



Frequently Asked Questions

CPDR
California Parkinson's Disease Registry

California Parkinson's Disease Registry

1. What data will CPDR collect and what will the data be used for?

CPDR, a program of the California Department of Public Health (CDPH), is collecting diagnostic information on individual Parkinson's disease cases from physicians and facilities providing care to Parkinson's patients. CPDR does not interview patients. This data will be used to:

- Determine the incidence and prevalence of Parkinson's disease in California
- Examine disparities in Parkinson's disease risk
- Conduct demographic and epidemiological research and other studies of Parkinson's disease



2. How does CPDR safeguard privacy and ensure data security? (Is patient information safe?)

Maintaining the confidentiality of persons whose medical data are reported to CPDR is mandated by law and is the highest priority in registry operations. Information about Parkinson's disease is kept private and confidentiality of data collected is strictly maintained. CDPH has more than 50 years' experience handling confidential records and all data is stored securely according to strict departmental protocols. Laws, regulations and programmatic safeguards are in place throughout the system to assure patient confidentiality.

Parkinson's disease researchers will go through a rigorous process to access CPDR data including an approval process by both a state-certified institutional review board and the CPDR advisory committee. If their application is approved, they

will receive only the required information for their approved purpose. CPDR will only release patient contact information to qualified researchers under tightly controlled circumstances. Policies and procedures for accessing confidential data for CPDR will be posted on the CPDR website when available.

3. What laws protect patients and ensure confidentiality of data?

Confidentiality of data collected is strictly maintained in accordance with Health and Safety Code Sections 103870 (g) and 103870.1 (a-f); Civil Code, Sections 56.05 and 1798; Government Code Sections, 6250-6265; and Federal Law PL 104-191.

4. Is there anything the patient must do to comply, or is this all done by doctors?

All reporting requirements are directed to providers so there is nothing patients must do.

5. If I have multiple doctors, which one reports, or are they all required to report?

According to statute, all providers diagnosing or treating a patient must report to the state, regardless of reporting by another provider.

6. 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 data in these reports are combined into groups for analysis.

The same law that mandates that all cases of Parkinson's disease diagnosed or treated in California be reported to the state, also requires that Parkinson's disease registry data only be released for specific research purposes relating to demographic, epidemiological, or other similar studies of the CPDR. The law mandates that patient identity be kept confidential, but also that confidential information may be released for research as described above.

CPDR takes the protection of a patient's confidential health information very seriously.

CPDR will only release information to qualified researchers under tightly controlled circumstances where the research has first been approved by both a state-certified institutional review board and the CPDR registry advisory committee. If their application is approved, they will receive only the required information for their approved purpose.

Patients have the right to refuse to participate in any research study without jeopardizing their current or future medical care. Parkinson's disease patients may request that their contact information be withheld from researchers by contacting CPDR at (916) 731-2500, or by email to CPDRhelp@cdph.ca.gov.

7. Will the California Department of Motor Vehicles have access to or be provided with Parkinson's disease registry information?

No.

8. Will I be able to access my personal data once it has been submitted to the registry?

Yes. Individuals will have the right to access records containing their personal information maintained by CPDR according to California Health and Safety Code 103870.1 (f) (2) and the California Information Practices Act, Civil Code Sections 1798–1798.78.

Parkinson's disease patients may request their CPDR record by contacting CPDR at (916) 731-2500, or by email to CPDRhelp@cdph.ca.gov.

