SENATE THIRD READING
SB 1047 (Niello and Allen)
As Amended May 14, 2026
Majority vote

SUMMARY

Expands data collection and reporting requirements for the California Neurodegenerative Disease Registry (CNDR) to include the incidence and prevalence of frontotemporal degeneration (FTD).

COMMENTS

Neurodegenerative Disease Registry Program. CNDR is California's statewide population-based neurodegenerative disease surveillance system. State law requires the Department of Public Health (DPH) to collect other neurodegenerative disease information (other than information on Parkinson's disease, for which the DPH began collecting information in 2018). According to DPH's website, DPH will use the data collected by CNDR to determine incidence and prevalence of other neurodegenerative diseases such as Alzheimer's disease, Multiple Sclerosis, Huntington's disease, and amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease in California.

Frontotemporal Degeneration. According to the information on the Association for Frontotemporal Degeneration's (AFTD) website, FTD, also frequently referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Pick's disease refers to a group of brain disorders caused by degeneration or nerve cell loss mainly in the brain's frontal lobes (the areas behind the forehead) and/or its temporal lobes (the regions behind the ears).

The nerve cell damage caused by FTD leads to loss of function in these brain regions. Symptoms vary, but common ones include uncharacteristic personality changes, apathy, and unexplained struggles with decision-making, movement, speaking or language comprehension. Often people appear physically healthy despite the neurodegeneration.

AFTD notes that although age of onset ranges from 21 to 80, most FTD cases occur between 45 and 64. According to Johns Hopkins Medicine's website, FTD disorders are some of the most common dementias that begin in people of younger ages than typically seen with dementia. AFTD states that the economic burden of FTD is approximately $120,000 per year, which is nearly double the amount associated with Alzheimer's.

FTD's estimated U.S. prevalence is around 60,000 cases, and many in the medical community remain unfamiliar with it. FTD is frequently misdiagnosed as Alzheimer's, depression, Parkinson's disease, or a psychiatric condition. On average, it currently takes 3.6 years to get an accurate diagnosis.

According to Johns Hopkins Medicine's website, the most common types of FTD are:

1) *Frontal variant.* This form of FTD changes behavior and personality; and,

2) *Primary progressive aphasia.* Aphasia means trouble with communication. This form has two subtypes:

a) Nonfluent aphasia, which affects the ability to speak fluently and causes grammar impairment; and,

b) Semantic dementia, which affects how a person uses and understands language. Unlike nonfluent aphasia, people are still able to speak fluently and grammatically, but their speech lacks meaning.

Less common forms of FTD affect movement, causing symptoms similar to Parkinson's disease or ALS. At this time, there is no cure for FTD, but healthcare providers may prescribe medicine to treat symptoms, including antidepressants to help treat anxiety and control obsessive-compulsive behaviors and other symptoms, prescription sleeping aids to help ease insomnia and other sleep disturbances, and antipsychotic medicines to reduce irrational and compulsive behaviors. Behavior modification may help control unacceptable or risky behaviors, and speech and language pathologists and physical and occupational therapists can help with adjustment to some of the changes caused by FTD.

FTD can lead to an increased risk for other illnesses that can be more serious. Failure to thrive and pneumonia are the most common causes of death for people with FTD. People are also at increased risk for infections and fall-related injuries.

Other Dementias. According to an article published in *Harvard Health Publishing* titled, "Alzheimer's disease versus other types of dementia: Understanding the differences," dementia is an umbrella term for a decline in cognitive ability. Alzheimer's disease is a type of dementia, and it's also the most common cause of dementia, accounting for 60% to 80% of all dementias. In addition to Alzheimer's disease, there are many causes of irreversible dementia, including:

1) *Vascular disease.* Vascular dementia is a type of dementia caused by brain damage from impaired blood flow. Dementia may occur following a large stroke, after multiple small strokes, or when small arteries in the brain narrow, leading to decreased blood flow. Vascular dementia is the second most common type of dementia, accounting for up to 20% of cases.

   a) *Lewy body disease (LBD).* LBD refers to dementia associated with accumulation of abnormal protein clumps inside brain cells. LBD causes 5% to 10% of dementias;

   b) *FTD.* As discussed, above;

   c) *Creutzfeldt-Jakob disease.* This disease is a rare, rapidly progressive dementia which occurs when a normal protein in the brain is transformed into an unhealthy one;

   d) *Degenerative diseases.* These include Huntington's disease, a rare inherited disorder linked to an abnormal gene that's also a type of dementia; and Pick's disease, characterized by abnormal clumps of tau protein found within neurons; and,

   e) *Mixed dementia.* Mixed dementia describes a case in which two or more types of dementia occur simultaneously. The most common combination is Alzheimer's disease and vascular dementia.

