Date of Hearing: March 24, 2026

ASSEMBLY COMMITTEE ON HEALTH
Mia Bonta, Chair
AB 1648 (Michelle Rodriguez) – As Introduced January 28, 2026

SUBJECT: Public health: California Epilepsy Program.

SUMMARY: Establishes the Californian Epilepsy Program with the State Department of Public Health (DPH). Specifically, **this bill**:

1) Defines, for purposes of this chapter, "epilepsy" to mean a disorder of the brain characterized by one or more unprovoked seizures or the diagnosis of an epilepsy syndrome.

2) Requires DPH to establish the California Epilepsy Program for the purposes of conducting epidemiological assessments of the incidence and prevalence of epilepsy and seizures.

3) Requires the program to encompass any area of the state for which epilepsy and seizure incidence or prevalence data are available.

4) Authorizes DPH to seek, receive, and spend any funds received through appropriations, grants, or donations from public or private sources for the purposes of the program.

5) Requires DPH to convene an advisory panel comprised of medical professionals with expertise in epilepsy and seizures, scientific researchers, advocates for individuals with epilepsy, and other individuals with relevant expertise to provide support and advice for the implementation of the program.

6) Authorizes DPH to contract with an entity, including, but not limited to, a health systems agency, single-county health department, multicounty health department grouping, or nonprofit professional association for the purposes of collecting and collating epilepsy and seizure incidence and prevalence data.

7) Requires DPH to analyze available epilepsy and seizure incidence and prevalence data, and to prepare and publish reports on its internet website as necessary.

8) Requires DPH to publish on its internet website a listing of public agencies that offer services to individuals affected by epilepsy, including, but not limited to, Medi-Cal, regional centers, and the Department of Education. Authorizes this list to include private entities that offer services to individuals affected by epilepsy.

EXISTING LAW:

1) Establishes the California Birth Defects Monitoring Program (CBDMP). Requires the State Public Health Officer (SPHO) to maintain a system for the collection of information related to birth defects, as specified. Requires the SPHO to require health facilities to make available to DPH the medical records of children suspected or diagnosed as having birth defects, as specified. Requires the SPHO to use the information collected and information available from other reporting systems and health providers to conduct studies to investigate the causes of birth defects, stillbirths, and miscarriages and to determine and evaluate measures designed to prevent their occurrence. Prohibits DPH's investigation of poor reproductive

outcomes from being limited to geographic, temporal, or occupational associations. Authorizes the inclusion of investigation of past exposures. Requires all information collected pursuant to the CBDMP to be confidential and used solely for the purposes of the CBDMP. [Health and Safety Code (HSC) §§ 103825-103855]

2) Establishes the Parkinson's Disease Registry. Requires DPH to conduct a program of epidemiological assessments of the incidence of Parkinson's disease encompassing all areas of the state for which Parkinson's disease incidence data are available as specified. Requires all physicians, hospitals, outpatient clinics and all other facilities, individuals, or agencies providing diagnostic or treatment services to patients to grant to DPH or its authorized representative access to all records that would identify cases of Parkinson's disease or would establish characteristics of Parkinson's disease, treatment of Parkinson's disease, or medical status of any identified Parkinson's disease patients. Requires all information collected to be confidential, as specified. [HSC §§ 103860-103865]

3) Establishes the California Neurodegenerative Disease Registry Program (CNDR). Requires DPH to collect data on the incidence of neurodegenerative disease, as defined, in California. Requires a hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment to a patient for a neurodegenerative disease to report each case of a neurodegenerative disease to DPH, as prescribed. Repeals these provisions on January 1, 2028. [HSC §§ 103871-103871.2]

4) Requires every physician and surgeon to report immediately to the local health officer (LHO) in writing, the name, date of birth, and address of every patient at least 14 years of age or older whom the physician and surgeon has diagnosed as having a case of a disorder characterized by lapses of consciousness. Authorizes a physician or surgeon, if they reasonably and in good faith believe that the reporting of a patient will serve the public interest, to report a patient's condition even if it may not be required under DPH's definition of disordered characterized by lapses of consciousness. Exempts a physician or surgeon who makes these required or authorized reports from being civilly or criminally liable to any patient. [HSC § 103900]

5) Requires the local health officer to report in writing to the Department of Motor Vehicles (DMV) the name, age, and address of every person reported to it as a case of disorder characterized by lapses of consciousness. Requires these reports to be for the information of the DMV in enforcing the Vehicle Code, and to be confidential and used solely for the purpose of determining the eligibility of any person to operate a motor vehicle on the highways of this state. [*Ibid.*]

