



**The Leukemia &
Lymphoma Society**
Fighting Blood Cancers

Facts 2009-2010

LEUKEMIA

LYMPHOMA

MYELOMA

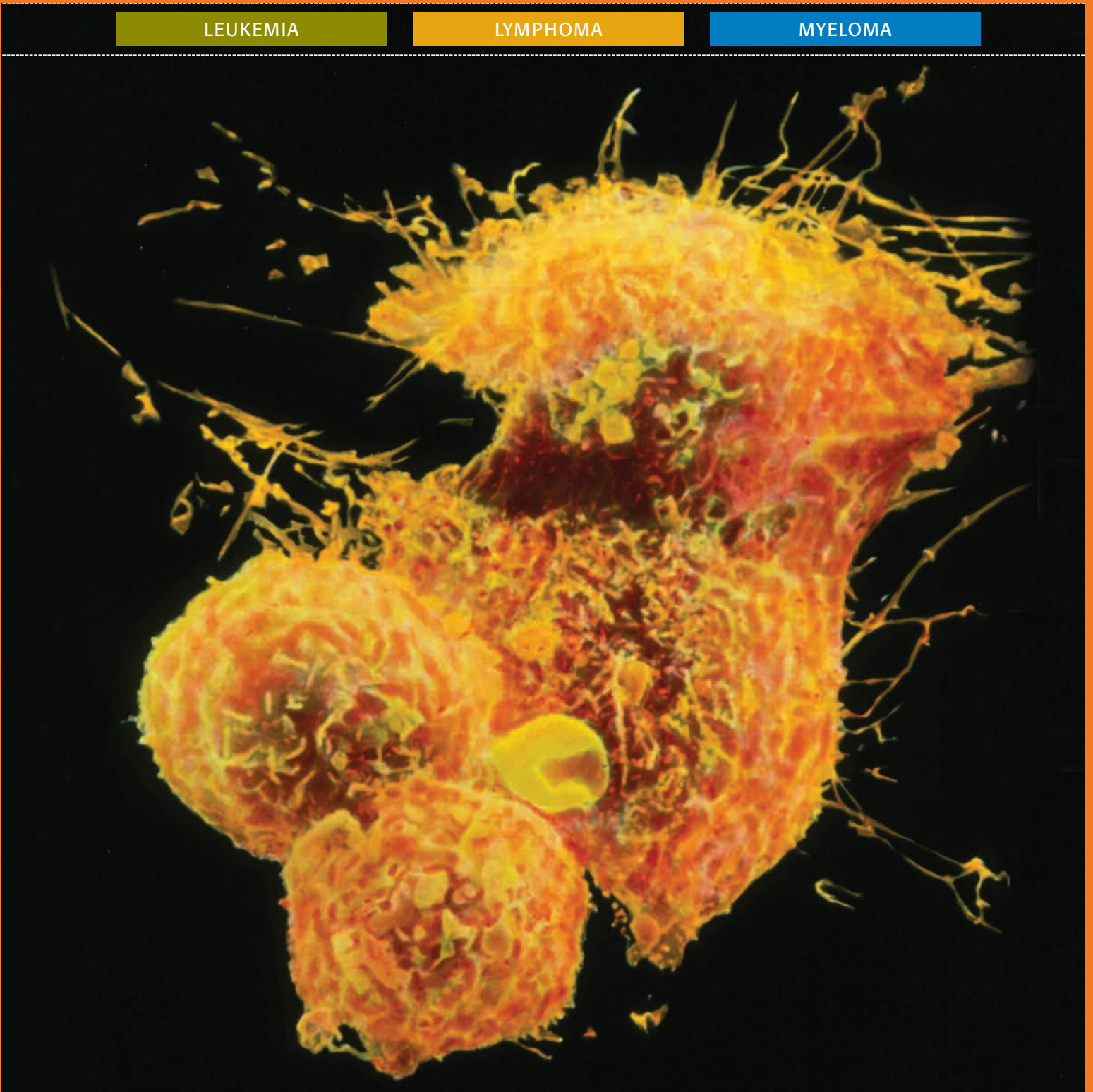


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Executive Summary

Facts 2009-2010, is an annual compilation of the most recent data available for leukemia, lymphoma, myeloma and myelodysplastic syndromes. The data within *Facts 2009-2010* reflect the most recent statistics from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, Cancer Statistics Review 1975-2006 (see *Notes and Definitions*, page 24). Most of these data were published online by SEER, www.seer.cancer.gov, in April 2009. The next SEER Cancer Statistics Review is expected to be published online in April 2010.

