State of Wisconsin
2025 - 2026 LEGISLATURE

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DOA:......Kirschbaum, BB0510 - Parkinson's disease registry

FOR 2025-2027 BUDGET -- NOT READY FOR INTRODUCTION

AN ACT ...; **relating to:** the budget.

Analysis by the Legislative Reference Bureau

EDUCATION

HIGHER EDUCATION

Parkinson's disease registry

This bill directs the Population Health Institute, or its successor, at the UW-Madison School of Medicine and Public Health (PHI) to establish and maintain a Parkinson's disease registry and to collect data on the incidence and prevalence of Parkinson's disease and parkinsonisms in this state. The bill defines "parkinsonism" as a condition that is similar or related to Parkinson's disease.

In addition, under the bill, if a health care provider treats or diagnoses a patient with Parkinson's disease or a parkinsonism, that health care provider or the health care facility that employs or contracts with the health care provider must report information about the patient's Parkinson's disease or parkinsonism to PHI for purposes of the Parkinson's disease registry. If a patient declines to participate in the Parkinson's disease registry, the health care provider or health care facility must report only the incident of the patient's Parkinson's disease or parkinsonism.

The bill directs PHI to create a website for the Parkinson's disease registry that includes annual reports on the incidence and prevalence of Parkinson's disease in this state. The bill also authorizes UW-Madison to enter into agreements in order to furnish data from the Parkinson's disease registry to another state's Parkinson's disease registry, a federal Parkinson's disease control agency, a local health officer, or a researcher who proposes to conduct research on Parkinson's disease, subject to certain confidentiality requirements. In addition, the bill requires the UW System to allocate from its general program operations appropriation $3,900,000 in fiscal year 2025-26 and $2,400,000 in fiscal year 2026-27 to establish the statewide Parkinson's disease registry.

For further information see the state fiscal estimate, which will be printed as an appendix to this bill.

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

SECTION 1. 36.47 of the statutes is created to read:

36.47 Parkinson's disease registry. (1) DEFINITIONS. In this section:

(a) "Department" means the Population Health Institute, or its successor, at the University of Wisconsin-Madison School of Medicine and Public Health.

(a) "Health care facility" has the meaning given in s. 155.01 (6).

(b) "Health care provider" means a physician, surgeon, physician assistant, or nurse practitioner.

(c) "Parkinsonism" means a condition that causes a combination of the movement abnormalities seen in Parkinson's disease, including tremor at rest, slow movements, muscle rigidity, stooped posture, or unsteady or shuffling gait, which often overlap with and can evolve from what appears to be Parkinson's disease. "Parkinsonism" includes multiple system atrophy, dementia with Lewy bodies, corticobasal degeneration, and progressive supranuclear palsy.

(d) "Parkinson's disease" means a chronic and progressive neurologic disorder resulting from deficiency of the neurotransmitter dopamine as the consequence of specific degenerative changes in the basal ganglia, which is characterized by tremor at rest, slow movements, muscle rigidity, stooped posture, and unsteady or shuffling gait.

(2) CONSULTATION BY THE DEPARTMENT OF HEALTH SERVICES. The department of health services may do all of the following:

(a) Assist the department in the establishment and maintenance of a Parkinson's disease registry, as provided under sub. (3).

(b) Make recommendations to the department on the data to be collected in the Parkinson's disease registry.

(c) Advise the department on the Parkinson's disease registry.

(d) Make recommendations to the department on the best practices for the establishment of the Parkinson's disease registry under sub. (3).

(3) PARKINSON'S DISEASE REGISTRY. (a) By no later than the first day of the 19th month beginning after the effective date of this paragraph .... [LRB inserts date], the department shall, after consultation with the department of health services, establish and maintain a Parkinson's disease registry for the collection, storage, and dissemination of information about the incidence and prevalence of Parkinson's disease and parkinsonisms in this state.

(b) The department shall collect and store in the Parkinson's disease registry data reported under s. 255.18 (2) by health care providers and health care facilities.

(c) The department shall prescribe the format for reporting information to the department under s. 255.18 (2).

(d) The department shall create, and regularly review and revise, a list of information that health care providers and health care facilities must report, subject to s. 255.18 (2) (d), to the department under s. 255.18 (2). The list shall include the incident of a patient's Parkinson's disease or parkinsonism; necessary triggering diagnostic conditions, consistent with the latest version of the International Statistical Classification of Diseases and Related Health Problems; resulting case data on issues including diagnosis, treatment, and survival; and patient demographic information, including age, gender, and race. The Board of Regents of the University of Wisconsin System may promulgate rules to implement and administer this paragraph.

(e) The University of Wisconsin-Madison may enter into agreements in order for the department to securely and confidentially receive information from data reporting entities and their associated electronic medical records vendors related to Parkinson's disease testing, diagnosis, and treatment.

(f) 1. The University of Wisconsin-Madison may enter into agreements in order for the department to disclose data collected in the Parkinson's disease registry to another state's Parkinson's disease registry, a federal Parkinson's disease control agency, a local health officer, or a researcher who proposes to conduct research on Parkinson's disease.

2. Before disclosing data containing confidential information to an entity under subd. 1., the University of Wisconsin-Madison shall require the entity to specify the purpose for the requested disclosure, agree in writing to maintain the confidentiality of the information and, if the entity is a researcher, provide all of the following to the University of Wisconsin-Madison:

a. A written protocol to perform research.

b. Documentation of approval of the research protocol by an institutional review board of a domestic institution that has a federalwide assurance approved by the office for human research protections of the federal department of health and human services.

c. Documentation that demonstrates to the University of Wisconsin-Madison's satisfaction that the researcher has established procedures and has the capability to maintain the confidentiality of the information.

