

NUMBERS TO CALL FOR INFORMATION:

**California Cancer Registry
Chronic Disease Surveillance and
Research Branch**
California Department of Public Health
1825 Bell Street, Suite 102
Sacramento, CA 95825
(916) 779-0300
<http://www.cccal.org>

Northern California Cancer Center
(510) 608-5000
Santa Clara Region (Monterey, San Benito,
Santa Clara and Santa Cruz Counties)
Bay Area Region (Alameda, Contra Costa,
Marin, San Francisco and San Mateo
Counties)

Cancer Registry of Central California
(559) 244-4522
Central Region (Fresno, Kern, Kings,
Madera, Mariposa, Merced, Stanislaus,
Tulare and Tuolumne Counties)

Cancer Surveillance Program
(916) 779-0300
Sacramento Region (Alpine, Amador,
Calaveras, El Dorado, Nevada, Placer,
Sacramento, San Joaquin, Sierra, Solano,
Sutter, Yolo and Yuba Counties)

Tri-Counties Cancer Surveillance Program
(916) 779-0300
Tri-County Region (San Luis Obispo, Santa
Barbara and Ventura Counties)

**Desert Sierra Cancer Surveillance
Program**
(909) 558-6170
Inland Empire Region (Inyo, Mono,
Riverside and San Bernardino Counties)

Cancer Registry of Northern California
(530) 345-2483
North Region (Butte, Colusa, Del
Norte, Glenn, Humboldt, Lake, Lassen,
Mendocino, Modoc, Napa, Plumas, Shasta,
Siskiyou, Sonoma, Tehama and Trinity
Counties)

**Cancer Surveillance Program of
Orange County and San Diego Imperial
Organization for Cancer Control**
(916) 779-0300
San Diego Region (Imperial and San Diego
Counties)
Orange County

Los Angeles Cancer Surveillance Program
(323) 442-2300
Los Angeles County



CALIFORNIA CANCER REGISTRY
CALIFORNIA DEPARTMENT OF PUBLIC HEALTH

*The mission of the California Cancer
Registry is to serve the public by
collecting statewide data, and conducting
surveillance and research into the causes,
controls, and cures of cancer and
communicating results to the public.*

1825 Bell Street, Suite 102
Sacramento, CA 95825
P • 916-779-0300
F • 916-779-0264

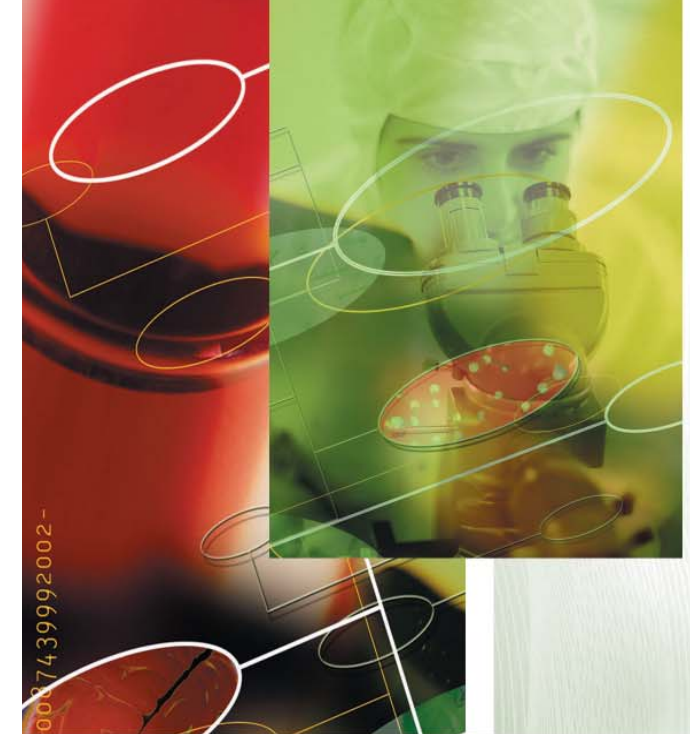


The California Cancer Registry is a collaborative effort between the California Department of Public Health, the Public Health Institute, and the regional cancer registries.



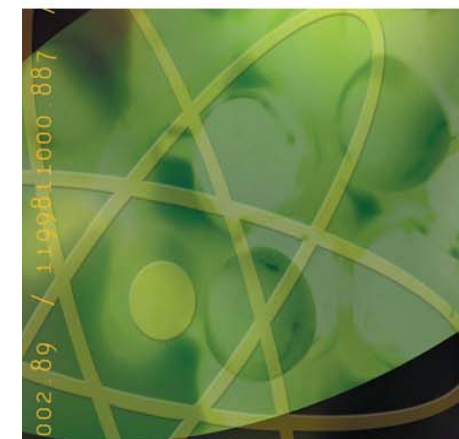
The mission of the California Cancer Registry is to serve the public by collecting statewide data, and conducting surveillance and research into the causes, controls, and cures of cancer and communicating results to the public.

