

Date of Hearing: June 16, 2026

ASSEMBLY COMMITTEE ON HEALTH  
Mia Bonta, Chair  
SB 1047 (Niello) – As Amended May 14, 2026

**SENATE VOTE:**

**SUBJECT:** Neurodegenerative disease registry program.

**SUMMARY:** Expands data collection and reporting requirements for the California Neurodegenerative Disease Registry (CNDR). Specifically, **this bill:**

- 1) Requires the State Department of Public Health (DPH) to establish a system for the collection of information determining the incidence and prevalence of frontotemporal degeneration (FTD) within the CNDR.
- 2) Specifies that the definition of “neurogenerative disease” includes other dementias (in addition to Alzheimer’s disease).
- 3) Extends the sunset date of the CNDR from 2028 to 2032.

**EXISTING LAW:**

- 1) Requires DPH 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. Requires DPH to designate the specified neurodegenerative diseases as a disease required to be reported in the state or any part of the state. Requires all cases of neurodegenerative disease diagnosed or treated in California to be reported to DPH. [Health and Safety Code (HSC) § 103871 (a) and (b)]
- 2) Requires DPH to provide notification of the mandatory reporting of neurodegenerative disease on its internet website and to also provide that information to associations representing physicians and hospitals and directly to the Medical Board of California at least 90 days prior to requiring information be reported. [HSC § 103871 (c)]
- 3) Requires a hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment for a patient with a neurodegenerative disease to report each case of a neurodegenerative disease to DPH in a format prescribed by DPH. [HSC § 103871 (d)]
- 4) Authorizes, if the hospital or other facility fails to report in a format prescribed by the department, DPH’s authorized representative to access the information from the hospital or the facility and report it in the appropriate format. Requires the hospital or other facility to reimburse DPH or the authorized representative for its costs to access and report the information. [HSC § 103871 (e)]
- 5) Requires a physician and surgeon, hospital, outpatient clinic, and any other facility, individual, or agency providing diagnostic or treatment services to a patient with a neurodegenerative disease to grant to DPH or the authorized representative access to all records that would identify a case of a neurodegenerative disease or would establish

characteristics of a neurodegenerative disease, treatment of a neurodegenerative disease, or medical status of any identified patient with a neurodegenerative disease. [HSC § 103871 (f)]

- 6) Makes willful failure to grant access to those records punishable by a civil penalty of up to five hundred dollars (\$500) each day access is refused. Requires any civil penalties collected to be deposited by DPH in the General Fund (GF). [*Ibid.*]
- 7) Requires, except as otherwise provided, all information collected pursuant to the CNDR to be confidential. [HSC § 103871 (g)]
- 8) Specifies “neurodegenerative disease” may also include, but need not be limited to, Alzheimer’s disease, multiple sclerosis (MS), and Huntington’s disease. [HSC § 103871 (i)]

**FISCAL EFFECT:** According to the Senate Appropriations Committee, unknown ongoing GF costs, potentially hundreds of thousands, for DPH for state administration and implementation.

#### **COMMENTS:**

**1) PURPOSE OF THIS BILL.** 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.

#### **2) BACKGROUND.**

**a) Neurogenerative Disease Registry Program.** CNDR is California's statewide population-based neurodegenerative disease surveillance system. State law requires 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, MS, Huntington's disease, and ALS, also known as Lou Gehrig's disease in California.

**b) 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:

- i) **Frontal variant.** This form of FTD changes behavior and personality; and,
- ii) **Primary progressive aphasia.** Aphasia means trouble with communication. This form has two subtypes:
  - (1) Nonfluent aphasia, which affects the ability to speak fluently and causes grammar impairment; and,
  - (2) 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.

- c) **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:
  - i) **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.
- ii) **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;
  - iii) **FTD.** Please see b) above for background;
  - iv) **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;
  - v) **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,
  - vi) **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.
- d) **What does this bill do?** This bill requires DPH to collect information on FTD within the CNDR and additionally specifies that the definition of neurodegenerative 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.
- 3) **SUPPORT.** AFTD is the sponsor of this bill and writes in support, stating that although neurodegenerative 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 neurodegenerative 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.
- 4) **RELATED LEGISLATION.** AB 1648 (M. Rodriguez) of 2026 would have required DPH to establish the California Epilepsy Program for the purposes of conducting epidemiological assessments of the incidence and prevalence of epilepsy and seizures. AB 1648 was held on the Assembly Appropriations suspense file.

**5) PREVIOUS LEGISLATION.**

- a) AB 829 (Sharp-Collins), Chapter 99, Statutes of 2025 establishes the Parkinson's Disease Registry Tax Contribution Fund. Authorizes a taxpayer to make a voluntary contribution to the fund on their state personal income tax return from tax year 2025 to 2032, if the fund meets the minimum contribution amount of \$250,000 annually. Directs contributions to the fund be allocated to DPH for the purposes of administering the Richard Paul Hemann Parkinson's Disease Program, as specified.
- b) AB 2680 (Aguilar-Curry), Chapter 335, Statutes of 2024 renames the Alzheimer's Disease and Related Disorders Advisory Committee to the Alzheimer's Disease and Related Conditions Advisory Committee, and expands the number of members serving on the committee from 14 to at least 16, but not more than 20, members. Prescribes the qualifications of certain members on the committee, and revise the duties of the committee. Revises references to Alzheimer's disease to also refer to related conditions.
- c) AB 424 (Bryan), Chapter 522, Statutes of 2023 requires the CNDR to collect information on the incidence and prevalence of ALS.
- d) AB 133 (Committee on Budget), Chapter 143, Statutes of 2021 establishes the CNDR.

**REGISTERED SUPPORT / OPPOSITION:****Support**

The Association for Frontotemporal Degeneration (sponsor)

ALS Association

ALS Network

Alzheimer's Greater Los Angeles

Alzheimer's Orange County

Alzheimer's San Diego

Biocom

Biocom California

California Life Sciences Association

Cure MAPT FTD

CureGRN

End Chronic Disease Inc.

Michael J. Fox Foundation for Parkinson's Research

The Bluefield Project to Cure FTD

**Opposition**

None on file

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