NOTICE OF PROPOSED RULEMAKING
Title 17, California Code of Regulations
DPH-23-008 California Neurodegenerative Disease Registry
Notice Published on: September 18, 2026

Notice is hereby given that the California Department of Public Health (Department) is proposing the regulation described below. This notice of proposed rulemaking commences a rulemaking to make the regulations permanent after considering all comments, objections, and recommendations regarding the regulation.

PUBLIC PROCEEDINGS

Public Comment Period

The Department will hold a virtual public hearing on November 6, 2026 (See "Public Hearing" for further details).

Written comments will be accepted from September 18, 2026 until 5:00pm on November 6, 2026. Written comments must be submitted as follows:

1. By email to: Regulations@cdph.ca.gov;
2. By fax transmission to: (916) 440-5747;
3. By postal service or hand delivered to: California Department of Public Health, Office of Regulations, 1415 L Street, Suite 500, Sacramento, CA 95814.

All comments, including email or fax transmissions, should include the regulation package identifier "**DPH-23-008 California Neurodegenerative Disease Registry**" in the subject line to facilitate the timely identification and review of the comment.

For the Department to provide copies of any notices for proposed changes to the regulation text of which additional comments may be solicited, include your name and your mailing address or email address with your written comment.

Public Hearing

The hearing will be held via Microsoft Teams ®, on November 6, 2026 from 10:00am to 12:00pm, and may be accessed at the following link:

Microsoft Teams meeting

Join: https://teams.microsoft.com/meet/241124853001496?p=vYhIW1QLf9sysXhEhs

Meeting ID: 241 124 853 001 496

Passcode: ZL2QX7XW

Dial in by phone

+1 916-306-8051,,499056735# United States, Sacramento

Find a local number

Phone conference ID: 499 056 735#

During the hearing, any person may present oral statements or arguments relevant to the proposed action described in this notice. The Department requests but does not require persons who make oral comments during the hearing to also submit a written copy of their testimony as follows:

1. By email to: Regulations@cdph.ca.gov;
2. By fax transmission to: (916) 440-5747;
3. By postal service or hand delivered to: California Department of Public Health, Office of Regulations, 1415 L Street, Suite 500, Sacramento, CA 95814.

All comments, including email or fax transmissions, should include the regulation package identifier "**DPH-23-008 California Neurodegenerative Disease Registry**" in the subject line to facilitate the timely identification and review of the comment.

For the Department to provide copies of any notices for proposed changes to the regulation text of which additional comments may be solicited, include your name and your mailing address or email address with your written comment.

An agenda for the public hearing will be made available upon request. For individuals with disabilities, the Department shall provide, upon request, assistive services such as sign-language interpretation, real-time captioning, note takers, reading or writing assistance, and conversion of written public hearing materials into Braille, large print, and audiocassette or computer disk.

Note: The range of assistive services available may be limited if requests are received without adequate preparation time prior to the public hearing.

Authority and Reference

Authority for the proposed regulatory change is provided in sections 131050, 131051, 131052, 131200, 103870, 103870.1, 103871, 103871.1, and 103871.2 of the Health and Safety Code.

INFORMATIVE DIGEST/POLICY STATEMENT OVERVIEW

Summary of the Proposed Regulations

The California Department of Public Health (hereafter "Department") proposes to adopt Subchapter 17 (sections 7201–7265) of Division 1, Chapter 4, Title 17 of the California Code of Regulations to establish standards and technical requirements for submitting case reports containing patient health data to the California Parkinson's Disease Registry (hereafter "Parkinson's Registry") and the California Neurodegenerative Disease Registry (hereafter "Neurodegenerative Registry"). The Department also proposes requirements for research institutions and government agencies to request access to confidential information gathered by the Parkinson's Registry and Neurodegenerative Registry (hereafter collectively called "registries"). The Department also proposes procedures for individual patients to access their own personal information, to limit their participation in research by joining a Do Not Contact List, and to request destruction of erroneous data reported to the registries. These proposed regulations will implement, interpret, and make specific the provisions in the Health and Safety Code that established the registries to provide clarity to the regulated community regarding how to report cases to the Department and how to request data from the registries.

