

House Bill 2978

Sponsored by Representative PHAM H, Senator GORSEK, Representative BYNUM; Representatives HUDSON, REYNOLDS (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**.

Establishes Parkinson's disease registry.

A BILL FOR AN ACT

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

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

SECTION 1. Definitions. (1) **As used in sections 1 to 6 of this 2023 Act:**

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

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

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

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

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

(2) **A health care facility, licensed health care practitioner or clinical laboratory, diagnosing or providing treatment to patients with Parkinson's disease or related Parkinsonisms shall report each case of Parkinson's disease or related Parkinsonisms to the authority in a format prescribed by the authority.**

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

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

(b) **Fulfill the authority's duties under sections 1 to 6 of this 2023 Act.**

(4) **The authority shall adopt rules establishing a Parkinson's Disease Registry Advisory Committee to assist in the development and implementation of the registry, determine what data shall be collected and generally advise the authority on issues related to carrying out the duties described in sections 1 to 6 of this 2023 Act. Membership of the advisory committee must include a neurologist, a movement disorder specialist, a primary care physician, a**

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.

1 physician informaticist, a patient diagnosed with Parkinson's disease, a person who is
2 knowledgeable about public health and safety, a population health researcher familiar with
3 registries and a Parkinson's disease researcher and other individuals the department deems
4 necessary. The advisory committee shall meet at least biannually.

5 (5) All patients diagnosed with Parkinson's disease or related Parkinsonisms shall be
6 provided a notice in writing and orally regarding the collection of information and patient
7 data on Parkinson's disease. Patients who do not wish to participate in the collection of data
8 under the registry system for purposes of research shall affirmatively opt-out in writing af-
9 ter an opportunity to review the documents and ask questions. A patient may not be forced
10 to participate in the registry.

11 (6) The authority shall establish a system for the collection and dissemination of infor-
12 mation determining the incidence and prevalence of Parkinson's disease and related
13 Parkinsonisms.

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

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

24 **SECTION 3. Confidentiality of information.** (1) All identifying information regarding in-
25 dividual patients, health care facilities and practitioners reported pursuant to section 2 of
26 this 2023 Act shall be confidential and privileged. Except as required in connection with the
27 administration or enforcement of public health laws or rules, no public health official, em-
28 ployee or agent shall be examined in an administrative or judicial proceeding as to the ex-
29 istence or contents of data collected under the registry system for Parkinson's disease and
30 related Parkinsonisms.

31 (2) All additional information reported in connection with a special study shall be confi-
32 dential and privileged and shall be used solely for the purposes of the study, as provided by
33 ORS 413.196. Nothing in this section shall prevent the Oregon Health Authority from pub-
34 lishing statistical compilations relating to morbidity and mortality studies that do not iden-
35 tify individual cases or prevent use of this data by third parties to conduct research as
36 provided by section 4 of this 2023 Act.

37 **SECTION 4. Use of confidential data; rules.** (1) The Oregon Health Authority shall adopt
38 rules under which confidential data may be used by third parties to conduct research and
39 studies for the public good. Research and studies conducted using confidential data from the
40 statewide registry must be reviewed and approved by the Committee for the Protection of
41 Human Research Subjects established in accordance with 45 C.F.R. 46.

42 (2) The authority may enter into agreements to exchange information with other regis-
43 tries for patients diagnosed with Parkinson's disease and related Parkinsonisms to obtain
44 complete reports of Oregon residents diagnosed or treated in other states and to provide
45 information to other states regarding the residents of other states diagnosed or treated in

1 Oregon. Before providing information to any other registry, the authority shall ensure that
 2 the recipient registry has comparable confidentiality protections.

3 **SECTION 5. Action for damages; license; disciplinary action prohibited for good faith**
 4 **participation in reporting of data.** (1) An action for damages arising from the disclosure of
 5 confidential or privileged information may not be maintained against any person, or the
 6 employer or employee of any person, who participates in good faith in the reporting of reg-
 7 istry data for Parkinson’s disease and related Parkinsonisms in accordance with sections 1
 8 to 5 of this 2023 Act.

9 (2) A license of a health care facility or practitioner may not be denied, suspended or
 10 revoked for the good faith disclosure of confidential or privileged information in the report-
 11 ing of registry data for Parkinson’s disease and related Parkinsonisms in accordance with
 12 sections 1 to 5 of this 2023 Act.

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

16 **SECTION 6. No requirement or prohibition regarding operation of separate registry.**
 17 Nothing in sections 1 to 5 of this 2023 Act shall prohibit a health care facility from operating
 18 its own registry for Parkinson’s disease and related Parkinsonisms or require a health care
 19 facility to operate its own registry for Parkinson’s disease and related Parkinsonisms.

20 **SECTION 7. Temporary provisions.** The Oregon Health Authority shall provide notifica-
 21 tion of the mandatory reporting of diagnoses of Parkinson’s disease and related
 22 Parkinsonisms on its website and shall also provide that information to associations repre-
 23 senting physicians and hospitals and directly to the boards regulating health care profes-
 24 sionals at least 90 days before requiring information be reported.

25 **SECTION 8. Section 7 sunset.** Section 7 of this 2023 Act is repealed on January 2, 2025.

26 **SECTION 9. Operative date.** (1) Sections 1 to 7 of this 2023 become operative January 1,
 27 2024.

28 (2) The members of the Parkinson’s Disease Registry Advisory Committee shall be ap-
 29 pointed no later than January 1, 2024.

30 (3) The registry system described in section 2 of this 2023 Act must be operative no later
 31 than July 1, 2024.

32 (4) The Oregon Health Authority may adopt rules and take any other action before the
 33 operative date specified in subsection (1) of this section that is necessary to enable the au-
 34 thority, on and after the operative date specified in subsection (1) of this section, to under-
 35 take and exercise all of the duties, functions and powers conferred on the authority by
 36 sections 1 to 7 of this 2023 Act.

37 **SECTION 10. Captions.** The section captions used in this 2023 Act are provided only for
 38 the convenience of the reader and do not become part of the statutory law of this state or
 39 express any legislative intent in the enactment of this 2023 Act.

40 **SECTION 11. Effective date.** This 2023 Act takes effect on the 91st day after the date on
 41 which the 2023 regular session of the Eighty-second Legislative Assembly adjourns sine die.
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