to the individuals so misclassified. Experts in this field are concerned that it would take significant staff time to verify the diagnoses after reporting, which could be costly and time consuming. It is our understanding that the Ohio Department of Health does not currently have the staff or the resources to review the information in a new database for accuracy. The concerns associated with data accuracy and the complexities of that data would be significantly increased if registry were expanded to other movement disorders.

Finally, It is also important to note that the federal Centers for Disease Control and Prevention (CDC) is also in the process of developing a national Parkinson's registry. With the information discussed earlier, it makes sense to wait for the development of the national registry, rather than spend resources on a state registry that may require significant changes once the federal registry is developed. The federal government may also provide assistance in set up state registries to assure that they communicate properly with individual states.

Parkinson's disease is a devastating, complex disease. We need to continue to work to address research opportunities that can hopefully lead to better treatment and eventually a cure. Creating a new registry, at this time, does not seem to present that best use of resources. Again, we truly appreciate the work of the House Health and Aging Committee to discuss the important issue of Parkinson's disease.

Sincerely,

A handwritten signature in black ink, appearing to read "Rick Frank". The signature is fluid and cursive, with the first name "Rick" being more prominent than the last name "Frank".

Rick Frank
Senior Director, Government Affairs
Ohio Hospital Association