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Fiscal Note & Local Impact Statement

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Version: As Introduced

Primary Sponsor: Sen. Rulli

Local Impact Statement Procedure Required: No

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Highlights

- The Ohio Department of Health (ODH) will experience an increase in costs to establish and maintain the Parkinson's Disease Registry required under the bill, including initial and ongoing information technology and administrative costs. Total costs will depend on a number of factors, such as the information technology requirements to allow for information submission and the number of additional staff that may be needed to perform associated duties.
- ODH will experience a minimal increase in costs to reimburse members of the Parkinson's Disease Registry Advisory Committee for any actual and necessary expenses and to provide staff, administrative, and meeting support.
- Government-owned hospitals could experience an increase in information technology or staff costs to submit the required information, which will depend on the data submission method available (e.g., will cases be reported and entered manually or can electronic health records be utilized).
- The Ohio Board of Nursing and the State Medical Board could experience an increase in costs if any disciplinary action is necessary for failure to report a case to the Registry; however, the number of violations is likely to be small.

Detailed Analysis

Parkinson's Disease Registry

The bill requires the Ohio Department of Health (ODH) to establish, maintain, and supervise a Parkinson's Disease Registry for the collection and dissemination of Ohio-specific data related to Parkinson's disease and Parkinsonisms, including data on the incidence and

prevalence in Ohio and any other epidemiological data related to the disease. The bill requires each individual case of Parkinson's disease or Parkinsonism to be reported to the Registry by certain health care professionals¹ who treated the individual or by the health care facility or hospital. ODH is required, within six months of the bill's effective date, to provide notice of the reporting requirements on its website and to certain entities. A health care provider may be disciplined by the provider's licensing board for failure to comply with the bill's reporting requirements.

As soon as practicable after an individual's diagnosis or treatment, the reporting health care provider must inform the individual about the Registry and the bill's reporting requirements. When ODH receives a report, it must notify the individual that is the subject of the report in writing certain information about the Registry, including the name and contact information for an ODH representative designated to answer questions. An individual may opt out in writing after receiving the notice. For each individual who participates in the Registry, ODH must develop a system for collecting and disseminating additional data related to the individual's diagnosis and treatment. Reporting health care providers may be required to report additional data to ODH. The bill authorizes ODH to enter into contracts, grants, and other agreements to administer the Registry, including data sharing contracts with data reporting entities to securely and confidentially receive information related to Parkinson's disease testing, diagnosis, and treatment. It also authorizes ODH to enter into agreements to furnish data collected in the Registry with other states' registries, federal Parkinson's disease control agencies, local health officers, or health researchers. ODH is required to establish a coding system that removes any identifying information about an individual to ensure confidentiality and must maintain an accurate record of all persons who are given access to confidential information under the bill. The bill provides that its provisions regarding the Registry take effect not later than 12 months after the act's effective date, except that ODH must provide notice of the reporting requirements on its website and to various boards and professional organizations within six months.

Fiscal impact

ODH will experience an increase in costs to establish and maintain the Parkinson's Disease Registry. Costs will depend on a number of factors, including the information technology (IT) costs necessary to develop and maintain the registry to allow information submission, if the registry is established in house or if ODH chooses to enter into a contract with another entity to perform these duties, and the number of additional staff that may need to be hired to perform associated duties. While a few other states have implemented a Parkinson's registry, costs associated with implementation are not widely available. California did allocate \$3.7 million in General Fund support between July 1, 2017 and June 30, 2020, to fund its registry and operation (see the section entitled "**Parkinson's disease registries in other states**" for more detail). ODH currently operates the Ohio Cancer Incidence Surveillance System (OCISS), which collects and analyzes approximately 125,000 cancer reports each year. OCISS is funded through a mix of federal funding from the U.S. Centers for Disease Control and Prevention (CDC) and state funds required for match or maintenance of effort requirements. OCISS uses Web Plus and also allows cancer case reporting through electronic health record systems. Web Plus is a web-based

¹ These specified professionals are regulated by the State Medical Board or State Board of Nursing.

application, developed and provided by the CDC, to collect cancer data over the internet. Thus, while ODH has prior experience with registries, Web Plus appears to be used exclusively for cancer-related data.

Government-owned hospitals could experience an increase in IT or staff costs to submit the required information. These costs will depend on the data submission method available. It is possible that reporting entities could have different options for submitting data, depending on the system implemented. These options could include automated electronic transfer of case files from electronic medical records or through manual case data submission through an online portal.² Submission through electronic medical records will likely require less staff time; however, if a patient's case information is to be manually entered into the registry, this could require more time and effort on the part of hospital staff. Manual transmission costs will depend on the number of cases a hospital has to enter.

Lastly, the Ohio Board of Nursing and the State Medical Board could experience an increase in costs if any disciplinary action is necessary in instances where practitioners specified in the bill fail to report a case to the Registry. Costs to these boards will depend on the number of violations, if any.

Parkinson's disease registries in other states

While other states have implemented Parkinson's disease registries, the overall implementation and maintenance costs are not widely available. A couple of examples of registries in other states is provided below.

California's Parkinson's Disease Registry was originally established in 2004. The legislation establishing this registry specified that provisions were to be implemented to the extent that funding was available. As a result, it appears that the registry was first launched in phases with a pilot project as the first stage. Funding was primarily through nonprofit organizations and some federal funds.³ In 2017, legislation was enacted that established the Richard Paul Hemann Parkinson's Disease Registry, requiring all health care providers that diagnose or provide treatment to specified patients to report data to the California Public Health Department. Mandated reporting began on July 1, 2018. The legislation required that these activities were to be done to the extent funds were available and repealed the provision on January 1, 2020. In response, the state allocated \$3.7 million in General Fund support between July 1, 2017 and June 30, 2020. Other legislation extended data collection until January 1, 2022, and associated documents show that the California Department of Public Health was requesting an appropriation of about \$410,000 to support this extension period, as well as to allow it to accept public or private funding sources. More recent legislation has provided funds (\$8.4 million) to the California Parkinson's Disease Registry to extend data collection and to expand the registry to include other neurodegenerative diseases as well over a period of four years.⁴ Other funding has been made available through entities such as the Michael J. Fox Foundation for Parkinson's Research (MJFF).

² *California Parkinson's Disease Registry Implementation Guide*, which can be accessed [here](#).

³ California Parkinson's Disease Registry informational site, which can be found [here](#).

⁴ Additional information on the California Parkinson's Disease Registry can be found [here](#), [here](#), and [here](#).

California, due to its large population size, likely has a larger number of people with Parkinson's disease. Thus, it would likely have more data reports than other states.

In Nebraska, the Parkinson's Disease Registry Act was enacted in 1996 and was the first Parkinson's registry in the country. However, due to a brief repeal and lack of funding, the registry was not fully utilized until 2006, when it received funding from the MJFF and the American Parkinson's Disease Association. Between 1997 and 2019, there were approximately 16,500 individuals diagnosed with Parkinson's disease in Nebraska.⁵

Parkinson's Disease Registry Advisory Committee

The bill creates within ODH a Parkinson's Disease Registry Advisory Committee. The bill specifies membership, appointment terms, duties, and meeting requirements. Members of the Committee are to serve without compensation but will receive payment for actual and necessary expenses incurred in the performance of their official duties. ODH is required to provide meeting space, staff, and other administrative support to the Committee.

Fiscal impact

ODH will experience a minimal increase in costs to reimburse members of the Committee for any actual and necessary expenses and to provide staff, administrative, and meeting support to the Committee.

⁵ Information on the Nebraska Parkinson's Registry can be accessed [here](#).