HOUSE OF REPRESENTATIVES STAFF FINAL BILL 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:** CS/SB 186

FINAL HOUSE FLOOR ACTION: 112 **Y's** 0 **N's** **GOVERNOR'S ACTION:** Approved

SUMMARY ANALYSIS

CS/HB 115 passed the House on March 6, 2024, as CS/SB 186.

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 20-member policy committee on progressive supranuclear palsy and other neurogenerative diseases. Members of the committee must be appointed by the State Surgeon General, the Speaker of the House of Representatives, and the President of the Senate.

The bill tasks the committee 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 Department of Health to submit a progress report by January 4, 2025, and a final report by January 4, 2026, with findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The bill provides a sunset date for the committee of July 1, 2026.

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

The bill was approved by the Governor on May 10, 2024, ch. 2024-165, L.O.F., and will become effective on July 1, 2024.

I. SUBSTANTIVE INFORMATION

A. EFFECT OF 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;

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[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).

- Blank stares with raised eyebrows; and
- 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 Committees

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, councils, commissions, and coordinating councils.

Under ch. 20, F.S., a committee 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.[21] Its existence

[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.

terminates upon the completion of its assignment.[22] Committee members may receive per diem and reimbursement for travel expenses, but they are prohibited from receiving compensation unless expressly authorized by specific statutory enactment.[23] Under ch. 20, F.S., a committee is required to keep the Legislature and the public informed of its numbers, purposes, memberships, activities, and expenses. All committee meetings must be open to the public unless an exemption is provided by law.[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 committee. The bill requires the Department of Health (DOH) to provide staff and administrative support to the committee.

Under the bill, the committee must:

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

The bill requires the committee to consist of 20 members, including the State Surgeon General, who must appoint 15 members who are 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 Speaker of the House of Representatives and the President of the Senate must appoint two members each. Further, the bill requires the State Surgeon General to appoint the chair of the committee and authorizes the chair to create subcommittees to assist with research, scheduling speakers on important subjects, and drafting a committee report and policy recommendations.

The bill requires the committee to hold 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. DOH must publish notices for meetings of the committee in advance on its website. The bill authorizes meetings of the committee to be held via teleconference or other electronic means.

The bill requires DOH to submit a progress report by January 4, 2025, and a final report by January 4, 2026, with findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives. DOH must make the report available on its website. The bill provides a sunset date for the committee of July 1, 2026.

[22] *Id.*
[23] S. 20.052, F.S.
[24] *Id.*

The bill 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.