9. How will I be able to get a copy of my CPDR file/information?

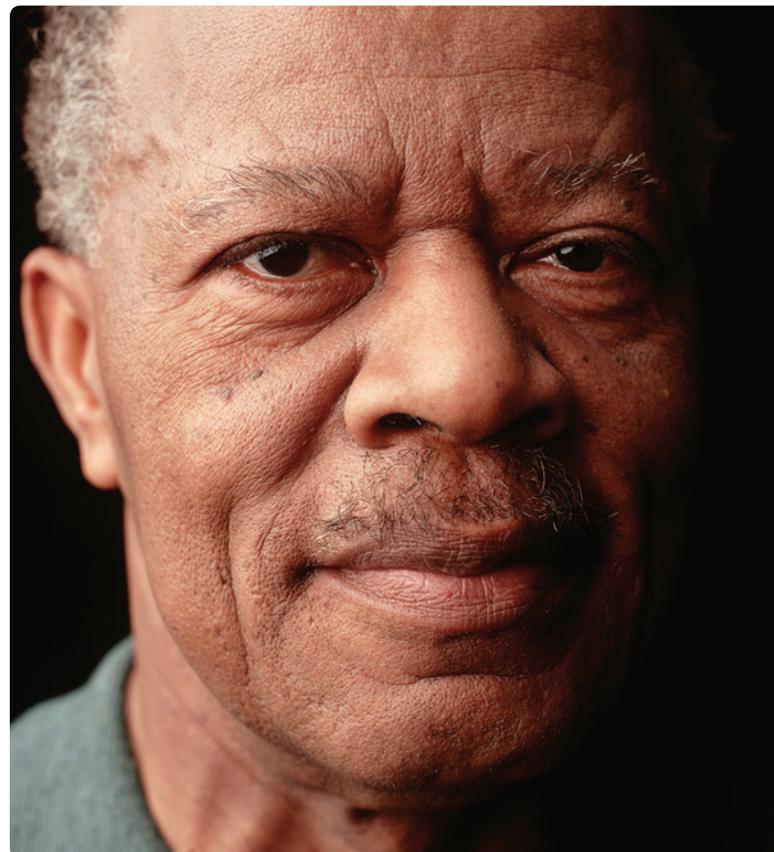
CPDR records will only be released to those who are legally authorized to obtain a patient's confidential information (i.e., self, surviving spouse, conservator, etc.). CPDR will require all patient record requests be made in writing with proof of identity. CPDR will provide an application form for this process. The application will be available on the CPDR website.

10. Can I remove my name and personal information from the CPDR?

The law mandates that all cases of Parkinson's disease diagnosed or treated in California be reported to the registry. There is no provision for removal of Parkinson's disease patient information from the registry. To fulfill its purpose of providing information and determining incidence and prevalence for Parkinson's disease, it is vital for CPDR records to be complete.

However, Parkinson's disease patients may request that their contact information be withheld from researchers accessing data. The law mandates that CPDR data only be released for research purposes and that patient identity be kept confidential. Confidential information may be released for such research and patients can refuse to participate in any particular research study or all research studies.

Parkinson's disease patients may request that their contact information be withheld from researchers by contacting CPDR at (916) 731-2500, or by email to CPDRhelp@cdph.ca.gov.



11. Are Parkinson's disease patients asked to participate in research studies?

The same state law that mandates that all cases of Parkinson's disease diagnosed or treated in California be reported to the registry, also requires that Parkinson's disease registry data only be released for specific research purposes relating to demographic, epidemiological, or other similar studies of Parkinson's disease. Some of these studies may require that researchers obtain additional information from individual Parkinson's disease patients, and these researchers may contact patients to find out if they want to participate in a research study.

Patients have the right to refuse to participate in any research study without jeopardizing their current or future medical care.

