

## Cancer in Nebraska

In an average week, almost 170 Nebraska residents learn from their physician that they have malignant cancer . . . and over 60 Nebraskans die from it.

### Cancer (All Sites) Diagnoses\* by Age, Nebraska, 2005-2009

Age at Diagnosis	Diagnoses	
	Number	Percent
	45,051	100
0-44	3,646	8
45-64	15,466	34
65+	25,939	58

\*malignant diagnoses only

This pattern continues week after week, year after year. As a result, cancer has become Nebraska's second leading cause of death, exceeded only by heart disease. Between 2005 and 2009, almost 17,000 Nebraskans died from cancer. Cancer costs our state nearly \$1.5 billion per year in medical expenses, lost workdays, and premature deaths. While the actual numbers will change for any other five-year period, the underlying characteristics are not expected to change.

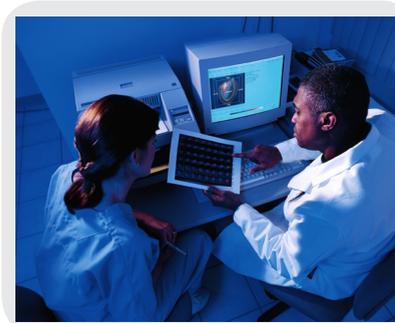
Cancer can strike at any age, but the risk of developing it increases as we get older. Of the more than 45,000 Nebraskans who were diagnosed with cancer between 2005 and 2009, almost 60 % were at least 65 years old at diagnosis, while only 8% were under the age of 45. Also, certain types of cancer occur much more often than other types. In Nebraska, more than 50% of the cases diagnosed between 2005 and 2009 were cancers of the lung, breast, prostate, colon

or rectum. These data also reflect national cancer statistics and other time periods.

## What is the Nebraska Cancer Registry?

A statewide cancer registry was first mandated in Nebraska in 1986 (Neb. Rev. Stat. 81-638) when the Legislature authorized funding to establish a system to collect and analyze information pertaining to cancer as it occurs in the State. The registry is called the Nebraska Cancer Registry, which is managed by the Nebraska Department of Health and Human Services. All U.S. states and Canadian provinces also have a central cancer registry or are beginning one, but Nebraska's registry is among the very few attaining the highest data quality standards as evidenced by 10 consecutive Gold Standard certificates from the North American Association of Central Cancer Registries.

The information collected, such as demographic and cancer-specific information, is used by the Nebraska Cancer Registry to develop a detailed statistical picture of how cancer affects Nebraskans, to investigate reports of cancer clusters in Nebraska communities, and to plan and evaluate efforts to reduce the burden of cancer in Nebraska. Without registries we would only know about persons who die from cancer, and much less information would be available for cancer prevention and control efforts.

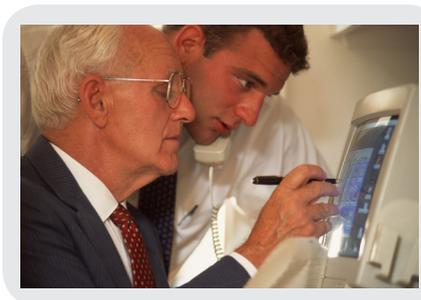


National statistics reported almost daily also rely on state and local registries that gather and release information to the Centers for Disease Control and Prevention (CDC), the National Cancer Institute (NCI) and the American Cancer Society (ACS) about the number of persons diagnosed with and treated for cancer.

Aggregate statistics and information that does not include personal identifiers are available to the public upon request. The most current Nebraska cancer statistics are published in an annual report by the Nebraska Cancer Registry, which can be accessed on the Nebraska Department of Health and Human Services website at: <http://www.dhhs.ne.gov/ced/cancer/data.htm>. Printed copies are also available by contacting the Nebraska Department of Health and Human Services using the information on the back cover of this brochure.

