

February 9, 2022

The Honorable Stephen A. Huffman, Chairman  
Senate Health Committee  
Senate Building  
1 Capitol Square  
Columbus, OH 43215

**RE: SB 99 – Ohio Parkinson’s Disease Registry (SUPPORT)**

Dear Chairman Huffman and members of the committee,

My name is Susan Davidson, and along with Barb Matheny, we are writing you this letter in advance of our proponent testimony before your committee next Wednesday, February 9 in support of SB 99. We are retired teachers who live and taught in Findlay. Both of us have Parkinson’s Disease (PD). I was diagnosed with the disease in 2016, although my neurologist stated at my time of diagnosis that I most likely had had Parkinson’s for five to ten years prior to that time. I recently found out that I have a genetic link to the disease. My father had Parkinson’s and I know how devastating the disease was for him and how it affected our whole family. Now, my sister and I are facing the same challenge of living with PD.

Barb was diagnosed in January of 2021. She had a tremor in her hand for a year that was misdiagnosed as an essential tremor. A year later, a neurologist confirmed that she has Parkinson’s. Barb also took part in a genetic study; however, she has no genetic link.

Nobody looking at us would think we have this disease. We both maintain a very active, healthy lifestyle. As is true of all Parkinson’s patients, both of us have our own unique symptoms that have impacted our lives. I have experienced balance difficulties with resultant falls, fatigue, neck rigidity and pain as well as swallowing and voice issues. Barb struggles with handwriting, hand tremors, and a weakness and some rigidity on her right side.

Our reason for speaking today is to present why we feel it is essential to establish a Parkinson’s Registry here in Ohio. Currently, there are four states that have a Parkinson’s Registry: California, Nebraska, Utah, and Massachusetts. There are seven other states that have introduced legislation for a Parkinson’s Registry. Besides Ohio, they are Maryland, West Virginia, South Carolina, Michigan, Colorado, and Hawaii. 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. There are over 31,000 people living with PD in Ohio.

Why someone develops PD is rarely evident. It could be genetic, environmental, a combination of the two, or completely unknown. This is not just a disease of the elderly. What is frightening is that there are many people who have young onset Parkinson’s and develop it in their 20’s, 30’s, and 40’s. Regardless of age, what is interesting is that there are non-motor symptoms such as the loss of sense of smell or chronic constipation which can occur years before the common motor symptoms of tremor, slow movement, muscle rigidity, and balance issues begin. When an early diagnosis is made, much can be done to improve one’s quality of life. Recent evidence has shown that intense exercise will help with symptoms and perhaps slow down the progression of

the disease. We are committed to an exercise routine: between the two of us we do yoga, box, swim, ski, bike, walk, and work out at our local YMCA. We are managing fine at this point, yet we know that our Parkinson's disease will continue to progress with more motor and non-motor symptoms.

Creating a Parkinson's Registry here in Ohio will enable doctors and health officials to gather state data about people who have Parkinson's such as the demographics and genetics of individuals, environmental risk factors, and potential clusters of cases in certain parts of our state. This clinical and epidemiological evidence could then accelerate research and progress toward earlier diagnosis of individuals, better treatments, and hopefully one day a cure for Parkinson's.

Both of us are not letting the disease take us down even though we know that as time progresses, it will not always be easy. Our motto is to "Keep on living" and "Be strong and carry on." We therefore strongly encourage you to support SB 99 not only for us, but for future generations of all citizens of Ohio. As we all know, knowledge is power! May we have the power to do what is best for the health and well being of all Ohioans. Thank you for your time and consideration of our testimony to support SB 99.

Sincerely,

Susan Davidson & Barb Matheny