Leukemia, lymphoma, myeloma and myelodysplastic syndromes are diseases that can affect the bone marrow, the blood cells, the lymph nodes and other parts of the lymphatic system. *About Blood Cancer Therapy* on page 3 provides an overview of the therapies used to treat individuals with these diseases.

Highlights From the Report

New Cases

Every 4 minutes one person is diagnosed with a blood cancer.

- An estimated 139,860 people in the United States will be diagnosed with leukemia, lymphoma and myeloma in 2009.
- New cases of leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma (NHL) and myeloma will account for 9.5 percent of the 1,479,350 new cancer cases diagnosed in the United States this year.

Incidence

Incidence rates are the number of new cases in a given year not counting the preexisting cases. The incidence rates are usually presented as a specific number per 100,000 population.

- Overall incidence rates per 100,000 population for leukemia, lymphoma and myeloma are almost identical for data reported in 2008 and 2009 [(leukemia 12.2, 2009 vs. 12.3, 2008); (NHL, 19.5, each year); (Hodgkin lymphoma, 2.8, each year); (myeloma, 5.6, each year)].
- Leukemia (27.1 percent), neoplasms of the brain and other nervous tissue (16.6 percent), Hodgkin lymphoma (7.2 percent) and NHL (6.6 percent) are the most common types of cancer in children ages 0 to 19 years.

Survival

Relative survival compares the survival rate of a person diagnosed with a disease to that of a person without the disease. Figure 1 shows the five-year relative survival rates for leukemia, lymphoma and myeloma in 1960-1963, 1975-1977 and 1999-2005. (Note that the most recent survival data available may not fully represent the outcomes of all current therapies and, as a result, may underestimate survival to a small degree.)

- An estimated 912,938 people in the United States are living with, or are in remission from, leukemia, Hodgkin lymphoma, NHL or myeloma.

Five-Year Relative Survival Rates 1960-1963 vs. 1975-1977 vs. 1999-2005

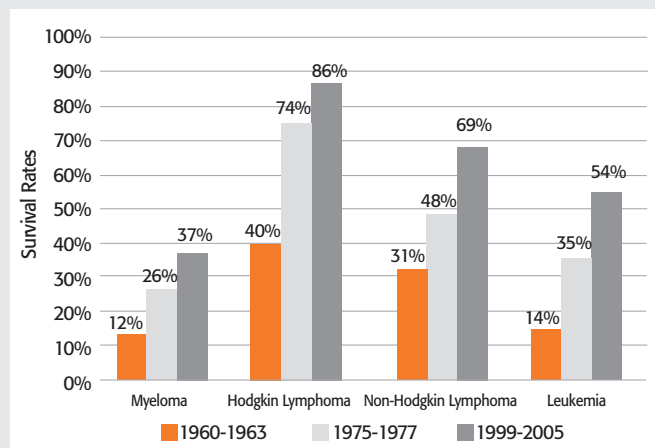


Figure 1. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2006, National Cancer Institute; 2009.

Deaths

Every 10 minutes, someone dies from a blood cancer. This statistic represents nearly 146 people each day, or more than six people every hour.

- Leukemia, lymphoma and myeloma will cause the deaths of an estimated 53,240 people in the United States this year.
- These diseases will account for nearly 9.5 percent of the deaths from cancer in 2009, based on the total of 562,340 cancer deaths.
- In general, the likelihood of dying from most types of leukemia, lymphoma or myeloma decreased from 1996 to 2005 (the most recent data available).

Leukemia

There are 245,225 people living with, or in remission from, leukemia in the United States.

- In 2009, 44,790 people will be diagnosed with leukemia.
- In 2009, 21,870 people will die of leukemia.
- Thirty-one percent more males are living with leukemia than females. More males than females are diagnosed with leukemia and die of leukemia.
- Leukemia causes about one-third of all cancer deaths in children younger than 15 years.

