

House Bill 2595

Sponsored by Representative HUDSON (Pre-session filed.)

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure as **introduced**. The statement includes a measure digest written in compliance with applicable readability standards.

Digest: The Act creates a system to track Parkinson's disease in Oregon. (Flesch Readability Score: 64.9).

Establishes Parkinson's disease registry.

A BILL FOR AN ACT

1
2 Relating to Parkinson's disease registry; and prescribing an effective date.

3 **Be It Enacted by the People of the State of Oregon:**

4 **SECTION 1. Definitions.** (1) As used in sections 1 to 6 of this 2025 Act:

5 (a) "Clinical laboratory" has the meaning given that term in ORS 432.500.

6 (b) "Health care facility" has the meaning given that term in ORS 432.500.

7 (c) "Parkinsonisms" means related conditions that cause a combination of the movement
8 abnormalities seen in Parkinson's disease, such as tremor at rest, slow movement, muscle
9 rigidity, impaired speech or muscle stiffness, which often overlap with and can evolve from
10 what appears to be Parkinson's disease, and that include multiple system atrophy, dementia
11 with Lewy bodies, corticobasal degeneration and progressive supranuclear palsy.

12 (d) "Parkinson's disease" means a chronic and progressive neurologic disorder that re-
13 sults from deficiency of the neurotransmitter dopamine as the consequence of specific de-
14 generative changes in the area of the brain called the basal ganglia and that is characterized
15 by tremor at rest, slow movement, muscle rigidity, stooped posture and unsteady or shuffling
16 gait.

17 **SECTION 2. Parkinson's disease registry; advisory committee; rules.** (1) The Oregon
18 Health Authority shall establish a registry system to collect data on the incidence and pre-
19 valence of Parkinson's disease in Oregon and other related data.

20 (2) A health care facility, licensed health care practitioner or clinical laboratory diag-
21 nosing or providing treatment to patients with Parkinson's disease or related parkinsonisms
22 shall report each case of Parkinson's disease or related parkinsonisms to the authority in a
23 format prescribed by the authority.

24 (3) The authority may contract with a public or private third party to:

25 (a) Operate or maintain the statewide registry; and

26 (b) Fulfill the authority's duties under sections 1 to 6 of this 2025 Act.

27 (4) The authority shall adopt rules establishing a Parkinson's Disease Registry Advisory
28 Committee to assist in the development and implementation of the registry, determine what
29 data shall be collected and generally advise the authority on issues related to carrying out
30 the duties described in sections 1 to 6 of this 2025 Act. Membership of the advisory commit-

NOTE: Matter in **boldfaced** type in an amended section is new; matter *[italic and bracketed]* is existing law to be omitted. New sections are in **boldfaced** type.

tee must include a neurologist, a movement disorder specialist, a primary care physician, a physician informaticist, a patient diagnosed with Parkinson's disease, a person who is knowledgeable about public health and safety, a population health researcher familiar with registries and a Parkinson's disease researcher and other individuals the department deems necessary. The advisory committee shall meet at least biannually.

(5) All patients diagnosed with Parkinson's disease or related parkinsonisms shall be notified orally and in writing regarding the collection of information and patient data on Parkinson's disease. Patients who do not wish to participate in the collection of data under the registry system for purposes of research shall affirmatively opt out in writing after having been provided with an opportunity to review the documents and ask questions. A patient may not be forced to participate in the registry.

(6) The authority shall establish a system for the collection and dissemination of information determining the incidence and prevalence of Parkinson's disease and related parkinsonisms.

(7) Diagnoses of Parkinson's disease and related parkinsonisms shall be reported, but the mere incidence of a patient diagnosis shall be the sole required information for the registry for any patient who chooses not to participate. For the subset of patients who choose not to participate, further data may not be reported to the registry.

(8) No later than December 1 of each year, the advisory committee shall submit a report in the manner provided in ORS 192.245, and may include recommendations for legislation, to the interim committees of the Legislative Assembly related to health care. The report submitted under this subsection must include, but is not limited to, a summary of the committee's findings relating to patients diagnosed with Parkinson's disease and related parkinsonisms.

