

The Florida Senate
BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Committee on Health Policy

BILL: SB 186

INTRODUCER: Senator Brodeur and others

SUBJECT: Progressive Supranuclear Palsy and Other Neurodegenerative Diseases Policy Workgroup

DATE: November 21, 2023 REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	<u>Morgan</u>	<u>Brown</u>	<u>HP</u>	<u>Pre-meeting</u>
2.	_____	_____	<u>AHS</u>	_____
3.	_____	_____	<u>FP</u>	_____

I. Summary:

SB 186 creates s. 408.0622, F.S., requiring the Secretary of the Agency for Health Care Administration (AHCA), in conjunction with the State Surgeon General, to establish a progressive supranuclear palsy and other neurodegenerative diseases policy workgroup (workgroup).

The workgroup is assigned specific duties to identify the impact of progressive supranuclear palsy and other neurodegenerative diseases on Floridians, while providing recommendations to improve health awareness, detection, and outcomes.

The bill establishes the membership of the workgroup and authorizes the workgroup chair to create subcommittees. The bill requires the Secretary of the AHCA to submit an annual report detailing findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The bill requires the Secretary of the AHCA to submit a final report to the Governor and the Legislature by January 4, 2026.

The bill provides that, once enacted, the act may be cited as the “Justo R. Cortes Progressive Supranuclear Palsy Act.”

The bill provides an effective date of July 1, 2024.

II. Present Situation:

Neurodegenerative disease is an umbrella term used for a plethora of conditions that gradually damage and destroy parts of the nervous system, especially areas of the brain. The effects and symptoms of these diseases tend to appear later in life and usually develop slowly.¹

Cases of such disorders are rare, with researchers estimating that neurodegenerative diseases affect more than 50 million people worldwide; however, most of these conditions are strongly attributed to age and are far more likely in persons over 65 years old.² According to the U.S. Census Bureau's 2020 population estimates, more than 55 million Americans are age 65 or older, one-fourth of whom live in California, Florida, and Texas.³ Florida's older residents compose 21.3 percent of the population, or approximately 4,638,000 of the state's 21,733,000 estimated residents.⁴

Diagnosing a neurodegenerative disease varies based on the suspected condition:

- Neurologic exam by a healthcare provider to discuss symptoms and medical history.
- Laboratory testing, such as blood and genetic tests.
- Imaging scans, such as computed tomography and magnetic resonance imaging scans.
- Histopathology, or microscopic tissue analysis, after death. Some neurodegenerative diseases are suspected, but a confirmed diagnosis is only possible after examining brain samples post autopsy.

Other tests are possible and continue to be developed.⁵

Neurodegenerative diseases are incurable and irreversible, but some of them can be treated in order to manage, limit, or slow symptom advancement and the resulting complications. Other neurodegenerative diseases have no treatment, meaning a more reactionary approach is taken versus preventive, i.e. treat the symptoms to promote the best quality of life.⁶

Progressive Supranuclear Palsy

Progressive supranuclear palsy (PSP)⁷ is a rare, complex condition that affects the brain, resulting in muscle weakness that worsens over time, limiting the ability to walk, and causing visual impairment. It is known as an atypical form of parkinsonism⁸, as well as a motor neuron disease.⁹

¹ Cleveland Clinic, *Neurodegenerative Diseases*, available at <https://my.clevelandclinic.org/health/diseases/24976-neurodegenerative-diseases> (last visited Dec. 1, 2023).

² *Supra* note 1.

³ Population Reference Bureau, *Which U.S. States Have the Oldest Populations?*, available at <https://www.prb.org/resources/which-us-states-are-the-oldest/> (last visited Dec. 1, 2023).

⁴ *Id.*

⁵ *Supra* note 1.

⁶ *Id.*

⁷ Johns Hopkins Medicine, *Progressive Supranuclear Palsy*, available at <https://www.hopkinsmedicine.org/health/conditions-and-diseases/progressive-supranuclear-palsy> (last visited Dec. 1, 2023).

⁸ Cleveland Clinic, *Parkinsonism*, available at <https://my.clevelandclinic.org/health/diseases/22815-parkinsonism> (last visited Dec. 1, 2023).

⁹ *Supra* note 1.

PSP Risk Factors

PSP occurs when brain cells in an area of the brain stem become damaged, but how or why these cells are damaged remains unknown. Although anyone could develop PSP, it is more common in men and those of late middle age or older.¹⁰

PSP Symptoms and Complications

Early signs of PSP can be subtle, but disease progression increases symptom severity. Problems with balance and rigidity or discomfort while walking often tend to be the first indicators of PSP.¹¹

Other symptoms include:¹²

- Increased forgetfulness and irritability.
- Unusual emotional outbursts, such as crying or laughing unexpectedly or at inappropriate times.
- Irrational anger.
- Hand tremors.
- Trouble controlling eye movement.
- Blurred vision.
- Slurred speech.
- Trouble swallowing.
- Dementia.
- Depression.
- Inability to control the eyelids, such as unwanted blinking or eye opening difficulty.