Hodgkin and Non-Hodgkin Lymphoma

There are 601,184 people living with, or in remission from, lymphoma in the United States.

- For Hodgkin lymphoma, 148,461 people are living with the disease or are in remission.
- For non-Hodgkin lymphoma (NHL) 452,723 people are living with the disease or are in remission.
- This year, 74,490 new cases of lymphoma will be diagnosed in the United States (8,510 cases of Hodgkin lymphoma, 65,980 cases of NHL).
- This year, 20,790 people will die from lymphoma (1,290 from Hodgkin lymphoma, 19,500 from NHL).
- NHL is the seventh most common cancer in the United States, and age-adjusted incidence (see *Definitions, Age-adjusted rate*, page 24) rose by more than 76 percent from 1975 to 2006.

Myeloma

There are 66,529 people living with, or in remission from, myeloma in the United States.

- This year, 20,580 people will be diagnosed with myeloma.
- The median age at diagnosis is 70 years; myeloma rarely occurs in people under age 45.
- This year, 10,580 people will die from myeloma.
- From 1975 to 2006, the incidence of myeloma increased by 9 percent.
- The incidence of myeloma in black men and women was 127 percent greater than myeloma incidence in white men and women in 2006.
- Mortality from myeloma has been decreasing from 1994 to 2005 (the most recent data available).

Myelodysplastic Syndromes

From 2002 to 2006, an average of 11,368 new cases of myelodysplastic syndromes (MDS) were diagnosed per year.

- The overall incidence rate of MDS is estimated at four cases per 100,000 population.
- White males have the highest MDS incidence rates (5.6 per 100,000 population).
- A possible cause of MDS (and some types of leukemia) is repeated exposure to benzene. Tobacco smoke is now the most common known cause of benzene exposure.
- Therapy-related MDS accounts for less than 2 percent of all cases.

About Blood Cancer Therapy

Leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma (NHL), myeloma and myelodysplastic syndromes (MDS) are types of cancer that can affect the bone marrow, the blood cells, the lymph nodes and other parts of the lymphatic system. These so-called “blood cancers” are related in the sense that they probably all result from one or more acquired mutations to the DNA of a single lymph- or blood-forming stem cell. The mutant stem cell produces clones, which generate high numbers of abnormal white cells (such as neutrophils, monocytes and lymphocytes). The cancer cells multiply and survive without the usual controls in place for healthy cells. The accumulation of the cancer cells in the marrow, blood and/or lymphatic tissue interferes with healthy blood cell and immune cell production and function. The disease process can lead to severe anemia, bleeding, an impaired ability to fight infection and death. Figure 2 shows the percentage of estimated new cases for leukemia, lymphoma and myeloma in 2009.

Estimated New Cases (%) of Leukemia, Lymphoma, and Myeloma, 2009

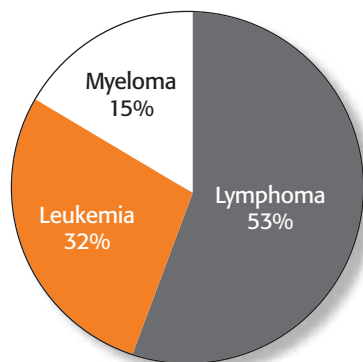


Figure 2. Source: *Cancer Facts & Figures, 2009*, American Cancer Society; 2009.

Drug and Radiation Therapy

The dramatic improvement in blood cancer treatment that began during the latter part of the 20th century is largely the result of chemotherapy (anticancer drugs). People living with some types and stages of blood cancer can benefit from treatment with radiation. When radiation therapy (RT) is used, it is usually part of a treatment plan that includes drug therapy. The type of radiation (called “ionizing radiation”) that is used for RT is the same type that is used for diagnostic x-rays, but it is given in higher doses. External beam radiation is the kind of ionizing radiation used most often for therapy. Current methods of delivering RT are improved so that there is less “scatter” of radiation to nearby healthy tissues.

