



357376

LEGISLATIVE ACTION

Senate	.	House
Comm: RCS	.	
12/05/2023	.	
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The Committee on Health Policy (Brodeur) recommended the following:

**Senate Amendment (with title amendment)**

Delete everything after the enacting clause  
and insert:

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

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

(1) The State Surgeon General shall establish a progressive  
supranuclear palsy and other neurodegenerative diseases policy



357376

11 committee, a committee as defined in s. 20.03. The Department of  
12 Health shall provide staff and administrative support to the  
13 committee for purposes of carrying out its duties and  
14 responsibilities.

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

16 (a) Identify the aggregate number of people in the state  
17 diagnosed with progressive supranuclear palsy or other  
18 neurodegenerative diseases annually.

19 (b) Identify how data is collected regarding diagnoses of  
20 progressive supranuclear palsy or other neurodegenerative  
21 diseases and adverse health outcomes associated with such  
22 conditions.

23 (c) Identify how progressive supranuclear palsy and other  
24 neurodegenerative diseases impact the lives of people in the  
25 state.

26 (d) Identify the standard of care for the surveillance,  
27 detection, and treatment of progressive supranuclear palsy and  
28 other neurodegenerative diseases.

29 (e) Identify emerging treatments, therapies, and research  
30 relating to progressive supranuclear palsy and other  
31 neurodegenerative diseases.

32 (f) Develop a risk surveillance system to help health care  
33 providers identify patients who may be at a higher risk of  
34 developing progressive supranuclear palsy and other  
35 neurodegenerative diseases.

36 (g) Develop policy recommendations to help improve patient  
37 awareness of progressive supranuclear palsy and other  
38 neurodegenerative diseases.

39 (h) Develop policy recommendations to help improve



357376

40 surveillance and detection of patients who may be at a higher  
41 risk of being diagnosed with progressive supranuclear palsy and  
42 other neurodegenerative diseases in licensed health care  
43 facilities, including hospitals, nursing homes, assisted living  
44 facilities, residential treatment facilities, and ambulatory  
45 surgical centers.

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

49 (j) Develop policy recommendations relating to providing  
50 patients and their families with written notice of increased  
51 risks of being diagnosed with progressive supranuclear palsy and  
52 other neurodegenerative diseases.

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

56 (a) The State Surgeon General shall appoint health care  
57 providers, family members or caretakers of patients who have  
58 been diagnosed with progressive supranuclear palsy and other  
59 neurodegenerative diseases, advocates, and other interested  
60 parties and associations.

61 (b) The President of the Senate and the Speaker of the  
62 House of Representatives shall each appoint two members to the  
63 committee.

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

66 (d) The State Surgeon General shall appoint the chair of  
67 the committee.

68 (e) The chair of the committee may create subcommittees to



357376

69 help conduct research, schedule speakers on important subjects,  
70 and draft reports and policy recommendations.

71 (f) Meetings of the committee shall be held through  
72 teleconference or other electronic means. The committee shall  
73 meet for its initial meeting by October 1, 2024. Thereafter, the  
74 committee may meet upon the call of the chair or upon the  
75 request of a majority of its members. Notices for any scheduled  
76 meetings of the committee must be published in advance on the  
77 department's website.

78 (4) (a) The State Surgeon General shall submit a progress  
79 report detailing committee activities, as well as his or her  
80 findings and recommendations, to the Governor, the President of  
81 the Senate, and the Speaker of the House of Representatives by  
82 January 4, 2025. The report must be made available on the  
83 department's website.

84 (b) The State Surgeon General shall submit a final report  
85 detailing committee activities, as well as his or her findings  
86 and recommendations, to the Governor, the President of the  
87 Senate, and the Speaker of the House of Representatives by  
88 January 4, 2026. The report must be made available on the  
89 department's website.

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

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

93  
94 ===== T I T L E A M E N D M E N T =====

95 And the title is amended as follows:

96 Delete everything before the enacting clause  
97 and insert:



357376

98                                   A bill to be entitled  
99           An act relating to a progressive supranuclear palsy  
100          and other neurodegenerative diseases policy committee;  
101          providing a short title; requiring the State Surgeon  
102          General to establish a progressive supranuclear palsy  
103          and other neurodegenerative diseases policy committee;  
104          requiring the Department of Health to provide staff  
105          and administrative support to the committee; providing  
106          for duties, membership, and meetings of the committee;  
107          requiring the State Surgeon General to submit a  
108          progress report and a final report by a specified date  
109          to the Governor and the Legislature; requiring the  
110          reports to be made available on the department's  
111          website; providing for the expiration of the  
112          committee; providing an effective date.