Background and Summary of Existing Laws and Regulations

The California Parkinson's Disease Registry and the California Neurodegenerative Disease Registry are modeled after the California Cancer Registry. After it was fully implemented in 1988, the California Cancer Registry quickly grew into one of the leading cancer registries in the world due to the size and diversity of the state's population and became a cornerstone for medical research worldwide. California lawmakers have since adapted this successful disease registry model to confront the public health challenges of Parkinson's disease and neurodegenerative disease.

In 2004, Health and Safety Code sections 103860 and 103865 were enacted to establish the California Parkinson's Disease Registry.

In 2017, Health and Safety Code sections 103870, 103870.1, and 103870.2 were enacted to establish the Richard Paul Hemann Parkinson's Disease Program with an original sunset date of January 1, 2020. The sunset date was amended in 2019 to extend the Richard Paul Hemann Parkinson's Disease Program to January 1, 2021.

In 2021, Health and Safety Code section 103870.2 was repealed to extend the Richard Paul Hemann Parkinson's Disease Program indefinitely and sections 103871, 103871.1, and 103871.2 were enacted to establish the California Neurodegenerative

Disease Registry. Section 103871 was amended in 2023 to include amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease.

Collectively, these provisions of the Health and Safety Code require the Department to conduct a program of epidemiological assessments, and to establish a statewide system for the collection of information for determining the incidence and prevalence of Parkinson's disease and neurodegenerative disease within the state. The Health and Safety Code further requires a hospital, facility, physician and surgeon, or other health care provider (collectively called "mandatory reporters") to report cases of Parkinson's disease and specified neurodegenerative diseases to the Department. The Department's proposed regulations would clarify how the Department will implement, interpret, and make specific the provisions of the Health and Safety Code and administer the Parkinson's Registry and Neurodegenerative Registry.

Policy Statement Overview:

Problem Statement:

The Department requires regulations to establish the standards and technical requirements for mandatory reporters who must submit cases of Parkinson's disease and neurodegenerative disease to the registries. The Department further requires regulations to establish procedures for research institutions and government agencies to request access to confidential information contained in the registries. The Department requires regulations to establish procedures for individual patients seeking to access their personal information, to limit patient participation in research by enabling patients to join a Do Not Contact List, and to request destruction of erroneous data reported to the registries. Finally, the Department requires regulations to establish the reporting schedule for each neurodegenerative disease.

Objectives (Goals): The broad objectives of this proposed regulatory action are:

- Establish the administrative framework of the Parkinson's Registry and Neurodegenerative Registry.
- Establish submission standards for mandatory reporters to transmit case reports containing patient health data to the registries.
- Establish the technical requirements for mandatory reporters to interface securely with the Department's reporting environment where case reports are collected.
- Establish the list of neurodegenerative diseases subject to reporting mandates.
- Establish the schedule for when each reporting mandate takes effect.

Benefits:

- Increased efficiency and consistency for the Department program administering the registries.
- Increased efficiency and consistency for mandatory reporters submitting case reports to the registries.
- Improved patient experiences for individuals whose data is reported to the registries.
- Improved reliability for research institutions and government agencies accessing data contained in the registries.

Evaluation as to Whether the Proposed Regulations are Inconsistent or Incompatible with Existing State and Federal Regulations

The Department has reviewed existing state and federal regulations and concludes that the proposed regulations are compatible with existing state and federal regulations.

Substantial Difference from Federal Regulation or Statute

The Department has determined these regulations are not substantially different from either a federal regulation or statute.

Local Mandate Determination

The Department has determined this regulatory action would not impose a mandate on local agencies or school districts, nor are there any costs for which reimbursement is required by part 7 (commencing with Section 17500) of division 4 of the Government Code.

Fiscal Impact Estimate

The Department has determined that the regulations will have no impact on:

A. Cost or savings to any local agency or school district:
None
B. Cost or savings to any state agency:
None
C. Other Nondiscretionary Cost or Savings Imposed on Local Agencies:
None
D. Cost or savings in federal funding to the state:
None

Housing Costs

The Department has determined that the regulations will not have an impact on housing costs.

Significant, Statewide Adverse Economic Impact on Business

The Department has made the initial determination that this action will not have a significant , statewide adverse economic impact directly affecting business, including the ability of California businesses to compete with businesses in other states.