1825 Bell Street, Suite 102
Sacramento, CA 95825
P • 916-779-0300
F • 916-779-0264



002.89 / 1199811000.887

**THE CALIFORNIA
CANCER REGISTRY AND
CANCER RESEARCH
IN CALIFORNIA:
SEARCHING FOR
CAUSES AND CURES**



002.89 / 1199811000.887

002.89 / 1199811000.887

WHAT IS A CANCER REGISTRY?

- ◆ A cancer registry is a system for collecting, storing, and studying data on persons with cancer.
- ◆ Cancer registries are needed to measure the burden of cancer in our communities, to help identify the causes of cancers, and to find cures for these diseases.
- ◆ California has a comprehensive cancer registry that covers the entire state. It is considered one of the best cancer registries in the world.
- ◆ State law requires that every cancer diagnosed in California be reported to the California Department of Public Health (CDPH) which manages the California Cancer Registry (CCR).

HOW DOES THE CCR GET INFORMATION ON CANCER CASES?

- ◆ The law requires doctors, hospitals, and other facilities that diagnose and treat cancer patients to report information on cancer cases to the CCR.
- ◆ The CCR and regional registries work with local reporting facilities to ensure that information on cancer cases is complete and accurate.
- ◆ The CCR collates all the data, performs additional quality control, and analyzes the data on a statewide basis.
- ◆ **At each step of the process, strict procedures are in place to protect patient confidentiality.**

WHAT DATA DOES THE CCR COLLECT?

- ◆ All data collected by the CCR are obtained directly from cancer patients' medical records. The CCR does not interview patients.
- ◆ The CCR collects demographic, diagnostic, and treatment information on individual cancer cases.
 - ▶ Demographic data include: patient's name, address at time of diagnosis, sex, race, and age at diagnosis.
 - ▶ Diagnostic data include: type of cancer (such as breast cancer) and stage of disease at time of diagnosis.
 - ▶ Treatment data include: whether the patient had surgery, radiation, or chemotherapy as the first course of treatment.

WHAT ARE THE DATA USED FOR?

Data collected by the CCR are used to:

- ◆ monitor the number of new cancer cases and cancer deaths over time;
- ◆ examine disparities in cancer risk, treatment, and survival;
- ◆ examine treatment choices and other predictors of survival;
- ◆ measure the success of cancer screening programs;
- ◆ respond to public concerns and questions about cancer; and
- ◆ conduct research to find the causes and cures of cancer.

WHAT HAPPENS TO THE DATA?

- ◆ The CCR and regional registries use the data to write summary reports that inform the public, local health workers, educators, and legislators about the status of cancer.
- ◆ These summary reports do **NOT** contain any information on individual cancer cases. The data in these reports are combined into groups for analysis.
- ◆ Researchers may examine these data to identify areas that have high cancer rates, and areas where people might benefit from cancer screening and education programs.
- ◆ Researchers can also use these data to look at trends in cancer diagnoses.

ARE CANCER PATIENTS ASKED TO PARTICIPATE IN RESEARCH STUDIES?

- ◆ Some studies require that researchers obtain additional information from individual cancer patients.
- ◆ The CCR and regional registries **are** permitted to release patient contact information to **qualified** researchers. These researchers may contact patients to find out if they want to participate in a research study.
- ◆ The CCR will only release information to qualified researchers under tightly controlled circumstances where the research has first been approved by the California Committee for the Protection of Human Subjects (CPHS).

WHAT RIGHTS DO PATIENTS HAVE?



- ◆ Patients have the right to refuse to participate in any research study without jeopardizing their current or future medical care.
- ◆ Patient rights are monitored and protected by CPHS. Patients are encouraged to report any complaints to the committee. You can contact CPHS at: 400 R Street, Suite 369 Sacramento, CA 95811-6213 Phone: (916) 326-3660 Fax: (916) 322-2512 E-mail: cphs-mail@oshpd.ca.gov
- ◆ Cancer patients may request that their contact information be withheld from researchers by contacting the CCR at the number on the back of this brochure.

WHY PARTICIPATE IN CANCER RESEARCH?

- ◆ It offers an opportunity to join the fight against cancer.
- ◆ Thanks to the participation of many cancer patients, their families, and people without cancer, hundreds of research studies have been conducted using CCR data.
- ◆ This research has contributed to the discovery of major risk factors for cancer, improved treatment, and better survival for cancer patients in California and across the United States.

