

A tumor registry is a cancer data system that provides continued follow-up care on all cancer patients in a given location, hospital, or state. A tumor registry documents and stores all significant elements of a patient's history and treatment. Many registry databases include information concerning demographics, medical history, diagnostic findings, primary site, histological type of cancer, stage of disease, treatment(s), recurrence, subsequent treatment, and end results. A variety of studies and reports can be generated from the information contained in tumor registries.

Several registries also collect patient specimens, such as blood samples or slides of resected tumors. These specimens may be used for educational purposes as case studies or for research purposes. Several tumor registries that collect tissue specimens are described below as well as some of the larger tumor registries. For a more complete listing of tumor registries, see Appendix F.

THE NATIONAL FAMILIAL PANCREAS TUMOR REGISTRY

The National Familial Pancreas Tumor Registry was established in 1994 at Johns Hopkins Hospital in Maryland. The goals of the registry include documenting whether or not neoplasms of the pancreas occur in families, evaluating selected families to gain a better understanding of the genetic basis for development of carcinoma of the pancreas, and serving as a resource to other investigators interested in pancreatic cancer. Currently, 131 families have been entered into the registry. Families referred to the registry will be asked to fill out a questionnaire, and medical records and pathology slides of each affected family member are reviewed to confirm all cases. Blood samples are drawn from selected cases for genetic analysis. The registry is currently supported by private donors.

CALIFORNIA TUMOR TISSUE REGISTRY

The California Tumor Tissue Registry is a nonprofit organization committed to the enhancement of patient care. It was established in 1947 and was first funded by the California Medical Association. The registry is at the Loma Linda University School of Medicine in California. The goals of the registry are to educate and improve patient care, to provide high-quality consultation, and to serve as a resource for rare tumors. Through its education program, the registry provides subscribers with slides of rare and unusual tumors. A repository is maintained by the registry with more than 30,000 accessions and 30,000 consultations. Although the registry's influence is predominantly in California, it has provided materials to several other states, countries, and pathology teaching programs.

NCI COOPERATIVE FAMILY REGISTRY FOR BREAST CANCER STUDIES AND NCI COOPERATIVE FAMILY REGISTRY FOR COLORECTAL CANCER STUDIES

The Cooperative Family Registry for Breast Cancer Studies (CFRBCS), initiated by the NCI in 1995, contains biological specimens from patients with a family history of breast cancer, breast/ovarian cancer, or Li-Fraumeni syndrome and from their relatives. Six CFRBCS sites collaborate to ascertain families at high and intermediate risk for breast cancer.¹ Specimens are in the form of tissue sections from paraffin-embedded breast and ovarian cancers, peripheral blood lymphocytes, serum, fresh-frozen tissue, and other biological fluids. The CFRBCS provides related family history (pedigrees), clinical, demographic, and epidemiologic data on risk factors exposures but will not provide patient identification. In addition, the CFRBCS provides follow-up epidemiologic data as well as data on recurrence, new morbidity, and mortality from participating families. The CFRBCS repository and related databases are available to researchers to provide a resource for interdisciplinary and translational breast cancer research.

The Cooperative Family Registry for Colorectal Cancer Studies, a similar resource for colorectal cancer, was established in 1998. NCI supports six registries throughout the world including four in the United States: the University of Washington in Seattle, the University of Hawaii, the Mayo Clinic in Min-

¹The six CFRBCS collaborating sites are the Australian Breast Cancer Family Registry, the Metropolitan New York Registry of Breast Cancer Families, the Northern California Cooperative Family Registry, the Ontario Registry for Studies of Familial Breast Cancer, the Philadelphia Familial Breast Cancer Registry, and the Utah Cooperative Breast Cancer Registry.

nesota, and the University of Southern California. These registries perform several tasks, including assembling and maintaining comprehensive lists of families with histories of colon cancer, collecting detailed information about possible factors involved in the cancer process, and serving as a storehouse of blood samples and tumor biopsies from family members for research purposes. The data and samples collected at any of these registries are available to investigators worldwide.

FAMILIAL BRAIN TUMOR REGISTRY

The mission of the Familial Brain Tumor Registry is to identify families who are at high risk for brain tumors and multiple cancer. The Familial Brain Tumor Registry is located at the University of Texas M.D. Anderson Cancer Center. The registry serves as a resource of families at high risk of cancer and allows for the study of genetic factors associated with the disease. Enrollment of families requires the occurrence of a brain tumor and another cancer in the immediate family. A short interview is conducted with the family to obtain a detailed family history of cancer. Blood samples or buccal smears are collected from family members.

SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS PROGRAM

The Surveillance, Epidemiology, and End Results (SEER) Program was established in 1971 and is supported by NCI. The goals of the SEER Program include assembling and reporting estimates of cancer incidence and mortality in the United States; monitoring annual cancer incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups; providing continuing information on changes over time in disease, trends in therapy, and patient survival rates; and promoting studies designed to identify factors amenable to cancer-control interventions, such as dietary or environmental exposures, screening practices, and treatment practices.

The SEER Program collects cancer data on a routine basis from designated population-based cancer registries in nine areas of the United States. The geographic areas represent an estimated 14 percent of the U.S. population. Trends in cancer incidence, mortality, and patient survival as well as many other studies are derived from the SEER database. The database contains information on approximately 2.3 million in situ and invasive cancers diagnosed between 1973 and 1996, with approximately 125,000 new cases accessioned each year.

NEW YORK STATE CANCER REGISTRY

The New York State Cancer Registry in Albany, New York, is administered by the New York State Department of Health with supporting funds from the Centers for Disease Control and Prevention. The registry collects, processes, and reports information about every New Yorker diagnosed with cancer. The New York State Cancer Registry is one of the oldest cancer registries in the country and has been collecting information on patients with cancer for more than 50 years.

The Cancer Registry includes reports of all malignant cancers, except selected skin cancers. The Cancer Registry receives more than 135,000 case reports each year, representing more than 83,000 new tumors. It collects data on the anatomic site of the tumor, the stage of diagnosis, morphology, and treatment information. It also collects specific sociodemographic information on each individual. In total, more than 100 different pieces of information on each person are collected.