

1 A bill to be entitled
 2 An act relating to a progressive supranuclear palsy
 3 and other neurodegenerative diseases policy workgroup;
 4 providing a short title; creating s. 408.0622, F.S.;
 5 requiring the Secretary of Health Care Administration,
 6 in conjunction with the State Surgeon General, to
 7 establish a progressive supranuclear palsy and other
 8 neurodegenerative diseases policy workgroup; providing
 9 for duties, membership, and meetings of the workgroup;
 10 requiring the secretary to submit annual reports and a
 11 final report by a specified date to the Governor and
 12 the Legislature; providing an effective date.

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

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 16 Section 1. This act may be cited as the "Justo R. Cortes
 17 Progressive Supranuclear Palsy Act."

18 Section 2. Section 408.0622, Florida Statutes, is created
 19 to read:

20 408.0622 Progressive supranuclear palsy and other
 21 neurodegenerative diseases policy workgroup.-

22 (1) The Secretary of Health Care Administration, in
 23 conjunction with the State Surgeon General, shall establish a
 24 progressive supranuclear palsy and other neurodegenerative
 25 diseases policy workgroup.

26 (2) The workgroup shall:

27 (a) Identify the aggregate number of people in the state
28 diagnosed with progressive supranuclear palsy and other
29 neurodegenerative diseases annually.

30 (b) Identify how data is collected regarding diagnoses of
31 progressive supranuclear palsy and other neurodegenerative
32 diseases and adverse health outcomes associated with such
33 conditions.

34 (c) Identify how progressive supranuclear palsy and other
35 neurodegenerative diseases impact the lives of people in the
36 state.

37 (d) Identify the standard of care for the surveillance,
38 detection, and treatment of progressive supranuclear palsy and
39 other neurodegenerative diseases.

40 (e) Identify emerging treatments, therapies, and research
41 relating to progressive supranuclear palsy and other
42 neurodegenerative diseases.

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

47 (g) Develop policy recommendations to help improve patient
48 awareness of progressive supranuclear palsy and other
49 neurodegenerative diseases.

50 (h) Develop policy recommendations to help improve

51 surveillance and detection of patients who may be at a higher
52 risk of being diagnosed with progressive supranuclear palsy and
53 other neurodegenerative diseases in licensed health care
54 facilities, including hospitals, nursing homes, assisted living
55 facilities, residential treatment facilities, and ambulatory
56 surgical centers.

57 (i) Develop policy recommendations relating to guidelines
58 that affect the standard of care for patients with progressive
59 supranuclear palsy and other neurodegenerative diseases.

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

64 (3)(a) The workgroup shall be composed of health care
65 providers, family members or caretakers of patients who have
66 been diagnosed with progressive supranuclear palsy and other
67 neurodegenerative diseases, advocates, and other interested
68 parties and associations.

69 (b) The President of the Senate and the Speaker of the
70 House of Representatives shall each appoint two members to the
71 workgroup.

72 (c) Members of the workgroup shall serve without
73 compensation.

74 (d) The State Surgeon General shall appoint the chair of
75 the workgroup.

76 (e) The chair of the workgroup may create subcommittees to
77 help conduct research, schedule speakers on important subjects,
78 and draft reports and policy recommendations.

79 (f) Meetings of the workgroup may be held through
80 teleconference or other electronic means.

81 (4) (a) The Secretary of Health Care Administration shall
82 submit an annual report detailing his or her findings and
83 providing recommendations to the Governor, the President of the
84 Senate, and the Speaker of the House of Representatives.

85 (b) The Secretary of Health Care Administration shall
86 submit a final report detailing his or her findings and
87 providing recommendations to the Governor, the President of the
88 Senate, and the Speaker of the House of Representatives by
89 January 4, 2026.

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