During the past decade, several important new drugs (and new

uses for established drugs) have greatly improved blood cancer cure and remission rates for many people. Today, there are several new classes of drugs with different mechanisms of action. These drugs may be used alone for certain types and stages of disease; however, they are often combined with chemotherapy. This is important because it may mean that cancer cells—which often elude the damaging effects of chemotherapy—are less likely to be resistant (or develop resistance) to the effects of novel agents and chemotherapy given in combination.

Some of the newer classes of drugs are BCR-ABL tyrosine kinase inhibitors [such as imatinib mesylate (Gleevec®), dasatinib (Sprycel®) and nilotinib (Tasigna®)], histone deacetylase inhibitors (HDACs) [such as vorinostat (Zolinza®)], hypomethylating or demethylating agents [such as azacitidine (Vidaza®) and decitabine (Dacogen®)], immunomodulators [such as lenalidomide (Revlimid®) and thalidomide (Thalomid®)], monoclonal antibodies (see *Immunotherapy*, page 4), and proteasome inhibitors [such as bortezomib (Velcade®)]. More than 50 individual drugs are used to treat people with blood cancers and a number of potential new therapies are under study in clinical trials. Many of the drugs are used to treat several types of blood cancer and are often given in various combinations of two or more drugs.

Some of the US Food and Drug Administration (FDA) approved drug therapies are:

Alemtuzumab (Campath®) is indicated as a single agent for chronic lymphocytic leukemia (CLL) treatment. It is especially active against the lymphocytes in CLL.

All-trans-retinoic acid or ATRA (Tretinoin®) in combination with chemotherapy (anthracycline antibiotic) has significantly improved the remission rate and duration of remission for people with acute promyelocytic leukemia [a type of acute myelogenous leukemia (AML)]. Arsenic trioxide (Trisenox®) also adds to the drugs available to treat this type of AML. Trisenox is indicated for people who have relapsed disease or are resistant to treatment with chemotherapy and ATRA.

Azacitidine (Vidaza) and *decitabine* (Dacogen) are two drugs that are indicated for all types of MDS. These drugs may help the marrow function more normally and may reduce the need for blood transfusions in some individuals with MDS.

Bendamustine (Treanda®) is a chemotherapeutic agent that is approved to treat CLL and indolent (slow-growing) B-cell NHL that has progressed during or within six months of treatment with rituximab (Rituxan®) or a Rituxan-containing regimen.

Bortezomib (Velcade) is indicated to treat people with myeloma and people with mantle-cell lymphoma who have had at least one prior therapy. Velcade in combination with pegylated doxorubicin (Doxil®) offers an important option for treating relapsed or refractory myeloma.

Cladribine (Leustatin®) induces long-term remissions in nearly 90 percent of individuals with hairy cell leukemia (HCL) who are treated at diagnosis for one only one week. Pentostatin (Nipent®) is another effective drug that can be used in people with HCL who do not respond to cladribine. There are other novel agents being studied for people with HCL who are resistant to both cladribine and pentostatin.

Clofarabine (Clolar®) is approved to treat children with relapsed or refractory acute lymphocytic leukemia (ALL) who have received at least two prior therapies. Clolar is being studied in clinical trials for adults with acute leukemia or MDS.

Dasatinib (Sprycel) is an approved “second-generation” oral drug for chronic myelogenous leukemia (CML) treatment. This oral therapy produces an excellent response in people who do not respond to Gleevec, develop resistance to it or cannot tolerate its side effects (see *Imatinib mesylate*).

Denileukin diftitox (Ontak®) is approved for the treatment of persistent or recurrent cutaneous T-cell lymphoma in patients whose malignant cells express the CD25 component of the interleukin-2 receptor (CD24+).

Gemtuzumab (Mylotarg®) is a monoclonal antibody that is indicated for people 60 years or older with CD33 positive acute myelogenous leukemia (AML) in first relapse. This agent is also being studied in clinical trials in combination with other drugs to treat children with relapsed AML.

Ibritumomab (Zevalin®) and *tositumomab* and *iodine I 131 tositumomab* (Bexxar®) are two conjugated monoclonal antibodies that are approved to treat individuals with relapsed B-cell NHL (see *Immunotherapy*).