6) Requires DPH, in cooperation with the DMV, to define disorders characterized by lapses of consciousness based upon existing clinical standards for that definition for purposes of this section and to include Alzheimer's disease and those related disorders that are severe enough to be likely to impair a person's ability to operate a motor vehicle in the definition. Requires DPH to consult with professional medical organizations whose members have specific expertise in the diagnosis and treatment of those disorders in the development of the definition of what constitutes a disorder characterized by lapses of consciousness as well as definitions of functional severity to guide reporting so that diagnosed cases reported are only those where there is reason to believe that the patients' conditions are likely to impair their ability to operate a motor vehicle. [*Ibid.*]

7) Defines "disorders characterized by lapses of consciousness" in regulations to include medical conditions that involve:

   a) A loss of consciousness or a marked reduction of alertness or responsiveness to external stimuli;

   b) The inability to perform one or more activities of daily living; and

   c) The impairment of the sensory motor functions used to operate a motor vehicle. [Title 17, California Code of Regulations (CDR) § 2806]

8) Provides that examples of medical conditions that do not always, but may progress to the level of functional severity described above include Alzheimer's disease and related disorders, seizure disorders, brain tumors, narcolepsy, sleep apnea, and abnormal metabolic states, including hypo- and hyperglycemia associated with diabetes. [*Ibid*.]

FISCAL EFFECT: Unknown. This bill has not been analyzed by a fiscal committee.

COMMENTS:

1) **PURPOSE OF THIS BILL.** According to the author, epilepsy affects hundreds of thousands of Californians, yet the state lacks a coordinated approach to understanding and addressing the needs of this population. The author continues that without reliable statewide data and clear pathways to services, individuals and families face unnecessary barriers to care, leading to poorer health outcomes and preventable emergency interventions. The author concludes that this bill establishes the California Epilepsy Program to improve data collection, coordination, and public access to resources, helping ensure that all Californians living with epilepsy have a fair opportunity to receive timely, effective care.

2) **BACKGROUND.** Epilepsy is a chronic noncommunicable disease of the brain characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized).

   According to the National Institute of Neurological Disorders and Stroke's website, epilepsy varies in severity and impact from person to person and can be accompanied by a range of co-existing conditions. Epilepsy is sometimes called "the epilepsies" because of the diversity of types and causes. Some people may have convulsions (muscles contract repeatedly) and lose consciousness. Others may simply stop what they are doing, have a brief lapse of awareness, and stare into space for a short period. Some people have seizures very infrequently, while other people may experience hundreds of seizures each day.

   The most common approach to treating epilepsy is to prescribe antiseizure medications. More than 40 different antiseizure medications are available today, all with different benefits and side effects. While antiseizure medications are effective for many people with epilepsy, some do not respond to or are not able to take medications. Those individuals may be candidates for surgery, dietary changes, or devices to stop their seizures.

   a) **Prevalence of Epilepsy.** According to a 2021 review "Epilepsy: A Clinical Overview" published in the *American Journal of Medicine*, epilepsy is the fourth most common

neurological disorder and affects 1 in 26 people in the United States and 65 million people worldwide.

According to the federal Centers for Disease Control and Prevention's (CDC's) National and State Estimates of the Numbers of Adults and Children with Active Epilepsy, in 2015, approximately 3 million U.S. adults and 470,000 children had active epilepsy. Estimated numbers of active epilepsy included more than 427,000 in California.

b) Barriers to Care. According to the CDC's 2022 Morbidity and Mortality Weekly Report reviewing Barriers to and Disparities in Access to Health Care Among Adults with Epilepsy in 2015 and 2017, adults with epilepsy have a harder time getting health care compared to adults without epilepsy. They were more likely to:

i) Be unable to afford any medicine or specialty care.

ii) Be unable to afford dental or vision care.

iii) Skip doses of medicine to save money.

iv) Have trouble finding a health care provider or specialist.

v) Delay care because of transportation barriers.

vi) Live in families having problems paying medical bills.

c) Rising Mortality Rates. The CDC published research in the June 2024 edition of *Epilepsy and Behavior* on epilepsy mortality rates over a 10-year period, identifying an increased rate of death for people with epilepsy from 2011 to 2021. Key findings include:

i) Epilepsy was linked to the deaths of 43,231 adults in the United States (U.S.) over the decade, 2011-2021. Among those deaths, close to 39% were reported with epilepsy as the underlying cause of death, and 61% were reported with epilepsy as a contributing factor.

ii) The U.S. mortality rate for epilepsy rose sharply from 2011 to 2021, particularly from 2019 to 2020 and into 2021.

iii) The rate of deaths with epilepsy as an underlying cause increased 84% (from 2.9 per million to 6.4 per million population) during the decade, while the rate with epilepsy as a contributing cause of death jumped 144% (from 3.3 per million to 11 per million population) over the same period.

iv) Some groups of the U.S. population experienced higher epilepsy-related mortality rates including older adults, males, non-Hispanic Black or American Indian/Alaska Native adults, those living in the West and Midwest, and those living in rural counties.