SECTION 3. Confidentiality of information. (1) All identifying information regarding individual patients, health care facilities and practitioners reported pursuant to section 2 of this 2025 Act shall be confidential and privileged. Except as required in connection with the administration or enforcement of public health laws or rules, no public health official, employee or agent shall be examined in an administrative or judicial proceeding as to the existence or contents of data collected under the registry system for Parkinson's disease and related parkinsonisms.

(2) All additional information reported in connection with a special study shall be confidential and privileged and shall be used solely for the purposes of the study, as provided by ORS 413.196. Nothing in this section shall prevent the Oregon Health Authority from publishing statistical compilations relating to morbidity and mortality studies that do not identify individual cases or prevent use of this data by third parties to conduct research as provided by section 4 of this 2025 Act.

SECTION 4. Use of confidential data; rules. (1) The Oregon Health Authority shall adopt rules under which confidential data may be used by third parties to conduct research and studies for the public good. Research and studies conducted using confidential data from the registry must be reviewed and approved by an institutional review board in accordance with 45 C.F.R. 46.

(2) The authority may enter into agreements to exchange information with other registries for patients diagnosed with Parkinson's disease and related parkinsonisms to obtain complete reports of Oregon residents diagnosed or treated in other states and to provide

1 information to other states regarding the residents of other states diagnosed or treated in
 2 Oregon. Before providing information to any other registry, the authority shall ensure that
 3 the recipient registry has comparable confidentiality protections.

4 **SECTION 5. Action for damages; license; disciplinary action prohibited for good faith**
 5 **participation in reporting of data.** (1) An action for damages arising from the disclosure of
 6 confidential or privileged information may not be maintained against any person, or the
 7 employer or employee of any person, who participates in good faith in the reporting of reg-
 8 istry data for Parkinson’s disease and related parkinsonisms in accordance with sections 1
 9 to 6 of this 2025 Act.

10 (2) A license of a health care facility or practitioner may not be denied, suspended or
 11 revoked for the good faith disclosure of confidential or privileged information in the report-
 12 ing of registry data for Parkinson’s disease and related parkinsonisms in accordance with
 13 sections 1 to 6 of this 2025 Act.

14 (3) Nothing in this section shall be construed to apply to the unauthorized disclosure of
 15 confidential or privileged information when such disclosure is due to gross negligence or
 16 willful misconduct.

17 **SECTION 6. No prohibition or requirement to operate separate registry.** Nothing in
 18 sections 1 to 6 of this 2025 Act shall prohibit a health care facility from operating its own
 19 registry for Parkinson’s disease and related parkinsonisms or require a health care facility
 20 to operate its own registry for Parkinson’s disease and related parkinsonisms.

21 **SECTION 7. Temporary provisions.** At least 90 days before requiring information to be
 22 reported, the Oregon Health Authority shall provide notification of the mandatory reporting
 23 of diagnoses of Parkinson’s disease and related parkinsonisms on its website, and shall also
 24 provide that information to associations representing physicians and hospitals and directly
 25 to the boards regulating health care professionals.

26 **SECTION 8. Section 7 sunset.** Section 7 of this 2025 Act is repealed on January 2, 2027.

27 **SECTION 9. Operative date.** (1) Sections 1 to 7 of this 2025 Act become operative January
 28 1, 2026.

29 (2) The members of the Parkinson’s Disease Registry Advisory Committee shall be ap-
 30 pointed no later than January 1, 2026.

31 (3) The registry system described in section 2 of this 2025 Act must be operative no later
 32 than July 1, 2026.

33 (4) The Oregon Health Authority may adopt rules and take any other action before the
 34 operative date specified in subsection (1) of this section that is necessary to enable the au-
 35 thority, on and after the operative date specified in subsection (1) of this section, to under-
 36 take and exercise all of the duties, functions and powers conferred on the authority by
 37 sections 1 to 7 of this 2025 Act.

38 **SECTION 10. Captions.** The section captions used in this 2025 Act are provided only for
 39 the convenience of the reader and do not become part of the statutory law of this state or
 40 express any legislative intent in the enactment of this 2025 Act.

41 **SECTION 11. Effective date.** This 2025 Act takes effect on the 91st day after the date on
 42 which the 2025 regular session of the Eighty-third Legislative Assembly adjourns sine die.