

To: Members of the House Health and Aging Committee

From: Amiel Mansur, System Program Director for Neuroscience Services
David Hinkle, MD, Neurology

Date: May 11, 2016

Re: HB 499 – Interested Party Written Testimony

OhioHealth is an eleven hospital health system serving the central Ohio region. In the past year, we opened a neuroscience center on the campus of Riverside Methodist Hospital in Columbus. The new Center provides subspecialized neuroscience care teams and treatment options for highly complex neuroscience conditions. In one location, patients can receive a complete range of care, such as inpatient and outpatient treatment, neurodiagnostics, interventional procedures, research clinical trials, surgery and education.

So, OhioHealth's commitment to patients with neurological diseases has never been stronger.

We appreciate the intent of HB 499, legislation that would establish a Parkinson's disease and other movement disorder registry. However, as an interested party and a large provider of neurological services, we have some concerns with the bill.

At a very basic level, it is important to note that there is no specific diagnostic test for Parkinson's disease. Arriving at such a diagnosis relies greatly upon clinical examinations, medical history and, of course, the education and experience of the assessing provider. So the fundamental question providers confront in a clinical environment is this: who exactly constitutes a Parkinson's disease patient?

Absent that answer, the potential for a "false positive" diagnosis does exist – potentially entering data that is not verifiably certain into a registry would seem to be counterproductive and would dilute the utility of the registry. For example, in areas where patients are diagnosed by primary care providers due to lack of neurologist availability, the risk of mislabeling the diagnosis increases, and yet this data would be **mandatorily reported in the registry.**

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We also have concerns with implementation of the registry. What patient information providers would be compelled to transmit to the Ohio Department of Health (ODH) – HB 499 identifies ODH as the agency charged with housing the new registry – and how that information would be transmitted are significant unanswered questions. Without a clearer understanding of what information is required and, more importantly, a simple, integrated mechanism in place to ensure efficient flow of information, we fear healthcare costs and physician availability will only get more cumbersome and expensive.

One final concern: this registry is to be inclusive of all movement disorders, not just Parkinson's. This brings an array of potential diagnoses into the fold and thus introduces challenges. Most notably, it would be quite difficult to prevent disease misclassification errors in the registry across such a broad spectrum of neurological conditions.

Thank you for your consideration of our concerns regarding HB 499.

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