

California Legislature Passes Bipartisan Bill to Expand Tracking of Neurodegenerative Diseases

End Chronic Disease co-sponsored legislation would add frontotemporal degeneration to California's statewide registry and extend the program through 2032

SACRAMENTO, CA, UNITED STATES, August 31, 2026 /EINPresswire.com/ -- The California Legislature has passed [Senate Bill 1047](#), bipartisan legislation co-sponsored by [End Chronic Disease](#) that would strengthen the state's tracking of neurodegenerative diseases and, for the first time, require the collection of statewide data on frontotemporal degeneration, or FTD.

The bill now heads to Governor Gavin Newsom for his signature.

Authored by Senator Roger Niello (R-Fair Oaks) and Senator Ben Allen (D-Santa Monica), SB 1047 builds on California's existing neurodegenerative disease registry by requiring the California Department of Public Health to collect information on the incidence and prevalence of FTD. The legislation would also allow the registry to include other neurodegenerative diseases and extend the program through January 1, 2032.

"For a disease like FTD, where we still have significant gaps in our understanding, building an infrastructure to collect reliable statewide data is essential," said [Kelly McKenna](#), CEO of End Chronic Disease. "Understanding how many people are affected, where they live and what patterns emerge can help researchers and public health leaders ask better questions, direct resources more effectively and ultimately improve our understanding of this devastating disease. SB 1047 is an important step toward building that clearer picture."

FTD is the most common form of dementia among people under age 60. It encompasses a group of progressive brain disorders that can affect personality, behavior, language and movement. Because its symptoms often overlap with those of other neurological and psychiatric conditions, FTD is frequently misdiagnosed or overlooked.

"When Senate Bill 1047 becomes law in California, data collection for frontotemporal degeneration represents far more than just policy. It is a lifeline in our relentless fight to improve the lives of families living with this devastating disease," said Senator Roger Niello. "I am grateful for the devotion of our legislators, advocates, and selfless caregivers who brought the bill this close to the finish line, and I urge Governor Newsom to sign this critical bill into law."

California has required the Department of Public Health to track neurodegenerative diseases since 2022. The registry currently covers conditions including ALS, Alzheimer's disease, multiple sclerosis and Huntington's disease. Adding FTD would help public health officials better understand the disease's prevalence, identify disparities, improve pathways to diagnosis and care, direct resources and support research into causes, treatments and potential prevention.

"Better data can help turn individual experiences into a clearer picture of what is happening across an entire population," McKenna said. "We were proud to join the Association for Frontotemporal Degeneration and a broad coalition of advocates in supporting this effort. We're grateful to Senators Niello and Allen, Assemblymember Irwin, and the families and organizations whose advocacy brought SB 1047 to this important point."

The bill's passage follows months of advocacy by lawmakers, health organizations and families affected by FTD. The Association for Frontotemporal Degeneration has been a leading advocate for the legislation, alongside a broad coalition of organizations representing people affected by FTD, ALS, Parkinson's disease and other neurodegenerative conditions.

Earlier this month, Senators Niello and Allen, Assemblymember Jacqui Irwin, the Association for Frontotemporal Degeneration, and FTD advocate and author Emma Heming Willis joined End Chronic Disease in urging the Legislature to approve the measure.

SB 1047 now moves to Governor Newsom for consideration.

INTERVIEW AVAILABILITY

Senator Roger Niello and End Chronic Disease CEO Kelly McKenna are available for interviews. To schedule an interview, contact Christina Pascucci at Christina@endchronicdisease.org.

ABOUT END CHRONIC DISEASE

End Chronic Disease is a national nonpartisan organization working to address the root causes of chronic illness through public education, policy advocacy and evidence-based solutions. The organization supports efforts that provide researchers, health care professionals and policymakers with the information and tools needed to improve prevention, care and health outcomes.

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