The Epilepsy Alliance of America (EAA), a national organization dedicated to serving the needs of people who live with seizures and epilepsy, summarized the CDC's key findings on their website and highlights that the reasons for the reported increases in U.S. epilepsy mortality rates during 2011-2021 are not fully understood.

EAA notes that the reported increases in mortality could be a function of several factors, including general population growth and recent efforts within the epilepsy field to improve reporting by more accurately identifying epilepsy cases during death investigations and certifications.

d) Data collection on epilepsy. Epilepsy- and seizure-related data collection and analysis have largely been conducted at the federal level, under the leadership of the CDC. In April 2025, the CDC eliminated staff positions within its Epilepsy Program. According to an April 2025 press release issued by the American Epilepsy Foundation titled "AES Recognizes the Impact of the CDC Epilepsy Program Amid Workforce Changes", changes to the CDC's workforce included the dismissal of nearly all the staff associated with the National Center for Chronic Disease Prevention and Health Promotion's Epilepsy Program (CDC Epilepsy Program). While the future structure of the program is not clear, the American Epilepsy Society (AES) highlighted the important role the CDC Epilepsy Program plays in advancing care for people with epilepsy and notes the following contributions of the program:

i) Providing epidemiologic and surveillance data about people living with epilepsy. Only through work at the CDC Epilepsy Program do we know that 3.4 million people in the U.S. suffer from epilepsy;

ii) Living Well with Epilepsy educational conferences, which support people living with epilepsy, their families, caregivers and health care professionals. These conferences provide a forum to share research and experience, leading to the development of programs and research initiatives that have improved the lives of people with epilepsy;

iii) The Managing Epilepsy Well Network was established in 2007 as a CDC thematic research network and has had unprecedented success. The program supported many research studies that provided needed evidence that self-management is effective and needed in epilepsy;

iv) The program provides funding opportunities, including the 2021 Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships, a program that supported the American Epilepsy Society's Documenting and Addressing Gaps in Epilepsy Care through Healthcare Provider Education and Training project. This five-year cooperative agreement is aimed at improving outcomes for underserved people with epilepsy by enhancing clinician education for both non-specialist healthcare providers and epilepsy specialists;

v) The CDC Epilepsy Program was integrally involved in the 2012 Institute of Medicine Report Epilepsy Across the Spectrum and reported on progress made in 2022; and,

vi) The Program leadership works on improving the quality of life of people with epilepsy through their advocacy, community partnerships, research support and informational campaigns.

According to DPH, they do not gather or maintain data related to the incidence or prevalence of epilepsy or have an established system to do so. DPH also does not have information on how many local health departments collect data on epilepsy, as there is no

specific program within DPH that gathers and coordinates epilepsy-related data. DPH's Maternal, Child, and Adolescent Health Division has published reports and information about epilepsy, seizures and pregnancy and epilepsy and children in California. These publications are not related to services.

This bill requires DPH to establish a program for the purpose of conducting epidemiological assessments on the incidence and prevalence of epilepsy and seizures and authorizes DPH to contract with a health systems agency, single-county health department, multicounty health department, or nonprofit professional association for the purpose of collecting and collating data. According to the sponsors of the bill, the goal of this bill is for these epidemiological assessments to guide public health interventions. The sponsors also state that they believe research institutions such as universities and biotechnology firms could use the data to inform scientific research and investment.

e) Other Statewide Programs.

i) Texas. Texas state law establishes the Epilepsy Program within the Texas Health and Human Services Commission. The program provides diagnostic services, treatment, and support services to eligible persons who have epilepsy.

ii) Florida. Florida state law establishes a program for the care and assistance of persons with epilepsy within the office of the Deputy State Health Officer. According to the Florida Department of Health's website, the Epilepsy Services Program provides patient assistance, referrals, education, and prevention services to all residents. The goal of this program is to increase the independence of individuals with epilepsy, awareness of epilepsy, research, and understanding the neurological functions in individuals with epilepsy. In addition to information about the Epilepsy Services Program, the website includes general public health information about epilepsy, including information about the causes of epilepsy, types of seizures that can occur, seizure first aid and safety, treatment and management, a listing of organizations that support people who have epilepsy, and some data and research estimating the prevalence of epilepsy in Florida.

iii) Minnesota. Minnesota state law requires the commissioner of health to collect, analyze and report data on epilepsy and related seizure disorders in Minnesota, including the number of diagnoses, clinical outcomes, mortality rates, and related population health data for each calendar years and requires deidentified data to be made publicly available. Minnesota state law further requires the commissioner of health to use the data on epilepsy and seizure disorders to identify areas of need and recommend strategies to address gaps, including inform statewide efforts and build coordinated systems and partnerships to support community-led and culturally responsive strategies to ensure that Minnesotans at risk for or living with epilepsy and seizure disorders and their caregivers have equitable access to opportunities and resources to support their well-being and quality of life.