Imatinib mesylate (Gleevec) is now the standard of care for newly diagnosed individuals with CML. Gleevec is an oral drug that blocks the oncogene-encoded protein product that allows for the development of the CML cell (see *Gene Therapy*, page 5). The effectiveness of the drug, its tolerance by older persons and the data from the eight-plus years of study in clinical trials clearly indicate that Gleevec prolongs remission when compared to former therapies for CML. A minority of people with CML either do not respond to Gleevec, develop resistance to it or cannot tolerate its side effects. For these individuals, there are second-generation oral therapies (see *Dasatinib* and *Nilotinib*). Gleevec, Sprycel and Tasigna may also be important in the treatment of Philadelphia-positive ALL, chronic eosinophilic leukemia, certain forms of myeloproliferative diseases and systemic mastocytosis. Clinical trials are under way to

determine if these second-generation drugs should be used for initial therapy for some, or all, people with CML, and if the combined use of two drugs would be better than one. A number of third-generation drugs are in early development. Some of these drugs are targeting a specific mutation in the *BCR-ABL* gene called “T315I.” This mutation is one of the more common ones observed when a response to one of the three approved oral CML drugs is lacking or lost.

Lenalidomide (Revlimid) is approved in combination with dexamethasone to treat people with myeloma who have received at least one prior therapy. Revlimid is also indicated for the treatment of people with a specific subtype of MDS that results from a partial deletion of chromosome 5. (In addition, Revlimid appears to benefit about 20 percent of people with MDS without this specific chromosome 5 abnormality).

Nilotinib (Tasigna) is an approved second-generation oral drug for CML treatment. This oral therapy produces an excellent response in people who do not respond to Gleevec, develop resistance to it or cannot tolerate its side effects (see *Imatinib mesylate*).

Rituximab (Rituxan) was initially indicated for the treatment of people with indolent types of lymphoma, such as follicular lymphoma. Rituxan is now also approved to treat aggressive lymphomas, such as diffuse large B-cell lymphoma, in combination with chemotherapy. Rituxan is also used in combination with chemotherapy to treat some individuals with myeloma or CLL. Rituxan in combination with fludarabine (Fludara®) and high-dose cyclophosphamide (Cytoxan®) appears to produce high-quality responses in previously untreated individuals with CLL.

Thalidomide (Thalomid), in combination with dexamethasone, is approved for newly diagnosed myeloma.

Vorinostat (Zolinza), an agent that is approved to treat cutaneous lymphoma, is also being studied to treat people who have MDS.

Immunotherapy. This treatment approach uses immune cells or antibodies to fight blood cancer. Immunotherapies enhance the specificity of treatment and reduce the toxic effects on healthy tissues. Monoclonal antibody therapy, cancer vaccines and donor lymphocyte infusion (DLI) are types of immunotherapy being used or being explored as treatments for people with blood cancer.

Monoclonal antibody therapies are laboratory-produced proteins that can be infused, when indicated, to treat individuals with certain blood cancers. These agents target specific antigens on the surface of cancer cells. The antigens are named by “cluster designation” (CD) and number. For example, the monoclonal antibody (mAb) Rituxan targets the CD20 antigen on B lymphocytes. The mAb Campath is directed against the antigen CD52 found on T and B lymphocytes. The mAb Mylotarg, which is linked to a

calicheamicin (a chemical toxin) is targeted to CD33 on leukemia blast cells. An mAb can also be linked to a radioactive isotope to deliver radiation directly to the cancer cells. The conjugated mAbs ibritumomab (Zevalin) and tositumomab and iodine I 131 tositumomab (Bexxar) are examples of this treatment. A number of potentially effective new monoclonal antibody therapies are being studied in clinical trials for several types of blood cancer.

Experimental vaccines are being studied to treat certain types of blood cancer. The goal is to extend the duration of remission achieved by various other types of therapy. Cancer vaccines would be used in people who have small amounts of residual blood cancer after chemotherapy or stem cell transplantation. Some cancer treatment vaccines under study are intended to induce an immune response against the cancer cells present in the individual.

Donor lymphocyte infusion is used for people who have relapsed disease after stem cell transplantation for certain blood cancers, such as CML or myeloma. The infusion of the original stem cell donor's lymphocytes may induce another remission. This type of treatment is being studied intensively to learn more about the basis for this immune cell effect and to expand it for use in other types of blood cancer.

