

CHAPTER 2024-165

Committee Substitute for Senate Bill No. 186

An act relating to a progressive supranuclear palsy and other neurodegenerative diseases policy committee; providing a short title; requiring the State Surgeon General to establish a progressive supranuclear palsy and other neurodegenerative diseases policy committee; requiring the Department of Health to provide staff and administrative support to the committee; providing for duties, membership, and meetings of the committee; requiring the State Surgeon General to submit a progress report and a final report by a specified date to the Governor and the Legislature; requiring the reports to be made available on the department's website; providing for the expiration of the committee; providing an effective date.

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

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

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

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

(b) Identify how data is collected regarding diagnoses of progressive supranuclear palsy or 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.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Approved by the Governor May 10, 2024.

Filed in Office Secretary of State May 10, 2024.