3) SUPPORT. Epilepsy Foundation Los Angeles (EFLA) is the sponsor of this bill and states this bill is a necessary first step in addressing the critical gap in public health efforts related to epilepsy and seizures. EFLA continues that epilepsy affects people of all ages and backgrounds and imposes economic, social, and emotional burdens on affected individuals and their families. EFLA continues that an epilepsy diagnosis can bring stigmatization based

on longstanding misconceptions about epilepsy; illegal workplace discrimination; and even the risk of injury and death, including from Sudden Unexpected Death in Epilepsy (SUDEP). EFLA continues that the program will deliver real-time, practical, and life-changing support for people with epilepsy, translating public health efforts into meaningful community impact. EFLA continues that Californians with epilepsy interact with multiple state agencies, including the Department of Health Care Services (DHCS), Department of Developmental Services (DDS), DMV, and Department of Education (CDE). EFLA continues that there is currently no official mechanism to share and study the data insights generated by these interactions and no subsequent ability to inform statewide policies that promote accessible, cost-effective solutions for addressing epilepsy in California. EFLA believes that the California Epilepsy Program will provide a valuable and necessary service, especially following the elimination of all staff positions within the federal CDC's Epilepsy Program in April 2025. EFLA contends that through this bill, California will ensure that the changes occurring on the federal level don't harm the hundreds of thousands of families affected by seizures and epilepsy.

4) **RELATED LEGISLATION.** AB 1129 (Celeste Rodriguez) permits an LHO to maintain a system for the collection of information necessary to accomplish a local-level monitoring and reporting program similar to, and independent of, the state-level birth defects monitoring program, subject to adequate funding. Makes conforming changes in existing law to facilitate a local-level monitoring and reporting program. AB 1129 is on the inactive file on the Senate Floor.

5) **PREVIOUS LEGISLATION.**

   a) AB 2680 (Aguiar-Curry), Chapter 355, Statutes of 2024 renames the Alzheimer's Disease and Related Conditions (ADRC) Advisory Committee within the California Health and Human Services Agency, expands the number of members serving on the Committee and revises references to Alzheimer's disease to also reference related conditions, among other clarifying changes.

   b) 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.

   c) AB 424 (Bryan), Chapter 522, Statutes of 2023 requires DPH, as part of the system it will establish for the collection of information on the incidence and prevalence of neurodegenerative disease, to also collect information on amyotrophic lateral sclerosis disease (ALS/Lou Gehrig's disease). Makes a conforming change in the definition of neurodegenerative disease.

   d) AB 133 (Committee on Budget), Chapter 143, Statutes of 2021, among other things, eliminated the sunset on the Parkinson's Disease Program and established the CNDR, which requires DPH to collect data on the incidence of neurodegenerative diseases in California. Requires hospitals, physicians and other health care providers to report diagnoses and treatment of patients for a neurodegenerative disease to DPH. Sunsets the Neurodegenerative Disease Registry on January 1, 2028.

e) SB 97 (Committee on Budget), Chapter 52, Statutes of 2017, a health omnibus trailer bill established the Richard Paul Hemann Parkinson's Disease Program, which, among other things, requires DPH to collect data on the incidence of Parkinson's disease in California, as specified. Beginning July 1, 2018, requires a hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment to Parkinson's disease patients to report each case of Parkinson's disease to DPH, as prescribed. Sunsets this program on January 1, 2020.

REGISTERED SUPPORT / OPPOSITION:

Support

Epilepsy Foundation Los Angeles (sponsor)
ASXL Rare Research Endowment Foundation
Biocom California
Cacna1a Foundation
California Life Sciences Association
California Neurology Society
Care & Cure Institute
Child Neurology Foundation
CSNK2A1 Foundation
Cure Epilepsy
Cure NDD
Cure SYNGAP1
CureGRIN Foundation
Danny Did Foundation
DEE-P Connections
Dravet Syndrome Foundation
Dup15q Alliance
Empatica
Epilepsy Alliance America
Epilepsy Foundation
Epilepsy Foundation of America
Epilepsy Foundation of Northern California
Epilepsy Foundation of San Diego County
Epilepsy Services of New Jersey
Epilepsy Support Network of Orange County
FamiliesSCN2A Foundation
GLUT1 Deficiency Foundation
GNB1 Advocacy Group
Hope for Hie
International Scn8a Alliance
Partners Against Mortality in Epilepsy
Phelan-Mcdermid Syndrome Foundation
SMC1A Foundation
SynGAP Research Fund
The Anita Kaufmann Foundation
The Cute Syndrome Foundation
TSC Alliance

UCB, Inc.
Young Adults With Epilepsy, Central Coast
YWHAG Research Foundation

Opposition

None on file

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