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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. 381.991, F.S.;
5	requiring the State Surgeon General to establish a
6	progressive supranuclear palsy and other
7	neurodegenerative diseases policy workgroup; providing
8	for duties, membership, and meetings of the workgroup;
9	requiring the State Surgeon General to submit annual
10	reports and a final report by a specified date to the
11	Governor and the Legislature; providing an effective
12	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 381.991, Florida Statutes, is created
19	to read:
20	381.991 Progressive supranuclear palsy and other
21	neurodegenerative diseases policy workgroup
22	(1) The State Surgeon General shall establish a
23	progressive supranuclear palsy and other neurodegenerative
24	diseases policy workgroup.
25	(2) The workgroup shall:
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CODING: Words stricken are deletions; words underlined are additions.

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Identify the aggregate number of people in the state (a) diagnosed with progressive supranuclear palsy and other neurodegenerative diseases annually. (b) Identify how data is collected regarding diagnoses of progressive supranuclear palsy and other neurodegenerative diseases and adverse health outcomes associated with such conditions. (c) Identify how progressive supranuclear palsy and other neurodegenerative diseases impact the lives of people in the state. (d) Identify the standard of care for the surveillance, detection, and treatment of progressive supranuclear palsy and other neurodegenerative diseases. (e) Identify emerging treatments, therapies, and research relating to progressive supranuclear palsy and other neurodegenerative diseases. (f) Develop a risk surveillance system to help health care providers identify patients who may be at a higher risk of developing progressive supranuclear palsy and other neurodegenerative diseases. (q) Develop policy recommendations to help improve patient awareness of progressive supranuclear palsy and other neurodegenerative diseases.

(h) Develop policy recommendations to help improve

50 surveillance and detection of patients who may be at a higher

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51	risk of being diagnosed with progressive supranuclear palsy and
52	other neurodegenerative diseases in licensed health care
53	facilities, including hospitals, nursing homes, assisted living
54	facilities, residential treatment facilities, and ambulatory
55	surgical centers.
56	(i) Develop policy recommendations relating to guidelines
57	that affect the standard of care for patients with progressive
58	supranuclear palsy and other neurodegenerative diseases.
59	(j) Develop policy recommendations relating to providing
60	patients and their families with written notice of increased
61	risks of being diagnosed with progressive supranuclear palsy and
62	other neurodegenerative diseases.
63	(3)(a) The workgroup shall be composed of health care
64	providers, family members or caretakers of patients who have
65	been diagnosed with progressive supranuclear palsy and other
66	neurodegenerative diseases, advocates, and other interested
67	parties and associations.
68	(b) The President of the Senate and the Speaker of the
69	House of Representatives shall each appoint two members to the
70	workgroup.
71	(c) Members of the workgroup shall serve without
72	compensation.
73	(d) The State Surgeon General shall appoint the chair of
74	the workgroup.
75	(e) The chair of the workgroup may create subcommittees to
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76	help conduct research, schedule speakers on important subjects,
77	and draft reports and policy recommendations.
78	(f) Meetings of the workgroup may be held through
79	teleconference or other electronic means.
80	(4)(a) The State Surgeon General shall submit an annual
81	report detailing his or her findings and providing
82	recommendations to the Governor, the President of the Senate,
83	and the Speaker of the House of Representatives.
84	(b) The State Surgeon General shall submit a final report
85	detailing his or her findings and providing recommendations to
86	the Governor, the President of the Senate, and the Speaker of
87	the House of Representatives by January 4, 2026.
88	Section 3. This act shall take effect July 1, 2024.

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