## Who reports information to the Nebraska Cancer Registry?

By law (Neb. Rev. Stat. 81-642 to 81-650), all non-federal hospitals and physicians in Nebraska are required to provide information to the Nebraska Cancer Registry about Nebraska residents who are diagnosed and/or treated for cancer on their premises. Other medical professionals (such as osteopaths and dentists)



as well as pathology laboratories and facilities (free standing surgery or radiation centers) also must report cases of cancer that they diagnose or treat. By agreement, federally operated hospitals in Nebraska and some hospitals and cancer registries in neighboring states also provide information about Nebraska residents who are diagnosed and/or treated for cancer at their facilities. With the exception of possible research proposals, staff from the Nebraska Cancer Registry do not contact patients.

## Who has access to the information in the Nebraska Cancer Registry?

All of the information collected by the Nebraska Cancer Registry is considered confidential and cannot even be subpoenaed by a court of law nor is it shared with outside parties such as employers or insurers. The Nebraska Cancer Registry is exempt from the privacy provisions in the federal Health Insurance Portability and Accountability Act (HIPAA) yet the registry standards meet or exceed all of the HIPAA privacy standards.



From time to time, the Nebraska Cancer Registry also receives requests from scientific researchers who want to contact persons in the registry to obtain additional information for a research study. The Nebraska Department of Health and Human

Services reviews every research request according to the criteria mandated in legislation. Proposals that involve contacting patients must also be approved by an Institutional Review Board that is responsible for seeing that the research follows federal safeguards for research subjects. Nebraska law requires that any researcher asking for case-specific information must explain the purpose of their study, what information they wish to collect, and how they will protect the confidentiality of the information that they collect (Neb. Rev. Stat. 81-663 to 81-675). If the request is approved, the registry staff must then secure permission from each study subject before the Nebraska Cancer Registry will release the name and address of that person to the researcher.

## If I am asked to participate in a research study, what are my options?

If you are asked to participate in a research study, you are under no obligation to do so. Even if you initially agree to participate in a research study, you are free to withdraw from it at any time. You should also be aware that, if you are asked to take part in a research study, you are entitled to a full disclosure about the study and participating in the study will have no effect on any treatment you might be receiving.

## In closing...

Now that you know about the existence of the Nebraska Cancer Registry and some basic information about cancer incidence and mortality, a few other facts and estimates might be of interest to you. Despite the increasing numbers of persons being diagnosed with cancer (and the NCI now expects the number of cancer cases will double between now and 2050), the death rates from cancer are declining. This is due to many more cancers being found at earlier stages of the disease and improvement in outcomes as medical science develops better treatments.

Thus, there are many more cancer “survivors” or persons who have lived at least five years past their diagnosis. The NCI estimates that almost 12 million cancer survivors are now living in the United States, and over 60,000 Nebraskans are among this group. This is the good news that is being documented in the cancer statistics collected in Nebraska and nationally.

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## For more information about the Nebraska Cancer Registry, contact:

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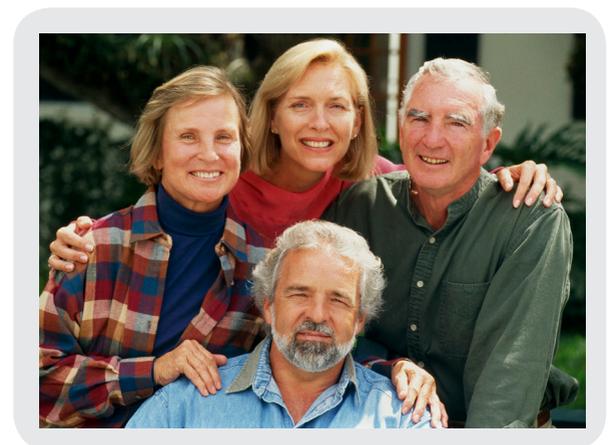
For more information about cancer, visit these Websites:

American Cancer Society:  
[www.cancer.org](http://www.cancer.org)  
(or call 1-800-ACS-2345)

National Cancer Institute: [www.cancer.gov](http://www.cancer.gov)

Centers for Disease Prevention and Control:  
[www.cdc.gov/health/cancer](http://www.cdc.gov/health/cancer)

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