

Date of Hearing: July 1, 2026

ASSEMBLY COMMITTEE ON APPROPRIATIONS

Buffy Wicks, Chair

SB 1047 (Niello) – As Amended May 14, 2026

Policy Committee: Health

Vote: 15 - 0

Urgency: No

State Mandated Local Program: No

Reimbursable: No

**SUMMARY:**

This bill expands California’s Neurodegenerative Disease Registry Program (CNDR) to include frontotemporal degeneration (FTD) and other dementias within the definition of neurodegenerative disease. The bill also extends the CNDR’s sunset date from January 1, 2028, to January 1, 2032.

**FISCAL EFFECT:**

The California Department of Public Health (CDPH) 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. CDPH states these costs include the following:

- 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.
- 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.
- Promulgating regulations: \$63,000.

**COMMENTS:**

- 1) **Purpose.** This bill is sponsored by the Association for Frontotemporal Degeneration (AFTD). According to the author:

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.

Existing law requires CDPH to collect and establish a registry for Parkinson's Disease, amyotrophic lateral sclerosis (ALS), multiple sclerosis and Huntington's disease. It is reported that 75% of physicians in California already use the necessary record-keeping system. [This bill] will help prioritize FTD so researchers can better identify and treat the FTD community. This will help speed research into the causes, treatments and hopefully cures for FTD. 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.

- 2) **Background. FTD.** According to the information on the AFTD website, FTD, also referred to as frontotemporal dementia, frontotemporal lobar degeneration, 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), temporal lobes (the regions near the ears), or both areas. FTD causes nerve cell damage, leading to loss of function in these brain regions. Common symptoms vary and may include personality changes; apathy; and unexplained struggles with decision-making, movement, speaking or language comprehension. 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.

The estimated U.S. prevalence of FTD is around 60,000 cases. FTD is frequently misdiagnosed as Alzheimer's disease, depression, Parkinson's disease, or a psychiatric condition. It takes an average of 3.6 years to get an accurate diagnosis of FTD.

**CNDR.** CNDR is California's statewide, population-based neurodegenerative disease surveillance system. CDPH states it will use CNDR data to determine incidence and prevalence of neurodegenerative diseases in California.

Existing CNDR funding expires at the end of FY 2026-27. Because this bill extends the sunset date for the entire CNDR, CDPH notes the fiscal estimate for the bill includes the full cost to operate the CNDR, including data collection for all conditions already designated in statute (ALS, Alzheimer's disease, multiple sclerosis, Huntington's disease, and other dementias), as well as FTD. The cost estimate therefore reflects the baseline cost of continued registry operations, and an additional FTE to incorporate FTD into data collection requirements.

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