Summary of the Economic Impact Assessment

The Department has determined that the regulations will have no impact on:

1. **The creation or elimination of jobs within California.**
2. **The creation or elimination of new businesses within California.**
3. **Expansion of businesses currently doing business in the state.**
4. **The benefits of the regulation to the health and welfare of California residents, worker safety, and the state's environment.**
   The proposed regulations will not improve worker safety or the state's environment, but may benefit the health and welfare of California's residents by improving patient experiences for individuals whose data is reported to the registries.

Cost Impacts on Representative Person or Business

The Department does not anticipate any statewide cost to individuals to comply with this regulation over its lifetime. This regulatory action only establishes the standards and technical requirements for mandatory reporters who must submit cases of Parkinson's Disease and neurodegenerative diseases to the registries to determine incidence and prevalence, and will designate Parkinson's Disease and/or Alzheimer's Disease, MS, and ALS as reportable to the Department. There is no direct cost to individuals diagnosed with Parkinson's Disease and/or Alzheimer's Disease, MS and ALS by making these diseases reportable to the Department.

The Department has determined that there is a variable cost to a hospital or facility since a hospital or facility may need to update their health information technology to enable the Department to collect neurodegenerative disease information to determine incidence and prevalence of reportable neurodegenerative disease(s). That cost may vary from $1,000 - $250,000 depending on the type of health information technology adopted by the hospital or facility. HSCs 103870 and 103871 already require hospitals and facilities diagnosing or providing treatment for a patient with neurodegenerative

diseases to report each case of a neurodegenerative disease to the Department in a format as prescribed.

Given the initial cost for reporting neurodegenerative disease(s) by a hospital or facility were established in HSCs, the Department has determined that any additional financial cost associated with this regulatory action is unknown.

Small Business

The Department has determined that there would not have an effect on small business. The proposed regulations only apply to hospitals and facilities that diagnose or provide treatment for patients with Parkinson's Disease (PD) and/or other neurodegenerative diseases (e.g., Alzheimer's Disease, multiple sclerosis [MS], and Amyotrophic Lateral Sclerosis [ALS]) in the state.

CONSIDERATION OF ALTERNATIVES

The Department must determine that no reasonable alternative it considered or that has otherwise been identified and brought to its attention would be more effective in carrying out the purpose for which the action is proposed, would be as effective and less burdensome to affected private persons than the proposed action, or would be more cost-effective to affected private persons and equally effective in implementing the statutory policy or other provision of law.

Availability Statements

The Department has prepared and has available for public review an initial statement of reasons for the proposed regulations, all the information upon which the proposed regulations are based, and the text of the proposed regulations. The Office of Regulations, 1415 L Street, Suite 500, Sacramento, CA 95814, will be the custodian of public records, including reports, documentation, and other material related to the proposed regulations (rulemaking file).

To request that a copy of this public notice, the regulation text, and the initial statement of reasons or alternate formats for these documents be mailed to you, please contact:

David Martin
Office of Regulations
1415 L Street, Suite 500,
Sacramento, CA 95814

Phone: (916) 440-7673

Email: david.martin@cdph.ca.gov or Regulations@cdph.ca.gov, or use the California Relay Service by dialing 711.

Backup contact:
Hannah Strom-Martin
Office of Regulations
1415 L Street, Suite 500,
Sacramento, CA 95814

Phone: (279) 217-0764

Email: hannah.strom-martin@cdph.ca.gov

Upon specific request, these documents will be made available in Braille, large print, audio format, or computer disk.

The full text of any regulation which is changed or modified from the express terms of the proposed action will be made available by the Department's Office of Regulations at least 15 days prior to the date on which the Department adopts, amends, or repeals the resulting regulation.

Final Statement of Reasons

A copy of the final statement of reasons (when prepared) will be available upon request from the Office of Regulations.

Internet Access

Materials regarding the action described in this notice (including this public notice, the text of the proposed regulations, and the initial statement of reasons) that are available via the Internet may be accessed at www.cdph.ca.gov by clicking on these links, in the following order: Decisions Pending & Opportunities for Public Participation, Proposed Regulations.