Gene Therapy. One approach to gene therapy (treatment that alters a gene's DNA or RNA) is to use agents that disable oncogenes and prevent the formation of corresponding oncoproteins. Oncoproteins cause the transformation to various types of cancer cells. For example, in CML treatment studies, researchers are trying to modify the *BCR-ABL* oncogene, which produces an oncoprotein that stimulates CML cell growth. (Note that the approved CML oral drug therapies, Gleevec, Sprycel and Tasigna do not alter the oncogene. These drugs work by interfering with BCR-ABL tyrosine kinase (the CML oncoprotein) and blocking its effect on the cell.)

Two other potentially important gene therapy approaches include the application of "RNA interference (RNAi)," a modality that uses molecules of RNA to silence disease-promoting genes, and "aptamer treatment," a technique that prepares small molecules in the laboratory that have the ability to inactivate disease-causing proteins. New forms of cancer therapy may be developed if RNAi can be applied to oncogenes and/or aptamer treatment can be applied to oncoproteins.

Risk-Adapted Therapy. Research is under way to identify biomarkers that may give doctors information about the type of therapy needed by different people who have the same broad diagnosis. Risk-adapted therapy may be viewed as "personalized medicine" that can be applied if there is enough information about the individual and/or the specific disease to tailor the treatment. Biomarkers may also be able to indicate which individuals have a higher-than-normal risk of developing specific long-term or late effects. Biomarkers can

be high levels of certain substances in the body, such as antibodies or hormones, or genetic factors that increase susceptibility to certain effects.

Stem Cell Transplantation

Stem cell transplantation, introduced about 50 years ago, is an important therapy for many children and adults who are treated for blood cancer. Between 1970, when the International Bone Marrow Transplant Registry (IBMTR) began tracking data, and today, the number of stem cell transplants for people with blood cancer has increased from hundreds to several thousand per year. As part of blood cancer treatment, the purpose of stem cell transplantation is to restore the function of the marrow (the blood-forming organ in the body). The marrow may be impaired due to the blood cancer and/or treatment.

Autologous and Allogeneic Transplantation. The main types of stem cell transplantation are autologous transplantation (the transplant patient has his or her own cells collected and infused back) and allogeneic transplantation (matched cells from a donor are collected and transplanted to the patient). For both types, stem cells are usually collected from the circulating blood, but may be collected from the marrow or, in some cases, from umbilical cord blood.

Compared to an autologous transplant, an allogeneic transplant is associated with a higher risk for serious side effects of the procedure, or death. In general, with autologous transplant there is a higher risk of disease recurrence than with a successful allogeneic transplant. The decision to do a transplant, and whether the transplant should be autologous or allogeneic, depends on the type of blood cancer, the age of the individual, the choice(s) of other effective treatment options and the availability of a stem cell donor.

To donate his or her own cells for autologous transplantation, an individual needs to have a sufficient number of healthy stem cells in his or her marrow or blood. Drugs such as plerixafor (Mozobil®), given with a white cell growth factor (see *Quality of Life, Physical Issues*, page 6) may be given to move stem cells from the marrow to the blood for collection and subsequent autologous transplantation.

The donor for an allogeneic transplant may be a sibling with the same tissue type as the transplant candidate (a "match"). The chance of having a full match with a sibling is about 25 percent. When a matched sibling donor is not available, a matched unrelated donor is sought through a search of the National Marrow Donor Program registry. The efforts of the National Marrow Donor Program and other donor registries have created a bank of more than 7.4 million potential stem cell donors.

Reduced-Intensity Transplantation. A modified form of allogeneic transplantation called “nonmyeloablative” or “reduced-intensity” allogeneic stem cell transplantation may be an option for people with certain types of blood cancer. If the results of ongoing clinical trials prove effective, this therapy will extend the upper age range of persons who can benefit from an allogeneic transplant.

