HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: CS/HB 115 Progressive Supranuclear Palsy and Other Neurodegenerative Diseases Policy Workgroup
SPONSOR(S): Healthcare Regulation Subcommittee, Bankson and others
TIED BILLS: **IDEN./SIM. BILLS:** SB 186

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
1) Healthcare Regulation Subcommittee	16 Y, 0 N, As CS	Guzzo	McElroy
2) Health Care Appropriations Subcommittee	11 Y, 0 N	Aderibigbe	Clark
3) Health & Human Services Committee	17 Y, 0 N	Guzzo	Calamas

SUMMARY ANALYSIS

Progressive supranuclear palsy (PSP) is a rare neurodegenerative disease that can severely inhibit an individual's balance and ability to walk, speech and ability to swallow, eye movements and vision, mood and behavior, and cognition. There is no cure for PSP and treatment is limited to managing the signs and symptoms. PSP is not fatal, but complications from PSP often lead to death, usually resulting from pneumonia or a serious fall. PSP worsens over time, so early diagnosis is preferred, however, it shares many symptoms with, and is often misdiagnosed as other neurogenerative diseases, including Parkinson's disease and Alzheimer's disease.

The bill creates the Justo R. Cortes Progressive Supranuclear Palsy Act to require the State Surgeon General to establish a progressive supranuclear palsy and other neurogenerative diseases policy workgroup. The bill tasks the workgroup with identifying PSP incidence and other data, identifying the standard of care for PSP, and developing a risk surveillance system and various policy recommendations, among other tasks.

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 neurogenerative diseases, advocates, and other interested parties and associations. The bill requires the Speaker of the House of Representatives and the President of the Senate to appoint two members each. Further, the bill requires the State Surgeon General to appoint the chair of the workgroup and authorizes the chair to create subcommittees to assist 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 via teleconference or other electronic means.

Finally, the bill requires the Department of Health to submit an annual report and a final report with findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives, by January 4, 2026.

The bill has no fiscal impact on state or local government.

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

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. EFFECT OF PROPOSED CHANGES:

Background

Neurodegenerative Diseases

Neurodegenerative diseases are conditions that gradually destroy parts of the nervous system, especially the brain.[1] These conditions usually develop slowly, and the effects and symptoms tend to appear later in life.[2] Neurodegenerative diseases are permanent and incurable, but many are now treatable, with the goal being to treat the symptoms and slow the progress of these conditions when possible.[3] Neurodegenerative diseases include Alzheimer's disease, Lewy body dementia, Parkinson's disease, amyotrophic lateral sclerosis (also known as Lou Gehrig's disease), and progressive supranuclear palsy.[4]

Progressive Supranuclear Palsy

Progressive supranuclear palsy (PSP) is a neurodegenerative disease that affects an individual's balance and ability to walk, speech, swallowing, eye movements and vision, mood and behavior, and cognition.

PSP is not fatal, but complications from PSP often lead to death.[5] The most common first sign of PSP is trouble with balance, which can lead to abrupt and unexplained falls. A person with PSP will begin to experience eye problems, such as difficulty opening and closing their eyes, blinking, seeing clearly or moving their eyes side to side or up and down, which can also result in falls.[6] Falls causing bone fractures and head trauma are a common cause of death in people with PSP.[7]

Slow or slurred speech and difficulty swallowing are also common in individuals with PSP. The inability to correctly swallow food and liquids can lead to leakage of food into the windpipe, which can result in pneumonia, the most common cause of death in individuals with PSP.[8]

Other symptoms include:[9]

- Depression;
- Lack of motivation;
- Changes in judgement, insight, and problem solving;
- Difficulty finding words;
- Forgetfulness;
- Loss of interest in activities the person used to enjoy;
- Increased irritability;
- Sudden laughing, crying, or angry outbursts for no apparent reason;
- Personality changes;
- Blank stares with raised eyebrows; and

[1] Cleveland Clinic, Neurodegenerative Diseases, available at https://my.clevelandclinic.org/health/diseases/24976-neurodegenerative-diseases (last visited December 5, 2023).
[2] Id.
[3] Id.
[4] Id.
[5] Cleveland Clinic, Progressive Supranuclear Palsy, available at https://my.clevelandclinic.org/health/diseases/6096-progressive-supranuclear-palsy (last visited December 5, 2023).
[6] Id.
[7] Id.
[8] Id.
[9] National Institute of Neurological Disorders and Stroke, Progressive Supranuclear Palsy, available at https://www.ninds.nih.gov/health-information/disorders/progressive-supranuclear-palsy-psp (last visited December 5, 2023).

- Insomnia.

Diagnosis

PSP is considered a rare disorder. It is currently estimated that 10 to 12 people per 100,000 are living with PSP, about 30,000–40,000 in the United States.[10] However, recent autopsy studies indicate PSP is under-diagnosed. These studies found PSP pathology in 2 to 4% of elderly people that had no diagnosis of PSP before death.[11]

Currently, there are several challenges to diagnosing someone in the early stages of PSP. There is no diagnostic laboratory or radiologic test for PSP. Next, PSP shares many symptoms with, and is often misdiagnosed as Parkinson's disease.[12] However, unlike Parkinson's disease, symptoms of PSP typically begin later in life, usually in an individual's late 60s or 70s.[13] PSP also progresses more rapidly than Parkinson's disease.[14] Finally, some patients with PSP present to their health care provider with cognitive impairment and are misdiagnosed with dementia.[15] These patients ultimately develop abnormalities of eye movement, speech, swallowing and gait in a few years.[16] As a result, most patients are diagnosed fairly late in the course of the illness.[17]

