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# OHIO LEGISLATIVE SERVICE COMMISSION

Office of Research  
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H.B. 476  
134<sup>th</sup> General Assembly

## Bill Analysis

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**Version:** As Reported by House Health

**Primary Sponsors:** Reps. Bird and Lightbody

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### SUMMARY

#### Parkinson's Disease Registry

- Requires the Ohio Department of Health to establish a Parkinson's Disease Registry for the collection and dissemination of Ohio-specific data related to Parkinson's disease and Parkinsonisms.
- Requires cases of Parkinson's disease and Parkinsonisms to be reported to the Registry by certified nurse practitioners, clinical nurse specialists, physicians, and physician assistants or by the employers of those health care providers.
- Creates the Parkinson's Disease Registry Advisory Committee to assist the Department in developing and implementing the Registry.
- Moves designated "Parkinson's Disease Awareness Month" from September to April.

### 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.<sup>1</sup> Parkinson's disease is a chronic and progressive neurological disorder that can be characterized by tremor at rest, slow movements, muscle rigidity, stooped posture, and unsteady or shuffling gait.<sup>2</sup> A Parkinsonism is a condition related to Parkinson's disease that (1) can cause a combination of the movement abnormalities

<sup>1</sup> R.C. 3701.25(B).

<sup>2</sup> R.C. 3701.25(A)(3).

seen in the disease that often overlaps with and can evolve from what appears to be Parkinson's disease and (2) is included on the list of Parkinsonisms developed by the Parkinson's Disease Registry Advisory Committee,<sup>3</sup> which the bill creates.

### **Health care provider reporting**

The bill requires each individual case of Parkinson's disease or a Parkinsonism to be reported to the Registry by a certified nurse practitioner, clinical nurse specialist, physician, or physician assistant who treated the individual's Parkinson's disease or Parkinsonism, or by the group practice, hospital, or other health care facility that employs such a health care provider. If multiple health care providers with a reporting obligation are caring for the same patient, a single report may be submitted.<sup>4</sup>

ODH is required, within six months of the bill's effective date, to provide notice of the reporting requirements on its website and to the Ohio Board of Nursing, the Ohio Association of Advanced Practice Registered Nurses, the Ohio Association of Physician Assistants, the Ohio Hospital Association, the Ohio State Medical Association, and the State Medical Board.<sup>5</sup> A health care provider may be disciplined by the provider's licensing board for failure to comply with the bill's reporting requirements.<sup>6</sup>

### **Patient notice**

As soon as practicable after an individual's diagnosis or treatment, the reporting health care provider must inform the individual or individual's representative about the Registry and the bill's reporting requirements.<sup>7</sup> When ODH receives a report, it must notify the individual that is the subject of the report or the individual's representative in writing about the Registry, including (1) a description of the Registry and the process for collecting additional data beyond the initial report, (2) a statement acknowledging that the individual is not required to participate in the Registry, (3) a statement informing the individual that their data and information is confidential, (4) a statement informing the individual that they have access to their data and information maintained in the Registry, and (5) the name and contact information for an ODH representative designated to answer questions. An individual may opt-out in writing after receiving the notice.<sup>8</sup>

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<sup>3</sup> R.C. 3701.25(A)(4).

<sup>4</sup> R.C. 3701.25(C)(1) and (2).

<sup>5</sup> R.C. 3701.25(F); Section 3(B).

<sup>6</sup> R.C. 4723.28, 4730.25, and 4731.22

<sup>7</sup> R.C. 3701.25(C)(3).

<sup>8</sup> R.C. 3701.25(D).

## Collection of additional information

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.<sup>9</sup>

## Contracts and agreements related to the registry

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' Parkinson's disease registries, federal Parkinson's disease control agencies, local health officers, or health researchers. Before confidential information is disclosed, the requesting entity must agree in writing to maintain the confidentiality of the information. If the disclosure is to a researcher, the researcher must also obtain approval from their respective committees for the protection of human subjects and provide documentation to ODH that demonstrates they are able, and have established procedures, to maintain confidentiality.<sup>10</sup>

## Confidentiality of information

Generally, all information collected pursuant to the bill is confidential. ODH must establish a coding system that removes any identifying information about an individual with Parkinson's disease.<sup>11</sup> The bill provides that an authorized disclosure must include only the data and information necessary for the stated purpose of the disclosure, be used only for the approved purpose, and not be further disclosed.<sup>12</sup>

So long as the security of confidentiality has been documented, the bill provides that furnishing confidential information to ODH does not expose any person, agency, or entity to liability and is not considered a waiver of any privilege or a violation of a confidential relationship.<sup>13</sup>

ODH is required to maintain an accurate record of all persons who are given access to confidential information under the bill. The record must include (1) the name of the person authorizing access, (2) the name, title, address, and organizational affiliation of any person given access, (3) the access dates, and (4) the specific purpose for which information is being

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<sup>9</sup> R.C. 3701.25(E).

