

Final Push for Bipartisan Neurodegenerative Disease Tracking Bill

Final Push for Bipartisan Bill to Expand California's Tracking of Neurodegenerative Diseases, Including a Devastating Form of Dementia in Younger People

SACRAMENTO, CA, UNITED STATES, July 31, 2026 /EINPresswire.com/ -- As neurodegenerative diseases affect a growing number of California families,

End Chronic Disease is joining lawmakers, medical advocates and patient families to urge passage of [Senate Bill 1047](#), with final legislative votes approaching.



Since 2022, California has required the Department of Public Health to track the incidence of neurodegenerative diseases, including ALS, Alzheimer's disease, multiple sclerosis and Huntington's disease, through a statewide registry. SB 1047 builds on that foundation, extending the registry program through 2030 and, for the first time, adding frontotemporal degeneration (FTD) and other dementias to the list of conditions the state formally tracks.

FTD is the most common form of dementia among people under age 60 and encompasses a group of progressive brain disorders affecting personality, behavior, language and motor function. Its symptoms often overlap with those of other neurological and psychiatric conditions, leaving it frequently misdiagnosed or overlooked. As scientific understanding of FTD and other neurological conditions continues to evolve, expanding the state's registry will help public health leaders better understand disease patterns, support research, and improve diagnosis, care, and prevention.

"The best solutions start with better understanding. As more families are affected by neurodegenerative diseases, high-quality public health data helps us see the bigger picture, connecting the dots and revealing patterns that can better inform decisions about research, prevention, and care," said [Kelly McKenna](#), CEO of End Chronic Disease.

The absence of systematic statewide data on FTD specifically has made it harder to determine how many Californians are affected, identify disparities, direct resources, improve pathways to

care, accelerate research into treatments, and better understand opportunities for prevention. Expanding the registry to include FTD can help close these gaps.

The August 3 press conference represents a critical final push ahead of the bill's remaining legislative votes. The bill's authors and advocates will discuss why California needs a stronger, more complete neurodegenerative disease registry, while families affected by FTD will share their personal experiences. Emma Heming Willis, whose husband, actor Bruce Willis, is living with FTD, will share her family's experience and discuss the urgent need for better data, resources and support.

Senator [Roger Niello](#) and FTD advocate and author Emma Heming Willis will be available for on-camera interviews for media attending the press conference.

"By strengthening California's neurodegenerative disease registry, SB 1047 will provide researchers, clinicians, public health officials, and policymakers with stronger data to improve our understanding of these conditions and ultimately help improve outcomes for patients and families. End Chronic Disease is proud to support this bipartisan legislation," McKenna said.

McKenna will be available for Zoom interviews to discuss why more comprehensive public health data is essential to preventing, treating and ultimately ending chronic disease.

WHO Senator Roger Niello (R-Fair Oaks), Joint Author Senator Ben Allen (D-Santa Monica), Joint Author Assemblymember Jacqui Irwin (D-Thousand Oaks), Co-author Meghan Buzby, Director of Advocacy and Volunteer Engagement, Association for Frontotemporal Degeneration Emma Heming Willis, Author and FTD Advocate

WHAT Senate Bill 1047 Press Conference

WHEN Monday, August 3, 2026 – 12:00 p.m.

WHERE California State Capitol, Room 112 – 1315 10th Street – Sacramento, CA 95814

INTERVIEW AVAILABILITY In person/on camera: Senator Roger Niello and Emma Heming Willis following the press conference. Via Zoom: End Chronic Disease CEO Kelly McKenna for journalists unable to attend in person. To arrange an interview, contact 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, healthcare professionals and policymakers with the information and tools needed to improve prevention, care and health outcomes.

Senator Roger Niello was elected in 2022 and represents California's 6th Senate District, which includes portions of Placer and Sacramento counties.

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