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1
2 An act relating to a progressive supranuclear palsy
3 and other neurodegenerative diseases policy committee;
4 providing a short title; requiring the State Surgeon
5 General to establish a progressive supranuclear palsy
6 and other neurodegenerative diseases policy committee;
7 requiring the Department of Health to provide staff
8 and administrative support to the committee; providing
9 for duties, membership, and meetings of the committee;
10 requiring the State Surgeon General to submit a
11 progress report and a final report by a specified date
12 to the Governor and the Legislature; requiring the
13 reports to be made available on the department's
14 website; providing for the expiration of the
15 committee; providing an effective date.
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17 Be It Enacted by the Legislature of the State of Florida:
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19 Section 1. This act may be cited as the "Justo R. Cortes
20 Progressive Supranuclear Palsy Act."

21 Section 2. Progressive supranuclear palsy and other
22 neurodegenerative diseases policy committee.-

23 (1) The State Surgeon General shall establish a progressive
24 supranuclear palsy and other neurodegenerative diseases policy
25 committee, a committee as defined in s. 20.03, Florida Statutes.
26 The Department of Health shall provide staff and administrative
27 support to the committee for purposes of carrying out its duties
28 and responsibilities.

29 (2) The committee shall do all of the following:

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30 (a) Identify the aggregate number of people in the state
31 diagnosed with progressive supranuclear palsy or other
32 neurodegenerative diseases annually.

33 (b) Identify how data is collected regarding diagnoses of
34 progressive supranuclear palsy or other neurodegenerative
35 diseases and adverse health outcomes associated with such
36 conditions.

37 (c) Identify how progressive supranuclear palsy and other
38 neurodegenerative diseases impact the lives of people in the
39 state.

40 (d) Identify the standard of care for the surveillance,
41 detection, and treatment of progressive supranuclear palsy and
42 other neurodegenerative diseases.

43 (e) Identify emerging treatments, therapies, and research
44 relating to progressive supranuclear palsy and other
45 neurodegenerative diseases.

46 (f) Develop a risk surveillance system to help health care
47 providers identify patients who may be at a higher risk of
48 developing progressive supranuclear palsy and other
49 neurodegenerative diseases.

50 (g) Develop policy recommendations to help improve patient
51 awareness of progressive supranuclear palsy and other
52 neurodegenerative diseases.

53 (h) Develop policy recommendations to help improve
54 surveillance and detection of patients who may be at a higher
55 risk of being diagnosed with progressive supranuclear palsy and
56 other neurodegenerative diseases in licensed health care
57 facilities, including hospitals, nursing homes, assisted living
58 facilities, residential treatment facilities, and ambulatory

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59 surgical centers.

60 (i) Develop policy recommendations relating to guidelines
61 that affect the standard of care for patients with progressive
62 supranuclear palsy or other neurodegenerative diseases.

63 (j) Develop policy recommendations relating to providing
64 patients and their families with written notice of increased
65 risks of being diagnosed with progressive supranuclear palsy and
66 other neurodegenerative diseases.

67 (3) The committee shall be composed of 20 members,
68 including the State Surgeon General. Members of the committee
69 must be appointed by September 1, 2024.

70 (a) The State Surgeon General shall appoint health care
71 providers, family members or caretakers of patients who have
72 been diagnosed with progressive supranuclear palsy and other
73 neurodegenerative diseases, advocates, and other interested
74 parties and associations.

75 (b) The President of the Senate and the Speaker of the
76 House of Representatives shall each appoint two members to the
77 committee.

78 (c) Members of the committee shall serve without
79 compensation and for the entirety of the committee's existence.

80 (d) The State Surgeon General shall appoint the chair of
81 the committee.

82 (e) The chair of the committee may create subcommittees to
83 help conduct research, schedule speakers on important subjects,
84 and draft reports and policy recommendations.

85 (f) Meetings of the committee shall be held through
86 teleconference or other electronic means. The committee shall
87 meet for its initial meeting by October 1, 2024. Thereafter, the

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88 committee may meet upon the call of the chair or upon the
89 request of a majority of its members. Notices for any scheduled
90 meetings of the committee must be published in advance on the
91 department's website.

92 (4) (a) The State Surgeon General shall submit a progress
93 report detailing committee activities, as well as his or her
94 findings and recommendations, to the Governor, the President of
95 the Senate, and the Speaker of the House of Representatives by
96 January 4, 2025. The report must be made available on the
97 department's website.

98 (b) The State Surgeon General shall submit a final report
99 detailing committee activities, as well as his or her findings
100 and recommendations, to the Governor, the President of the
101 Senate, and the Speaker of the House of Representatives by
102 January 4, 2026. The report must be made available on the
103 department's website.

104 (5) The committee shall sunset July 1, 2026, and this
105 section is repealed on that date.

106 Section 3. This act shall take effect July 1, 2024.