This bill requires DPH to collect information on FTD within the CNDR and additionally specifies that the definition of neurogenerative disease includes other dementias (in addition to

Alzheimer's disease), explicitly authorizing DPH to collect information on these diseases as well. This bill also extends the sunset of the CNDR from 2028 to 2032.

According to the Author
This bill adds FTD to the CNDR. FTD is a terminal and incurable neurodegenerative disease, causing impairments to speech, personality, behavior, and motor skills which constitutes a major public health concern. FTD represents an estimated 5-15% of dementia cases and is the most common form of dementia for people under 60. The author continues that this bill will help prioritize FTD so researchers can better identify and treat the FTD community and help to speed research into the causes, treatments and hopefully cures for FTD. The author continues that adding FTD to the registry will provide a deeper understanding of the patient population which will help inform patients of clinical trials, a critical tool for those dealing with this disease. The author concludes that this bill also extends the sunset date of CNDR to continue their work on behalf of other previously approved neurodegenerative diseases.

Arguments in Support
AFTD is the sponsor of this bill and writes in support, stating that although neurogenerative diseases may differ in symptoms and progression, they are united by common challenges: delayed or inaccurate diagnoses, limited or nonexistent treatment options, significant caregiver burdens, and profound economic and emotional costs. AFTD continues that neurogenerative diseases are not isolated from one another; many share underlying biological mechanisms and genetic risk factors, with certain gene mutations implicated across multiple disorders. AFTD continues that individuals diagnosed with one neurodegenerative condition may later exhibit features of another, reflecting shared pathways of neurodegeneration. AFTD states that because of this interconnectedness, improving data collection for one condition strengthens understanding across the field. AFTD continues that this bill also extends the sunset date of the CNDR to continue its important work on behalf of the broader neurodegenerative community. AFTD continues that the CNDR is a vital and cost-effective resource for researchers, clinicians, and public health leaders working to understand disease impact, appropriately allocate resources, and improve pathways to care.

Arguments in Opposition
None on file.

FISCAL COMMENTS

According to the Assembly Appropriations Committee, DPH estimates General Fund costs of approximately $2.7 million per year in fiscal years (FYs) 2027-28 through 2031-32 to implement provisions of this bill. DPH states these costs include the following:

1) *Staff*: 7.3 full-time equivalents (FTEs) to support programmatic functions, two FTEs for information technology support, and an additional FTE to incorporate FTD into data collection requirements. Staff serve as subject matter experts, perform data management system (DMS) activities and analysis, create datasets, conduct outreach, and provide technical assistance to data providers, associations, and partners to ensure data accuracy and to meet the statutory mandate.

2) *Information technology*: $400,000 to support the CNDR DMS, including costs associated with the California Reportable Disease Information Exchange manual entry web portal,

integration and data validation tool, associated software, and maintenance and operations of the DMS.

3) *Promulgating regulations*: $63,000

VOTES

SENATE FLOOR: 39-0-1
YES: Allen, Alvarado-Gil, Archuleta, Arreguín, Ashby, Becker, Blakespear, Cabaldon, Caballero, Cervantes, Choi, Cortese, Durazo, Gonzalez, Grayson, Grove, Hurtado, Jones, Laird, Limón, McGuire, McNerney, Menjivar, Niello, Ochoa Bogh, Padilla, Pérez, Reyes, Richardson, Rubio, Seyarto, Smallwood-Cuevas, Stern, Strickland, Umberg, Valladares, Wahab, Weber Pierson, Wiener
ABS, ABST OR NV: Dahle

ASM HEALTH: 15-0-1
YES: Bonta, Chen, Addis, Aguiar-Curry, Ahrens, Caloza, Carrillo, Mark González, Patel, Patterson, Celeste Rodriguez, Sanchez, Schiavo, Sharp-Collins, Stefani
ABS, ABST OR NV: Johnson

ASM APPROPRIATIONS: 15-0-0
YES: Wicks, Hoover, Arambula, Calderon, Caloza, Dixon, Fong, Mark González, Krell, Pacheco, Pellerin, Sharp-Collins, Solache, Ta, Tangipa

UPDATED

VERSION: May 14, 2026

CONSULTANT: Lara Flynn / HEALTH / (916) 319-2097 FN: 0003586