Umbilical Cord Blood Stem Cell Transplantation. Umbilical cord blood is another source of stem cells for allogeneic transplantation, especially for children and smaller adults. To date, there have been about 6,000 cord blood stem cell transplants from unrelated donors and several hundred from sibling donors, worldwide. The National Marrow Donor Program registry includes nearly 90,000 cord blood units. The numbers of stem cells in cord blood are often insufficient for the needs of larger adolescent and adult patients. Clinical trials of transplantation with two cord blood units (double cord blood transplant) have shown promising results with more rapid engraftment than those seen with single-unit transplants, and improved survival. Researchers are also studying methods to increase the number of stem cells so that cord blood transplants will engraft faster. Expanding the number of stem cells by growing them in a test tube would especially benefit full-grown adolescents and adults.

Haploidentical Transplantation. Research is under way to improve haploidentical allogeneic transplantation. This approach is important because it has the potential to increase the number of suitable donors for children. With haploidentical transplantation, donor stem cells from a partially matched family member are used, meaning that a parent could be the donor.

Quality of Life

Care for people with blood cancer includes providing good quality of life. Supportive care is given to prevent or treat psychosocial and physical aspects of disease and/or treatment.

Psychosocial Issues. Supportive care includes helping people with blood cancer who have depression, anxiety, a lack of information or skills, a lack of transportation or other challenges that disrupt work or school. Left unaddressed, psychosocial problems not only create or exacerbate suffering, but also interfere with treatment.

Physical Issues. Physical aspects of supportive care include the use of antibiotics, immunoglobulins or growth factors to treat infections, a common complication of blood cancer or its treatment. White cell growth factors include filgrastim (Neupogen®), pegfilgrastim (Neulasta®) and sargramostim (Leukine®). Blood transfusions may be used to treat anemia, another common side effect of the disease or treatment. Red cell growth factors such as Aranesp® (darbepoetin alfa) and Procrit® (epoetin alfa) may be used

to treat chemotherapy-induced anemia in specific types of blood cancer. People who receive frequent blood transfusions may be treated with iron chelation therapy [for example, deferasirox (Exjade®) and deferoxamine mesylate (Desferal®)].

Survivorship

The risk of long-term effects of anticancer therapy has been recognized for years. In response, treatments continue to evolve. To minimize the risk, the lowest effective doses of drugs and radiation are used. Regular medical follow-up is encouraged to enable doctors to assess the full effect of therapy, to detect and treat disease recurrence, and to identify and manage long-term or late effects. Survivors need physical examinations yearly or more often. Regular examinations include cancer screening and screening for long-term and late effects of treatment. Some studies indicate that few childhood survivors are aware of the kinds of therapy they received and only a small proportion receive care focused on the specific risks resulting from their prior cancer therapy.

There are survivorship programs, focusing on life after cancer, at several major hospitals around the country. Survivors do not necessarily need a cancer specialist for routine checkups and screening, but they do need to see doctors who understand their previous treatment and its risks. Coordination between specialists and primary care physicians is essential to provide the best care. Some treatment centers have follow-up clinics that provide a comprehensive, multidisciplinary approach to monitoring and supporting cancer survivors. Some follow-up clinics specialize in pediatric cancer survivors; some others follow adult cancer survivors.

The Children’s Oncology Group has established *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* (www.survivorshipguidelines.org). While designed for children, many of the recommendations can be adapted as a starting point for adults.

Several organizations are working on guidelines for adults with blood cancer and their doctors; these guidelines will help to standardize follow-up care and increase awareness about long-term and late effects. Developing evidence-based guidelines for survivors diagnosed with cancer as adults is a complex process. One reason is that cancer survivors are a heterogeneous group; the risk for recurrence or late effects often depends on the diagnosis, stage, characteristics of their disease, the treatments received, when the treatments were given and underlying risk factors independent of their cancer or its treatment. The National Comprehensive Cancer Network (NCCN) has incorporated limited recommendations for surveillance and management of common issues facing survivors into their treatment guidelines (www.nccn.org).

Leukemia

“Leukemia” is the term for the four major types of leukemia (see Table 1 and Table 2).

The Four Major Types of Leukemia

Acute lymphocytic leukemia (ALL)	Chronic lymphocytic leukemia (CLL)
Acute myelogenous leukemia (AML)	Chronic myelogenous leukemia (CML)

Table 1

The terms “myelogenous (myeloid)” and “lymphocytic (lymphoblastic)” denote the cell types involved. In general, leukemia is characterized by the uncontrolled accumulation of blood cells. However, the natural history of each type, and the therapies used to treat people with each type, are different.

