



### Your rights continued.

if patients do not want to take part in a research study.

You may report any concerns about Neurodegenerative disease research to the Committee for the Protection of Human Subjects (CPHS) (<https://www.cdii.ca.gov/committees-and-advisory-groups/committee-for-the-protection-of-human-subjects-cphs/>). If you do not want your information shared with any researchers, you can request to restrict use and disclosure of personal information by completing CDPH forms 6240 or 6241 and submit it to the **California Department of Public Health, Office of Legal Services, 1415 L Street, Suite 500, Sacramento, CA 95814**. To access these forms please go to:

- <https://www.cdph.ca.gov/CDPH%20Document%20Library/ControlledForms/cdph6240.pdf>
- <https://www.cdph.ca.gov/CDPH%20Document%20Library/ControlledForms/cdph6241.pdf>

If you have any questions, please contact CNDR at (916) 731-2500, or by email at [CDSRBhelp@cdph.ca.gov](mailto:CDSRBhelp@cdph.ca.gov).

### Where can I go for more information?



[www.cdph.ca.gov/CNDR](http://www.cdph.ca.gov/CNDR)  
Phone: (916) 731-2500  
Email: [CDSRBhelp@cdph.ca.gov](mailto:CDSRBhelp@cdph.ca.gov)

  
1431 Alhambra Blvd, Suite 200  
Sacramento, CA 95814  
Phone: (916) 731-2500  
Email: [CDSRBhelp@cdph.ca.gov](mailto:CDSRBhelp@cdph.ca.gov)

# Patient Information



## What is the California Neurodegenerative Disease Registry (CNDR)?

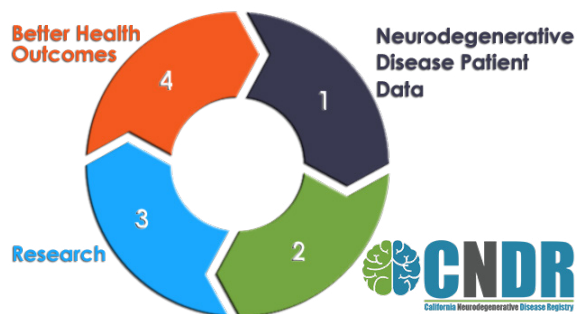
CNDR is a statewide population-based registry that will be used to measure the incidence (the number of new cases of Neurodegenerative disease diagnosed each year) and prevalence (how many people have Neurodegenerative disease) in California.

## It is the law in California that all cases of Neurodegenerative disease be reported to CNDR.\*

Beginning July 1, 2023, the California Department of Public Health (CDPH) shall collect data on the incidence and prevalence of neurodegenerative disease in California. "Neurodegenerative disease" may include, but is not limited to, Alzheimer's disease, multiple sclerosis, Huntington's disease, and amyotrophic lateral sclerosis, also known as Lou Gehrig's disease.

## Why this registry is important.

Currently little is known about how Neurodegenerative disease is distributed among different population groups and whether the patterns of disease are changing over time. California's large and diverse population makes it ideal for providing important information about this disease. CNDR will expand our understanding of Neurodegenerative disease to ultimately improve the lives of those affected.



## What data is CNDR collecting?

CNDR is collecting information on Neurodegenerative disease cases from physicians and facilities providing care to Neurodegenerative patients. All data collected by CNDR are obtained directly from patients' medical records. CNDR does not interview patients.

## What happens to the data?

CNDR will use the data to write reports that inform the public, health care providers, public health agencies, advocates, and legislators about the status of Neurodegenerative disease. These summary reports do **NOT** contain any information about individual Neurodegenerative cases. The information collected by the registry may also be used to invite people to join research studies.

## Can I get a copy of my CNDR record/information?

CNDR records can only be released to those who are legally authorized to obtain a patient's confidential information (i.e., self, surviving spouse, conservator, etc.) CNDR requires all patient record requests be made in writing with copy of identification (driver's license, official state-issued identification card, passport, certified copy of birth certificate, etc.). To request your information please complete CDPH form 6236 (Personal Information). To request access by parent, guardian, or personal representative please complete CDPH form 6237. Forms must be submitted to the **California Department of Public Health, Office of Legal Services, 1415 L Street, Suite 500, Sacramento, CA 95814.**

To access form 6236 and 6237 please go to:

- <https://www.cdph.ca.gov/CDPH%20Document%20Library/ControlledForms/cdph6236.pdf>
- <https://www.cdph.ca.gov/CDPH%20Document%20Library/ControlledForms/cdph6237.pdf>

If you have any questions, please contact CNDR at (916) 731-2500, or by email at [CDSRBhelp@cdph.ca.gov](mailto:CDSRBhelp@cdph.ca.gov).



## Your information is safe.

Information about Neurodegenerative disease is kept private and secure. Your information will not be shared with other

State agencies such as the Department of Motor Vehicles. Patient's health information is protected by law. Researchers may request access to CNDR registry data and may contact you to join a study. They never share names or personal details with others.



## You may be invited to join a research study.

If researchers have approval from the California Committee for the Protection of Human Subjects, they can use your record to contact you to join a research study. The California Committee for the Protection of Human Subjects protects you by reviewing research activities.

## Your rights.

You do not have to join a research study. Medical care and Neurodegenerative disease treatment will not be affected