

By Senator Calatayud

38-01287-26

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A bill to be entitled

An act relating to the Parkinson's Disease Registry; amending s. 1004.4352, F.S.; defining the term "department"; subject to a specific appropriation, requiring the Department of Health to contract with the Consortium for Parkinson's Disease Research within the University of South Florida for a specified purpose; requiring the department contract with the consortium to require use of a nationally recognized platform to collect data for the registry; beginning on a specified date, requiring physicians who diagnose or treat a patient with Parkinson's disease to report specified information to the registry; requiring the department to adopt certain rules in consultation with the Parkinson's Disease Research Board, the Board of Medicine, and the Board of Osteopathic Medicine; requiring physicians to notify patients orally and in writing of specified information before submitting reports to the registry; providing procedures for a patient to opt out of the registry; requiring the Parkinson's Disease Research Board to submit quarterly reports to the department; requiring the department to submit annual reports to the Governor and the Legislature; providing requirements for the reports; requiring the department to publish certain information and the annual reports on its website; providing physicians immunity from liability and disciplinary action under certain circumstances; providing an effective date.

38-01287-26

20261684__

Be It Enacted by the Legislature of the State of Florida:

Section 1. Subsection (3) of section 1004.4352, Florida Statutes, is amended, and subsection (5) is added to that section, to read:

1004.4352 Parkinson's disease research.—

(3) DEFINITIONS.—As used in this section, the term:

(a) "Board" means the Parkinson's Disease Research Board.

(b) "Consortium" means the Consortium for Parkinson's Disease Research.

(c) "Department" means the Department of Health.

(5) PARKINSON'S DISEASE REGISTRY.—Subject to a specific appropriation, the department shall contract with the consortium to establish and maintain a Parkinson's Disease Registry to ensure that the Parkinson's disease data required to be submitted under paragraph (a) is maintained and available for use for research to advance therapies, improve patient outcomes, and find potential cures for the disease. The department contract must require the consortium to use a nationally recognized platform to collect data from physicians as required in paragraph (a).

(a) Beginning January 1, 2027, each physician licensed under chapter 458 or chapter 459 who diagnoses or treats a patient with Parkinson's disease shall report to the registry information specified by the department, by rule, which indicates patient demographics, diagnosis, stage of disease, medical history, any laboratory data, the methods of diagnosis or treatment used, and any other information the board

38-01287-26

20261684__

recommends for inclusion in the registry. In adopting rules under this paragraph, the department shall consult with the board, the Board of Medicine, and the Board of Osteopathic Medicine.

(b) A physician who diagnoses a patient with Parkinson's disease shall notify the patient orally and in writing about the registry and the required reporting under this subsection. If a patient does not want his or her personal identifying information included in the registry, the physician must certify in writing that the patient has been notified of the registry, provided information about the operation of the registry, and afforded the opportunity to ask questions, but wishes to opt out of the registry. If a patient opts out of the registry, only deidentified personal health information may be submitted for inclusion in the registry.

(c) The board shall provide quarterly reports to the department on the data collected. By January 1, 2028, and annually thereafter, the department shall submit a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives detailing all of the following:

1. The incidence and prevalence of Parkinson's disease in this state, by county.

2. Demographic information, including, but not limited to, patients' age, sex, and race.

3. Any recommendations from the board for legislative changes necessary for improving operation of the registry.

(d) The department shall publish on its website information on Parkinson's disease, including ongoing research, available resources for persons diagnosed with Parkinson's disease, and

38-01287-26

20261684__

the annual report prepared under paragraph (c).

(e) A physician who in good faith complies with the requirements of this subsection is not liable for damages and may not be subject to disciplinary action for the sole reason of having submitted information to the registry as required under paragraph (a).

Section 2. This act shall take effect July 1, 2026.