

Amendment No.1

COMMITTEE/SUBCOMMITTEE ACTION

ADOPTED (Y/N)
ADOPTED AS AMENDED (Y/N)
ADOPTED W/O OBJECTION (Y/N)
FAILED TO ADOPT (Y/N)
WITHDRAWN (Y/N)
OTHER

1 Committee/Subcommittee hearing bill: Health & Human Services
2 Committee

3 Representative Trabulsy offered the following:

4

5 **Amendment**

6 Remove lines 30-128 and insert:

7 diagnoses or treats a patient for Parkinson's disease or
8 atypical parkinsonism shall report to the statewide Parkinson's
9 disease registry, established pursuant to s. 1004.4352,
10 information containing nationally recognized Parkinson's disease
11 performance measures.

12 (2) A liability of any kind or character for damages or
13 other relief may not arise or be enforced against a physician by
14 reason of having provided such information to the statewide
15 Parkinson's disease registry.

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16 **Section 2. Section 459.075, Florida Statutes, is created to**
17 **read:**

18 459.075 Parkinson's disease registry; reporting
19 requirement.—

20 (1) Beginning January 1, 2027, each physician who
21 diagnoses or treats a patient for Parkinson's disease or
22 atypical parkinsonism shall report to the statewide Parkinson's
23 disease registry, established pursuant to s. 1004.4352,
24 information containing nationally recognized Parkinson's disease
25 performance measures.

26 (2) A liability of any kind or character for damages or
27 other relief may not arise or be enforced against a physician by
28 reason of having provided such information to the statewide
29 Parkinson's disease registry.

30 **Section 3. Section 464.0124, Florida Statutes, is created**
31 **to read:**

32 464.0124 Parkinson's disease registry; advanced practice
33 registered nurse reporting requirement.—

34 (1) Beginning January 1, 2027, each advanced practice
35 registered nurse who diagnoses or treats a patient for
36 Parkinson's disease or atypical parkinsonism shall report to the
37 statewide Parkinson's disease registry, established pursuant to
38 s. 1004.4352, information containing nationally recognized
39 Parkinson's disease performance measures.

40 (2) A liability of any kind or character for damages or

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41 other relief may not arise or be enforced against a physician by
42 reason of having provided such information to the statewide
43 Parkinson's disease registry.

44 **Section 4. Paragraphs (b) and (e) of subsection (4) of**
45 **section 1004.4352, Florida Statutes, are amended, and subsection**
46 **(5) is added to that section, to read:**

47 1004.4352 Parkinson's disease research.—

48 (4) CONSORTIUM FOR PARKINSON'S DISEASE RESEARCH.—

49 (b) The Parkinson's Disease Research Board is established
50 to direct the operations of the consortium. The board shall be
51 composed of one member appointed by the President of the Senate,
52 one member appointed by the Speaker of the House of
53 Representatives, and members representing each participating
54 university or academic medical center, appointed by the
55 president or chief executive officer of each participating
56 university or academic medical center. Board members, other than
57 those appointed by the President of the Senate or the Speaker of
58 the House of Representatives, must have experience as a movement
59 disorder specialist and in informatics or population health
60 research and Parkinson's disease research in a variety of
61 scientific fields, including, but not limited to, neurology,
62 psychology, nutrition, and genetics. Members shall be appointed
63 to 3-year ~~4-year~~ terms and may be reappointed to serve
64 additional terms. The chair shall be elected by the board from
65 among its members to serve a 2-year term. The board shall meet

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66 at least semiannually at the call of the chair or, in his or her
67 absence or incapacity, the vice chair. Four members constitute a
68 quorum. A majority vote of the members present is required for
69 all actions of the board. The board may prescribe, amend, and
70 repeal a charter governing the manner in which it conducts its
71 business. Board members shall serve without compensation, but
72 are entitled to receive reimbursement for travel expenses by the
73 consortium or the organization he or she represents in
74 accordance with s. 112.061.

75 (e) By October 15 of each year, the board shall issue a
76 report to the Governor, the President of the Senate, and the
77 Speaker of the House of Representatives on research projects,
78 research findings, and community outreach initiatives conducted
79 or funded by, and future plans for the consortium. Beginning on
80 October 15, 2028, and annually thereafter, the report shall
81 include a summary update on the incidence and prevalence of
82 Parkinson's disease and atypical parkinsonism in the state by
83 county, how many records have been included and reported into
84 the registry, and demographic information such as patients by
85 age, gender, and race.

86 (5) PARKINSON'S DISEASE REGISTRY.—

87 (a) Subject to a specific appropriation, the Florida
88 Institute for Parkinson's Disease within the University of South
89 Florida shall establish and maintain a statewide Parkinson's
90 disease registry to ensure that the Parkinson's disease and

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91 atypical parkinsonism performance measures required to be
92 submitted under paragraph (b) are maintained and available for
93 use to improve or modify the Parkinson's disease and atypical
94 parkinsonism care system, ensure compliance with standards and
95 nationally recognized guidelines, and monitor Parkinson's
96 disease and atypical parkinsonism patient outcomes.

97 (b) Physicians licensed under chapter 458 or chapter 459,
98 pursuant to ss. 458.352 and 459.075, and advanced practice
99 registered nurses, pursuant to s. 464.0124, shall regularly
100 report to the statewide Parkinson's disease registry information
101 containing nationally recognized Parkinson's disease and
102 atypical parkinsonism performance measures.

103 (c) Beginning January 1, 2028, the Institute for
104 Parkinson's Disease within the University of South Florida shall
105 create and maintain a public website dedicated solely to the
106 Parkinson's disease registry which must include, at a minimum,
107 downloadable annual reports on the incidence and prevalence of
108 Parkinson's disease and atypical parkinsonism, information on
109 the consortium, and other