Treatment

Currently, there is no treatment that effectively stops or slows the progression of PSP, and symptoms do not respond well to medications.[18]

The cause of PSP is not known, but it is a form of tauopathy, in which abnormal phosphorylation of the protein tau is associated with destruction of vital protein filaments in nerve cells, which is hypothesized to cause the death of nerve cells.[19] Most experimental treatments are aimed at preventing tau pathology.[20]

Executive Branch Adjunct Bodies

Chapter 20, F.S., creates the organizational structure of the Executive Branch of state government, including the creation of certain adjunct bodies to Executive Branch departments, agencies, or offices. Such bodies include committees or task forces, commissions, councils or advisory councils, and coordinating councils.

A committee or task force is an advisory body created without specific statutory enactment for a time not to exceed one year or created by specific statutory enactment for up to three years and appointed to study a specific problem and recommend a solution or policy alternative. Its existence terminates upon the completion of its assignment.[21]

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[10] Cure PSP, Unlocking the Secrets of Brain Disease, available at https://www.psp.org/iwanttolearn/progressive-supranuclear-palsy/ (last visited December 5, 2023).
[11] Kovacs GG, Milenkovic I, Wöhrer A, et al. Non-Alzheimer neurodegenerative pathologies and their combinations are more frequent than commonly believed in the elderly brain: a community-based autopsy series. Acta Neuropathol 2013; 126: 365–84. *See also* Yoshida K, Hata Y, Kinoshita K, Takashima S, Tanaka K, Nishida N. Incipient progressive supranuclear palsy is more common than expected and may comprise clinicopathological subtypes: a forensic autopsy series. Acta Neuropathol. 2017 May;133(5):809-823. doi: 10.1007/s00401-016-1665-7. Epub 2017 Jan 7. PMID: 28064358.
[12] *Supra* note 5.
[13] Mayo Clinic, Diseases and Conditions, Supranuclear Palsy, available at https://www.mayoclinic.org/diseases-conditions/progressive-supranuclear-palsy/symptoms-causes/syc-20355659 (last visited December 5, 2023).
[14] Id.
[15] *Supra* note 9.
[16] Id.
[17] Id.
[18] *Supra* note 11.
[19] *Supra* note 9.
[20] Id.
[21] S. 20.03(5), F.S.

A commission is 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 Governor.[22]

A council or advisory council is 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.[23]

A coordinating council is 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.[24]

Effect of the Bill

The bill creates the Justo R. Cortes Progressive Supranuclear Palsy Act to require the State Surgeon General, to establish a progressive supranuclear palsy and other neurogenerative diseases policy workgroup. For purposes of chapter 20, F.S., the workgroup is considered a committee or task force. The bill tasks the workgroup with:

- Identifying the aggregate number of people in this state who are diagnosed with PSP and other neurogenerative diseases annually;
- Identifying how data is collected regarding diagnoses of PSP and other neurogenerative diseases, and adverse outcomes associated with these conditions;
- Identifying how PSP and other neurogenerative diseases impact the lives of Floridians;
- Identifying the standard of care for PSP and other neurogenerative diseases surveillance, detection, and treatment;
- Identifying emerging treatments, therapies, and research relating to PSP and other neurogenerative 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 neurogenerative diseases;
- Developing policy recommendations to help improve patient awareness of PSP and other neurogenerative 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 neurogenerative 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 used that affect the standard of care for patients with PSP and other neurogenerative diseases; and
- Developing policy recommendations relating to providing patients and their families with written notice of increased risks of being diagnosed with PSP and other neurogenerative 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 neurogenerative diseases, advocates, and other interested parties and associations. The bill requires the Speaker of the House of Representatives and the President of the Senate to appoint two members each. Further, the bill requires the State Surgeon General to appoint the chair of the workgroup and authorizes the chair to create subcommittees to assist 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 via teleconference or other electronic means.

Finally, the bill requires the Department of Health (DOH) to submit an annual report and a final report with findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives, by January 4, 2026.

[22] S. 20.03(4), F.S.
[23] S. 20.03(7), F.S.
[24] S. 20.03(6), F.S.

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

B. SECTION DIRECTORY:

Section 1: Cites the act as the "Justo R. Cortes Progressive Supranuclear Palsy Act."
Section 2: Creates s. 381.991, F.S., relating to progressive supranuclear palsy and other neurogenerative diseases policy workgroup.
Section 3: Provides an effective date of July 1, 2024.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

   None.

2. Expenditures:

   None.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

   None.

2. Expenditures:

   None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

   Not applicable. The bill does not appear to affect local or municipal governments.

2. Other:

   None.

B. RULE-MAKING AUTHORITY:

The bill does not require rule adoption to implement it.

C. DRAFTING ISSUES OR OTHER COMMENTS:

None.

IV. AMENDMENTS/COMMITTEE SUBSTITUTE CHANGES

On December 14, 2023, the Healthcare Regulation Subcommittee adopted two amendments and reported the bill favorably as a committee substitute. The amendments:

- Required DOH to establish the workgroup instead of AHCA; and
- Required DOH, instead of AHCA, to submit the annual and final reports to the Governor and the Legislature.

This analysis is drafted to the committee substitute as passed by the Healthcare Regulation Subcommittee.