A careful evaluation of symptoms can help diagnose PSP, but signs often mirror those of Parkinson's disease, or even an inner ear infection, increasing the likelihood of misdiagnosis. However, key differences include:¹³

- Significant difficulty with speech and swallowing.
- Problems with eye movement, specifically when looking up or down.
- Leaning and falling backward versus forward.

While PSP is not fatal, symptoms will worsen and, like all neurodegenerative diseases, it cannot be cured. Nevertheless, complications, such as pneumonia from the inhalation of food particles while choking, can be life threatening.¹⁴

¹⁰ *Supra* note 7.

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ *Id.*

PSP Treatment

Although there is no medicine or procedure to completely control the symptoms of PSP, there are strategies and methods available to assist in the management of symptoms, such as medications for the treatment of Parkinson's disease to improve balance, flexibility of the muscles, and depression.¹⁵

Other treatment options include:¹⁶

- Special glasses with prisms to improve vision.
- A weighted tool or aid to assist in walking and prevent falling backwards.
- Physical therapy and exercise to improve flexibility and decrease muscle atrophy.
- A feeding tube for when swallowing becomes too difficult.

Other Neurodegenerative Diseases

Other types of neurodegenerative diseases include:¹⁷

- Dementia-type diseases, which can cause progressive damage to various areas of the brain, resulting in neuron death and a wide range of symptoms. These include Alzheimer's disease, frontotemporal dementia, chronic traumatic encephalopathy, Lewy body dementia, and limbic predominant age-related TDP-43 encephalopathy.
- Demyelinating diseases, which involve myelin damage or loss and can affect the sending and relaying of nerve signals. These include conditions such as multiple sclerosis and neuromyelitis optica spectrum disorder.
- Parkinsonism-type diseases, which involve damage to specific neurons in the brain that help manage coordination and precise control of muscle movements. These include Parkinson's disease and other forms of parkinsonism.
- Motor neuron diseases, which involve the death of neurons that control movement. These include conditions such as amyotrophic lateral sclerosis and PSP.

Risk Factors

Although there are multiple causation factors attributed to most neurodegenerative diseases, a few have been identified as a stronger indicator than others.¹⁸

- Age: Older individuals are more likely to develop a neurodegenerative disease.
- Genetics: Spontaneous mutations can occur, specific mutations can be inherited, and a combination of genes can increase the risk of developing a neurodegenerative disease.
- Environment: Exposure to pollution, chemicals and toxins, certain types of infections, address, etc.
- Medical history: Specific medical events can catalyze or exacerbate some neurodegenerative conditions.
- Lifestyle: Habits, routine, and choices, such as food, fitness, smoking, etc.

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ *Supra* note 1.

¹⁸ *Id.*

Symptoms and Complications

The symptoms of neurodegenerative diseases can vary widely, even among people with the same condition, as each brain is unique, the causes of the disease can differ, and the symptoms are dependent on the part of the brain or nervous system that has been affected. However, a commonality in those diagnosed is the correlation between progression and independence, i.e., the further the disease advances, the less self-reliant an afflicted individual becomes.¹⁹

In general, the following symptoms and complications are associated with neurodegenerative diseases:²⁰

- Dementia-type diseases: Confusion, memory loss, trouble thinking or concentrating, and behavior changes.
- Demyelinating diseases: Tingling or numbness, pain, muscle spasms, weakness and paralysis, coordination issues, and fatigue.
- Parkinsonism-type diseases: Slowed movements, shaking and tremors, balance problems, shuffling steps, and hunched posture, as well as decreased strength, flexibility, agility, and reflexes, increasing the risk of falls and fractures.
- Motor neuron diseases: Muscle weakness that progresses to paralysis, as well as increased risk of pneumonia and other respiratory conditions.

