



## Where can I go for more information?

California Parkinson's Disease Registry  
[www.cdph.ca.gov/parkinsons](http://www.cdph.ca.gov/parkinsons)  
Phone: (916) 731-2500  
Email: [CDSRBhelp@cdph.ca.gov](mailto:CDSRBhelp@cdph.ca.gov)



**CPDR**  
California Parkinson's Disease Registry  
P.O. Box 997377 MS 7205  
Sacramento, CA 95899-7377  
Phone: (916) 731-2500  
Email: [CPDRhelp@cdph.ca.gov](mailto:CPDRhelp@cdph.ca.gov)

# Patient Information



**CPDR**  
California Parkinson's Disease Registry

## What is the California Parkinson's Disease Registry (CPDR)?

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

## It is the law in California that all cases of Parkinson's disease be reported to CPDR. \*

Since July 1, 2018, health care providers diagnosing or providing treatment to Parkinson's disease patients are required to report each case of Parkinson's disease to the California Department of Public Health.

## Why this registry is important.

Currently little is known about how Parkinson's 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. CPDR will expand our understanding of Parkinson's disease to ultimately improve the lives of those affected.



**Parkinson's Disease Patient Data**  
**California Parkinson's Disease Registry**  
**Research**  
**Better Health Outcomes**

## What data is CPDR collecting?

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

## What happens to the data?

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

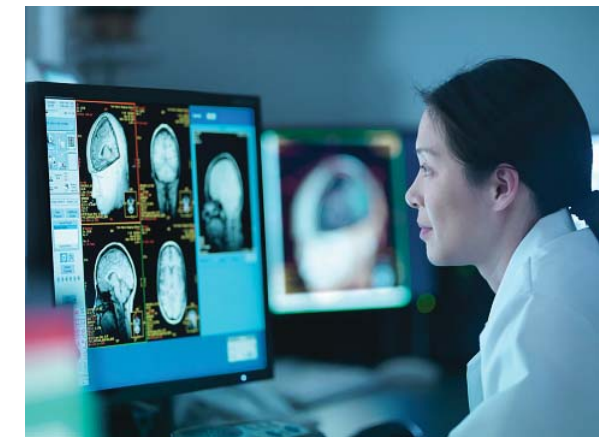


## Your information is safe.

Information about Parkinson's 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 have access to CPDR registry 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 Parkinson's disease treatment will not be affected if patients do not want to take part in a research study.

You may report any concerns about Parkinson's disease research to the California Committee for the Protection of Human Subjects. If you do not want your information shared with any researchers, you can contact CPDR and your information will not be released for research.