<sup>10</sup> R.C. 3701.25(G) and (H).

<sup>11</sup> R.C. 3701.25(I).

<sup>12</sup> R.C. 3701.25(J).

<sup>13</sup> R.C. 3701.25(K).

used. The record of access must be open to public inspection during normal ODH operating hours.<sup>14</sup>

Confidential information is not available for subpoena or disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other tribunal or court for any reason.<sup>15</sup>

The bill does not prevent (1) ODH from publishing reports and statistical compilations that do not identify or tend to identify individual cases or individual sources of information or (2) a professional, hospital, or facility with reporting obligations under the bill that provides diagnostic or treatment services to individuals with Parkinson's disease from maintaining Parkinson's disease registries.<sup>16</sup>

## **Parkinson's Disease Registry Advisory Committee**

The bill creates in ODH a Parkinson's Disease Registry Advisory Committee. The ODH Director must appoint the following as members: (1) four physicians, one each specializing in neurology, movement disorders, primary care, and clinical informatics, (2) an individual who represents patients diagnosed with Parkinson's disease, (3) an individual who specializes in public health, (4) a population health researcher with disease registry experience, (5) an individual with experience conducting Parkinson's disease research, and (6) an individual deemed necessary by the ODH Director.<sup>17</sup>

### **Appointments**

Initial appointments must be made within 60 days of the bill's effective date, with four appointments for terms of two years and five appointments for terms of three years. After that, all terms are for three years. Vacancies are required to be filled in the same manner as appointments. Successors for expired terms are to be appointed in the same manner as the initial appointment. Members may be reappointed for one additional term.<sup>18</sup>

### **Meetings and compensation**

The first meeting must be held within 90 days after the bill's effective date. Thereafter, meetings must be twice a year. The Committee must select a chairperson and may transact official business if at least five members are present. Members serve without compensation but receive payment for actual and necessary expenses incurred in the performance of their official

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<sup>14</sup> R.C. 3701.25(L).

<sup>15</sup> R.C. 3701.25(M).

<sup>16</sup> R.C. 3701.25(N).

<sup>17</sup> R.C. 3701.251(A).

<sup>18</sup> R.C. 3701.251(B).

duties.<sup>19</sup> ODH must provide meeting space, staff, and other administrative support to the Committee.<sup>20</sup>

### **Duties**

The Committee is required to do all of the following:

1. Assist ODH in developing and implementing the Registry;
2. Determine the data to be collected and maintained;
3. Develop and periodically update a list of Parkinsonisms to be reported, including multiple system atrophy, dementia with Lewy Bodies, corticobasal degeneration, and progressive supranuclear palsy;
4. Advise ODH as necessary.<sup>21</sup>

### **Effective date**

The bill provides that the Registry must be established within one year of the bill's effective date.<sup>22</sup> The reporting requirements begin once the Director of Health determines that the Registry is capable of receiving reports.<sup>23</sup> ODH must provide notice of the reporting requirements on its website and to various boards and professional organizations, as discussed above, within six months of the bill's effective date.<sup>24</sup>

### **Parkinson's Disease Awareness Month**

The bill changes the month designated as "Parkinson's Disease Awareness Month" from September to April.<sup>25</sup>

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## **HISTORY**

Action	Date
Introduced	11-01-21
Reported, H Health	03-30-22

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<sup>19</sup> R.C. 3701.251(C).

<sup>20</sup> R.C. 3701.251(E).

<sup>21</sup> R.C. 3701.251(D).

<sup>22</sup> R.C. 3701.25(B).

<sup>23</sup> Section 3.

<sup>24</sup> R.C. 3701.25(F).

<sup>25</sup> R.C. 5.27.