CS/SB 186 — Progressive Supranuclear Palsy and Other Neurodegenerative Diseases Policy Committee

by Health Policy Committee and Senators Brodeur, Pizzo, Wright, Boyd, Burgess, Rouson, Hutson, Davis, Ingoglia, Garcia, Book, and Stewart

The bill provides that the act may be cited as the "Justo R. Cortes Progressive Supranuclear Palsy Act" and creates a non-statutory section of the L.O.F, to require the State Surgeon General to establish a Progressive Supranuclear Palsy and Other Neurodegenerative Diseases Policy Committee (committee).

The bill requires the Department of Health (DOH) to provide staff and administrative support to the committee for the purposes of carrying out the duties and responsibilities established in the bill.

The bill requires that the committee be composed of 20 members, including the State Surgeon General, health care providers, family members or caretakers of patients who have been diagnosed with progressive supranuclear palsy (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 and the State Surgeon General to appoint the chair and all other members of the Committee. Members of the Committee must be appointed by September 1, 2024, and will serve without compensation for the entirety of the committee's existence.

The bill authorizes the Chair to create subcommittees to help with research, scheduling speakers, and drafting committee reports and policy recommendations. Meetings of the committee must be held through teleconference or other electronic means. The committee must meet for its initial meeting by October 1, 2024. Thereafter, the committee must meet upon the call of the chair or at the request of a majority of the members. Notices for any scheduled meetings of the committee must be published in advance on the DOH website.

The bill requires the State Surgeon General to submit a progress report detailing committee activities, as well as findings and recommendations, to the Governor, the President of the Senate, and the Speaker of the House of Representatives by January 4, 2025. The bill also requires the State Surgeon General to submit a final report to the Governor and the Legislature by January 4, 2026. Both reports must be made available on the DOH website.

The bill provides that the committee will sunset July 1, 2026, and repeals this section of law on that date.

If approved by the Governor, or allowed to become law without the Governor's signature, the bill takes effect July 1, 2024. *Vote: Senate 39-0; House 112-0*