Office of Senate Floor Analyses
(916) 651-4171

THIRD READING

Bill No: SB 1047
Author: Niello (R) and Allen (D), et al.
Amended: 5/14/26
Vote: 21

SENATE HEALTH COMMITTEE: 11-0, 3/25/26
AYES: Weber Pierson, Valladares, Caballero, Durazo, Gonzalez, Grove, Menjivar, Padilla, Pérez, Rubio, Smallwood-Cuevas

SENATE APPROPRIATIONS COMMITTEE: 7-0, 5/14/26
AYES: Cervantes, Seyarto, Cabaldon, Dahle, Grayson, Richardson, Wahab

SUBJECT: Neurodegenerative disease registry program

SOURCE: Association for Frontotemporal Degeneration

DIGEST: This bill (1) expands data collection and reporting requirements for the California Neurodegenerative Disease Registry Program (CNDRP) to include frontotemporal degeneration; (2) extends the CNDRP to January 1, 2032.

ANALYSIS:

Existing law:

1) Requires the California Department of Public Health (CDPH), under the CNDRP and until January 1, 2028, to collect data on the incidence and prevalence of neurodegenerative disease in California, including, but not limited to, amyotrophic lateral sclerosis (ALS). [Health and Safety Code (HSC) §103871 and §103871.2]

2) Allows CDPH to designate which neurodegenerative diseases must be reported and to prescribe the data collection method and data format. [HSC §103871]

3) Requires a hospital, facility, physician, or other health care provider diagnosing or treating a patient with a neurodegenerative disease to report all cases diagnosed or treated in the state to CDPH. [HSC §103871]

4) Specifies that neurodegenerative disease may include but is not limited to Alzheimer's disease, multiple sclerosis, and Huntington's disease. [HSC §103871]

This bill:

1) Expands data collection and reporting requirements for the CNDRP to include frontotemporal degeneration (FTD).

2) Extends the sunset date of the CNDRP to January 1, 2032.

Comments

According to the author of this bill:

> This bill will direct the CNDRP to collect data on FTD and require hospitals and health care professionals to report cases. FTD is a terminal and incurable neurodegenerative disease, causing impairments to speech, personality, behavior, and movement, and 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. 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, speeding research into the causes, treatments, and hopefully cures for FTD, as well as informing patients of clinical trials, a critical tool for those dealing with this disease. This bill also extends the sunset date to continue the work on behalf of other previously approved neurodegenerative diseases.

Background

CNDRP. The CNDRP, within CDPH's Chronic Disease Surveillance and Research Branch, was established in 2021 to collect data on the incidence of neurodegenerative disease in the state to better understand its prevalence among different populations and changes over time. The CNDRP has authority to determine which diseases must be reported. Statute requires that ALS cases be reported, and CDPH separately requires reporting for Alzheimer's disease and multiple sclerosis. According to the CNDRP, the program began collecting data on

multiple sclerosis on July 1, 2023, and has expanded reporting requirements to include Alzheimer's in July of 2025 and ALS in July of 2026. Parkinson's disease is reported via the Richard Paul Hemann California Parkinson's Disease Registry, a similar program that predates the CNDRP.

CNDRP data are obtained from patients' medical records and include their identifying information, demographic data, patient visit information, primary physician information, primary ICD-10 diagnosis code, and disease onset information. CDPH accepts data from registered providers through either manual data entry into a secure web portal or the automated electronic transfer of case files from electronic medical record systems. The data collected by CNDRP are confidential, meaning that detailed data may only be disclosed to researchers who have obtained approval from their institutional review board and have demonstrated their ability to maintain data security, other state neurodegenerative disease registries, federal neurodegenerative disease control agencies, and local health officers. The data can only be used for the stated purpose of their request. Patients and those legally authorized to obtain a patient's confidential information can also access their data.

FTD. 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.

FTD is usually diagnosed in three different categories: behavioral variant frontotemporal dementia (bvFTD); primary progressive aphasia (PPA); and movement disorders. Patients diagnosed with bvFTD display changes in personality, behavior, and judgment, with or without problems with cognition or memory. Those with PPA have difficulty with speaking, reading, writing, and understanding words. PPA patients often display cognitive symptoms of dementia as the disease progresses, and occasionally display behavioral changes as well. FTD-induced movement disorders include corticobasal syndrome, progressive

supranuclear palsy, FTD with parkinsonism, and FTD-ALS. Corticobasal syndrome is characterized by difficulty using hands or arms, sometimes beginning on one side of the body before progressing to both. Those with progressive supranuclear palsy have difficulty walking, balancing, and moving facial muscles, and it is characterized by a fixed stare due to trouble with eye movements. Individuals with FTD with parkinsonism display symptoms similar to Parkinson's disease, including slowed movement, stiffness, and balance issues. FTD-ALS is a combination of bvFTD and ALS, including ALS symptoms like progressive muscle weakness and muscle jerks or wiggling. The movement disorders may also include symptoms affecting behavior, thinking, and language. According to the Association for Frontotemporal Degeneration, an estimated 50,000-60,000 Americans have FTD. Unlike Alzheimer's and many other dementias, FTD primarily affects middle-aged individuals. About 60% of diagnoses occur between 45 and 64 years of age, when many are still working and caring for family members. The life expectancy for those with FTD ranges from two to 20 years from the onset of symptoms.

FISCAL EFFECT: Appropriation: No Fiscal Com.: Yes Local: No

According to the Senate Appropriations Committee, unknown ongoing General Fund costs, potentially hundreds of thousands, for CDPH administration and implementation.

SUPPORT: (Verified 5/14/26)

Association for Frontotemporal Degeneration (source)
ALS Association
ALS Network
Alzheimer's Greater Los Angeles
Alzheimer's Orange County
Alzheimer's San Diego
Biocom California
Bluefield Project
California Life Sciences Association
Cure MAPT FTD
Cure GRN
Michael J. Fox Foundation for Parkinson's Research
Eleven individuals

OPPOSITION: (Verified 5/14/26)

None received

ARGUMENTS IN SUPPORT: The sponsors of this bill, the Association for Frontotemporal Degeneration, along with a coalition of ALS, FTD, and Parkinson's disease organizations, write that it is their goal to ensure every person living with a neurodegenerative disease is seen, counted, and supported through data-informed public policy and research investment. The interconnectedness of many neurodegenerative diseases means improving data collection for one condition strengthens understanding across the field. They also support extending the sunset date of the CNDRP, describing the program as a vital and cost-effective resource for those working to understand disease impact, appropriately allocate resources, and improve pathways to care. Several supporters highlight that the explicit inclusion of FTD and other dementias within the definition of neurodegenerative disease reflects the current state of the science around the interconnectedness of neurodegenerative diseases and emphasize that comprehensive data collection will better inform research, care, resource allocation, and eventually, outcomes for patients. California Life Sciences writes that the existing registry infrastructure uses electronic medical records and established reporting mechanisms to collect data without creating unnecessary administrative burden.

Prepared by: Natalie Gehred / HEALTH / (916) 651-4111
5/18/26 15:19:35

****** END ******