

## NUMBERS TO CALL FOR INFORMATION:

### California Cancer Registry Chronic Disease Surveillance and Research Branch

California Department of Public Health  
1631 Alhambra Blvd, Suite 200  
Sacramento, CA 95816  
(916) 731-2500  
<http://www.ccrca.org>

### Region 1/8

#### Cancer Prevention Institute of California (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)

### Region 2

#### Cancer Registry of Central California (916) 779-0300

Central Region (Fresno, Kern, Kings,  
Madera, Mariposa, Merced, Stanislaus,  
Tulare and Tuolumne Counties)

### Region 3

#### Sacramento and Sierra Cancer Registry (916) 779-0300

Sacramento Region (Alpine, Amador,  
Calaveras, El Dorado, Nevada, Placer,  
Sacramento, San Joaquin, Sierra, Solano,  
Sutter, Yolo and Yuba Counties)

### Region 4

#### Central Coast Cancer Registry (916) 779-0300

Tri-County Region (San Luis Obispo, Santa  
Barbara and Ventura Counties)

### Region 5

#### Desert Sierra Cancer Surveillance Program (909) 558-6174

Inland Empire Region (Inyo, Mono,  
Riverside and San Bernardino Counties)

### Region 6

#### Cancer Registry of Northern California (916) 779-0300

North Region (Butte, Colusa, Del  
Norte, Glenn, Humboldt, Lake, Lassen,  
Mendocino, Modoc, Napa, Plumas, Shasta,  
Siskiyou, Sonoma, Tehama and Trinity  
Counties)

### Region 7/10

#### Cancer Registry of San Diego and Imperial Counties (916) 779-0300

San Diego Region (Imperial and San Diego  
Counties)  
Orange County

### Region 9

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

Los Angeles County



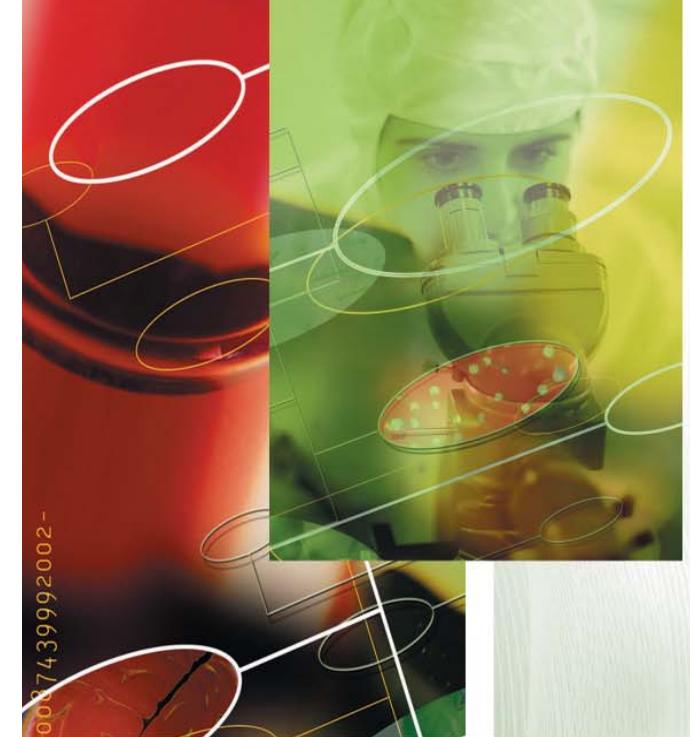
**CALIFORNIA CANCER REGISTRY**  
CALIFORNIA DEPARTMENT OF PUBLIC HEALTH

*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.*

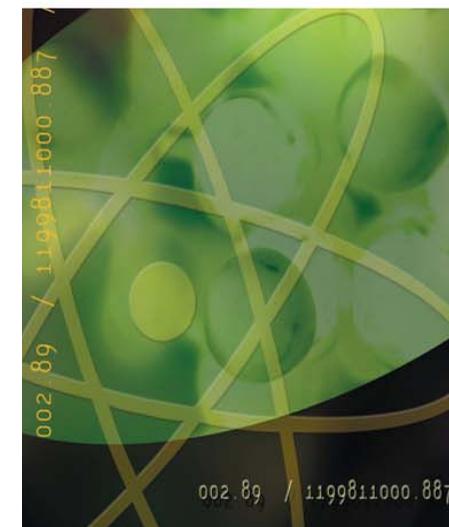
1631 Alhambra Blvd., Suite 200  
Sacramento, CA 95816  
P · 916-731-2500  
F · 916-454-1538



The California Cancer Registry is a collaborative effort between the California Department of Public Health, the Institute for Population Health Improvement, UC Davis Health Systems, and the regional cancer registries.



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



## 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 a federally approved Institutional Review Board (IRB) at the researcher's institution. Patients are encouraged to report any concerns or complaints to the IRB. Information about how to contact the IRB should be included in the initial contact letter from the researcher.
- ◆ 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.