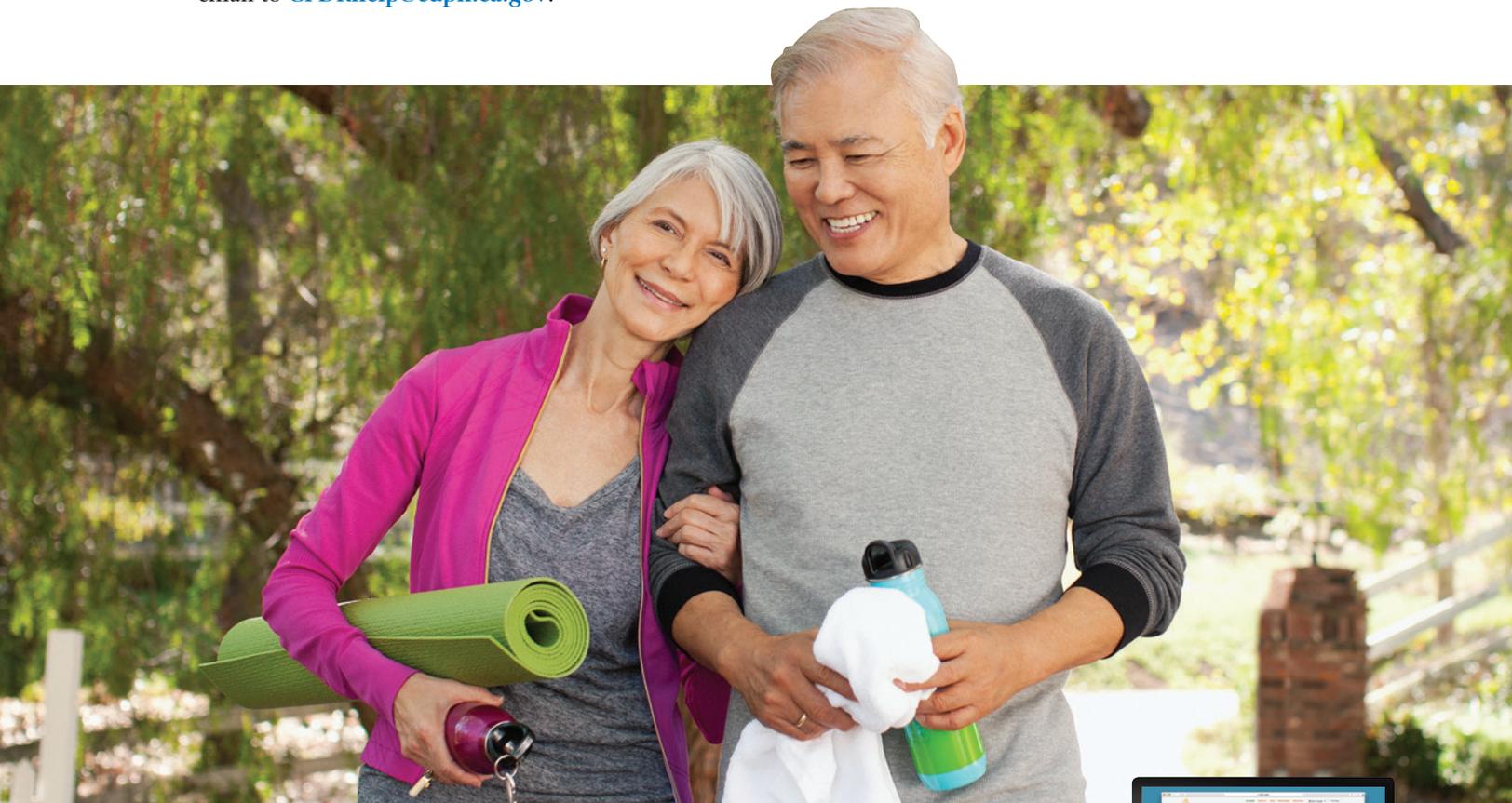
Parkinson's disease patients may request that their contact information be withheld from researchers by contacting the CPDR at (916) 731-2500, or by email to CPDRhelp@cdph.ca.gov.

12. Why participate in Parkinson's disease research?

- It offers an opportunity to contribute to increasing knowledge about the prevention and optimal treatment of Parkinson's disease.
- This research has the potential to further understand Parkinson's disease including associated causes and risk factors.
- Expanding our understanding of Parkinson's disease has the potential to ultimately improve the lives of those affected and those at risk.

13. How or will I be notified when I am put in this registry?

Providers are not required by law to inform their patients that their information is entered into this registry. CPDR has informational materials available on its website to facilitate patient notification by providers should they choose to do so.



Find more information at
www.cdph.ca.gov/parkinsons or
email us at CPDRhelp@cdph.ca.gov