Executive Branch Structure

Chapter 20, F.S., creates the organizational structure of the Executive Branch of state government, and s. 20.03, F.S., provides definitions for uniform nomenclature throughout the structure of the Executive Branch, including bodies created as adjuncts to Executive Branch departments, agencies, or offices. Several such adjuncts are defined, including:

- Commission: Unless otherwise required by the State Constitution, “commission” means a body created by specific statutory enactment within a department, the office of the Governor, or the Executive Office of the Governor and exercising limited quasi-legislative or quasi-judicial powers, or both, independently of the head of the department or the Governor.
- Committee or Task Force: A “committee” or “task force” means an advisory body created without specific statutory enactment for a time not to exceed one year or created by specific statutory enactment for a time not to exceed three years and appointed to study a specific problem and recommend a solution or policy alternative with respect to that problem. Its existence terminates upon the completion of its assignment.
- Coordinating Council: A “coordinating council” means an interdepartmental advisory body created by law to coordinate programs and activities for which one department has primary responsibility but in which one or more other departments have an interest.
- Council or Advisory Council: A “council” or an “advisory council” means an advisory body created by specific statutory enactment and appointed to function on a continuing basis for the study of the problems arising in a specified functional or program area of state government and to provide recommendations and policy alternatives.

¹⁹ *Id.*

²⁰ *Id.*

III. Effect of Proposed Changes:

Section 1 provides that, once enacted, the act may be cited as the “Justo R. Cortes Progressive Supranuclear Palsy Act.”

Section 2 creates s. 408.0622, F.S., to establish a PSP and other neurodegenerative diseases policy workgroup. The bill requires the Secretary of the AHCA, in conjunction with the State Surgeon General, to establish workgroup duties with the following:

- Identifying the aggregate number of people diagnosed with PSP and other neurodegenerative diseases each year in this state.
- Identifying how data is collected regarding diagnoses of PSP and other neurodegenerative diseases and adverse health outcomes associated with such conditions.
- Identifying how PSP and other neurodegenerative diseases impact the lives of people in the state.
- Identifying the standard of care for the surveillance, detection, and treatment of PSP and other neurodegenerative diseases.
- Identifying emerging treatments, therapies, and research relating to PSP and other neurodegenerative diseases.
- Developing a risk surveillance system to help health care providers identify patients who may be at a higher risk of developing PSP and other neurodegenerative diseases.
- Developing policy recommendations to help improve patient awareness of PSP and other neurodegenerative diseases.
- Developing policy recommendations to help improve surveillance and detection of patients who may be at a higher risk of being diagnosed with PSP and other neurodegenerative diseases in licensed health care facilities, including hospitals, nursing homes, assisted living facilities, residential treatment facilities, and ambulatory surgical centers.
- Developing policy recommendations relating to guidelines that affect the standard of care for patients with PSP and other neurodegenerative diseases.
- Developing policy recommendations relating to providing patients and their families with written notice of increased risks of being diagnosed with PSP and other neurodegenerative diseases.

The bill requires the workgroup to be composed of health care providers, family members or caretakers of patients who have been diagnosed with PSP and other neurodegenerative diseases, advocates, and other interested parties and associations.

The bill requires the President of the Senate and the Speaker of the House of Representatives to each appoint two members to the workgroup, and the State Surgeon General to appoint the chair of the workgroup. The bill authorizes the chair to create subcommittees to help with research, scheduling speakers on important subjects, and drafting a workgroup report and policy recommendations.

The bill authorizes meetings of the workgroup to be held through teleconference or other electronic means and prohibits workgroup members from being compensated.

The bill requires the Secretary of the AHCA to submit an annual report detailing findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The bill requires the Secretary of the AHCA to submit a final report to the Governor and the Legislature by January 4, 2026.

Section 3 provides an effective date of July 1, 2024.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

D. State Tax or Fee Increases:

None.

E. Other Constitutional Issues:

None.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

The bill may have an indeterminate fiscal impact on state revenues or state expenditures as it is silent regarding reimbursement for per diem or travel expenses incurred in relation to potential in-person meetings.

VI. Technical Deficiencies:

None.

VII. Related Issues:

While the bill does not specifically designate staff from either the AHCA or the Florida Department of Health to provide administrative support to assist with workgroup duties, both agencies will incur an insignificant operational impact to coordinate and manage the workgroup, as well as prepare the interim and final reports.

The bill does not speak to the total number of members and is silent as to whose responsibility it is to appoint those workgroup members not chosen by the President of the Senate or the Speaker of the House or appointed as the chair by the State Surgeon General.

The bill creates a “workgroup,” which is undefined in ch. 20, F.S. If the workgroup is deemed to be a committee or taskforce, s. 20.03, F.S., requires it to sunset in three years; however, if the workgroup is deemed a council or advisory council, statute authorizes its perpetual existence. The bill is silent as to when or if the workgroup sunsets, stating only that a final report must be submitted to the Legislature by January 4, 2026.

The bill is silent as to when the interim annual reports should be submitted each year.

VIII. Statutes Affected:

This bill creates section 408.0622 of the Florida Statutes.

This bill creates one non-statutory section of the Laws of Florida.

IX. Additional Information:

A. **Committee Substitute – Statement of Changes:**
(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

B. **Amendments:**

None.