



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

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

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

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

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

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

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

49 (h) Develop policy recommendations to help improve  
50 surveillance and detection of patients who may be at a higher

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

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.