
SENATE COMMITTEE ON APPROPRIATIONS

Senator Sabrina Cervantes, Chair
2025 - 2026 Regular Session

SB 1047 (Niello) - Neurodegenerative disease registry program

Version: April 6, 2026

Urgency: No

Hearing Date: April 13, 2026

Policy Vote: HEALTH 11 - 0

Mandate: No

Consultant: Agnes Lee

Bill Summary: SB 1047 would require the California Department of Public Health (CDPH) to collect information determining the incidence and prevalence of frontotemporal degeneration (FTD).

Fiscal Impact: Unknown ongoing General Fund costs, potentially hundreds of thousands, for the CDPH for state administration and implementation.

Background: Current law requires CDPH to establish a system for the collection of information determining the incidence and prevalence of neurodegenerative diseases, including, but not limited to, amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. Current law provides that "neurodegenerative disease" may also include, but need not be limited to, Alzheimer's disease, multiple sclerosis, and Huntington's disease. The CDPH operates the California Neurodegenerative Disease Registry (CNDR) to collect this information. Current law sunsets these provisions on January 1, 2028.

According to the National Institute of Neurological Disorders and Stroke, FTD (also known as frontotemporal dementia, frontotemporal disorder, frontotemporal lobar degeneration, or Pick's disease) is caused by damage to neurons in the frontal and temporal lobes of the brain. Neuronal damage results in progressive atrophy of the lobes, disrupting the functions associated with these regions, such as planning and decision-making, emotional regulation, memory, and language. Depending on what area of the brain is affected, patients may also display difficulty with motor control. Because FTD is progressive, an individual's symptoms will change over time as more parts of the brain are affected. FTD is diagnosed by neurological and cognitive exams and behavioral evaluations, family history and genetic testing, brain imaging, and laboratory tests that exclude the possibility of Alzheimer's, but can only be confirmed postmortem.

Proposed Law: Specific provisions of the bill would:

- Require the CDPH to additionally collect information determining the incidence and prevalence of FTD.
- Provide that "neurodegenerative disease" may also include other dementias.
- Extend the sunset date from January 1, 2028 to January 1, 2032.

-- END --