(4) WEBSITE. (a) By no later than the first day of the 19th month beginning after the effective date of this paragraph .... [LRB inserts date], the department shall establish and maintain a public website dedicated to the Parkinson's disease registry under sub. (3). The department shall include on the website all of the following:

1. Downloadable annual reports on the incidence and prevalence of Parkinson's disease in this state.

2. Relevant data, as determined by the department, about Parkinson's disease and parkinsonisms for the 5-year period prior to the effective date of this subdivision .... [LRB inserts date].

3. Other helpful resources about Parkinson's disease, as determined by the department.

(b) By no later than January 1 of each year, the department shall update the information specified in par. (a) 1. on the website maintained under par. (a).

(c) The department shall publish on its website notice of the reporting requirement under s. 255.18 no fewer than 90 days before the reporting requirement takes effect.

(5) CONFIDENTIALITY. (a) Any information reported to the department under s. 255.18 (2) that could identify an individual who is the subject of the report or a health care provider submitting the report is confidential.

(b) To ensure privacy, the department shall use a coding system for the data stored in the Parkinson's disease registry that removes any identifying information about an individual who is the subject of a report under s. 255.18.

(c) 1. If the University of Wisconsin-Madison or the department discloses confidential information as authorized under sub. (3) (f), the University of Wisconsin-Madison or department may include in the disclosure only the information necessary for the purpose specified under sub. (3) (f) 2.

2. A person who obtains confidential information from the University of Wisconsin-Madison or the department under sub. (3) (f) may use the information only for the purpose specified under sub. (3) (f) 2. and may not redisclose the information.

(d) The department shall maintain an accurate record of all persons given access to confidential information under this section. The record shall include all of the following:

1. The name of the person authorizing access.
2. The title, address, and organizational affiliation of any person given access.
3. The dates of access.
4. The specific purpose for which the information is to be used.

(e) The department shall make the records maintained under par. (d) available for public inspection during the department's normal operating hours.

(f) Confidential information under this section is not available for subpoena and may not be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding. Confidential information under this section is not admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

SECTION 2. 146.82 (2) (a) 8m. of the statutes is created to read:

146.82 **(2)** (a) 8m. To the Population Health Institute, or its successor, at the University of Wisconsin-Madison School of Medicine and Public Health under s. 255.18 (2) and to the persons specified under s. 36.47 (3) (f). The release of a patient health care record under this subdivision shall be limited to the information specified in the list under s. 36.47 (3) (d).

SECTION 3. 255.18 of the statutes is created to read:

255.18 Parkinson's disease registry reporting. (1) DEFINITIONS. In this section:

(a) "Health care facility" has the meaning given in s. 155.01 (6).

(b) "Health care provider" means a physician, surgeon, physician assistant, or nurse practitioner.

(c) "Parkinsonism" has the meaning given in s. 36.47 (1) (c)

(d) "Parkinson's disease" has the meaning given in s. 36.47 (1) (d).

(e) "Parkinson's disease registry" means the Parkinson's disease registry established and maintained by the Population Health Institute under s. 36.47 (3).

(f) "Population Health Institute" means the Population Health Institute, or its successor, at the University of Wisconsin-Madison School of Medicine and Public Health.

(2) REPORTING REQUIRED. Beginning on the first day of the 25th month beginning after the effective date of this subsection .... [LRB inserts date], if a health care provider diagnoses a patient with Parkinson's disease or a parkinsonism in this state or, for a health care provider who has primary responsibility for treating a patient's Parkinson's disease or parkinsonism, treats a patient's Parkinson's disease or parkinsonism in this state, that health care provider or the health care facility that employs or contracts with the health care provider shall do all of the following:

(a) Offer the patient the opportunity to do all of the following:

1. Review any informational materials developed by the Population Health Institute about the Parkinson's disease registry.

2. Speak with and ask questions of their health care provider about the Parkinson's disease registry.

3. Affirmatively decline, in writing, to participate in the collection of data for purposes of the Parkinson's disease registry.

(b) Except as provided in par. (d), report the information specified in the list under s. 36.47 (3) (d) about the patient's case to the Population Health Institute in the format prescribed by the Population Health Institute under s. 36.47 (3) (c).

(c) Notify the patient orally and in writing about the reporting requirement under par. (b).

(d) If the patient affirmatively declines in writing to participate in the collection of data for purposes of the Parkinson's disease registry, report only the incident of the patient's Parkinson's disease or parkinsonism to the Population Health Institute in the format prescribed by the Population Health Institute under s. 36.47 (3) (c).

(3) CONFIDENTIALITY. Any information reported to the Population Health Institute under sub. (2) that could identify an individual who is the subject of the report or a health care provider submitting the report is confidential. Confidential information obtained or reported in compliance with sub. (2) is not available for subpoena and may not be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding. Confidential information obtained or reported in compliance with sub. (2) is not admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

(4) RESPONSIBILITY. A health care facility that employs or contracts with a health care provider diagnosing a patient with, or treating a patient with, Parkinson's disease or a parkinsonism is ultimately responsible for meeting the requirements under sub. (2).

SECTION 9147. Nonstatutory provisions; University of Wisconsin System.

(1) FUNDING ALLOCATION FOR A STATEWIDE PARKINSON'S DISEASE REGISTRY. From the appropriation under s. 20.285 (1) (a), the Board of Regents of the University of Wisconsin System shall allocate in fiscal year 2025-26, at least $3,900,000, and in fiscal year 2026-27, at least $2,400,000, to establish the statewide Parkinson's disease registry under s. 36.47.

(END)