Living with Leukemia

An estimated 245,225 people in the United States are living with, or are in remission from, leukemia.

ALL and AML are diseases that progress rapidly without treatment. They result in the accumulation of immature, functionless cells in the marrow and blood. The marrow often stops producing enough normal platelets, red cells and white cells. Anemia, a deficiency of red cells, develops in virtually all people who have leukemia. The lack of normal white cells impairs the body’s ability to fight infections. A shortage of platelets results in bruising and easy bleeding.

CLL and CML usually progress slowly compared to acute types of leukemia. The slower disease progression allows greater numbers of more mature, functional cells to be made.

Approximate US Prevalence of the Four Major Types of Leukemia as of January 1, 2006

Type	Prevalence*
Chronic lymphocytic leukemia	85,713
Chronic myelogenous leukemia	22,473
Acute lymphocytic leukemia	53,273
Acute myelogenous leukemia	27,838

Table 2. Source: Surveillance, Epidemiology, and End Results (SEER) Program, SEER*Stat Database, Incidence-SEER 17 Regions Limited-Use + Hurricane Katrina impacted Louisiana cases, November 2008 submission (1973-2006 varying). Linked to county attributes. Total US, 1969-2006 counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2009, based on the November 2008 submission.

New Cases

An estimated 44,790 new cases of leukemia will be diagnosed in the United States this year. Cases of chronic leukemia account for nearly 11 percent more cases than acute leukemia (see Table 3).

Total Estimated Number of New Leukemia Cases in the United States for 2009

Type	Individuals	Male	Female
Acute lymphocytic leukemia	5,760	3,350	2,410
Chronic lymphocytic leukemia	15,490	9,200	6,290
Acute myelogenous leukemia	12,810	6,920	5,890
Chronic myelogenous leukemia	5,050	2,930	2,120
Unclassified forms of leukemia	5,680	3,230	2,450
Total	44,790	25,630	19,160

Table 3. Source: Cancer Facts & Figures 2009, American Cancer Society; 2009.

- Most cases of leukemia occur in older adults and the median age at diagnosis is 66 years.
- In 2009, leukemia is expected to strike more than 10 times as many adults (44,790) as children (3,509, aged 0-14 years).
- The most common types of leukemia in adults are AML and CLL (see Figure 3).
- The most common type of leukemia in children is ALL.
- In 2006, the latest year for which data are available, 70 percent of new cases of ALL occurred among children (2,887 cases, aged 0 to 19 years).
- Most cases of CML occur in adults. Only about 2.4 percent of new cases of leukemia in children aged 0 to 19 years are CML. Slightly less than 1 percent of all cases of CML are in children aged 15 to 19 years.

Estimated Proportion of New Cases (%) in 2009 for Types of Leukemia, Adults and Children*

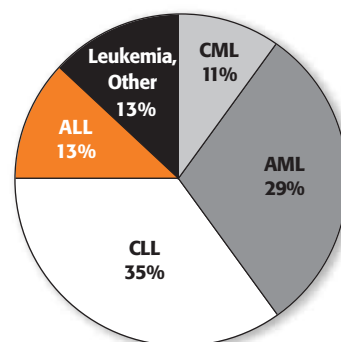


Figure 3. Source: Cancer Facts & Figures 2009, American Cancer Society; 2009. *Total is more than 100% due to rounding.

Incidence

Gender. Incidence rates for all types of leukemia are higher among males than among females. In 2009, males are expected to account for more than 57 percent of the new cases of leukemia.

Race and Ethnicity. Leukemia is one of the top 15 most frequently occurring types of cancer in all races or ethnicities.

- Leukemia incidence is highest among whites (12.8 per 100,000 population) and lowest among American Indian and Alaska Native populations (7.0 per 100,000), Asian and Pacific Islander populations (7.3 per 100,000).
- While incidence rates for all types of cancer combined are nearly 5 percent higher among blacks* than among whites, leukemia rates are higher among whites than among other races or ethnicities.
- From 1997 to 2006, incidence rates for leukemia have shown the greatest decline in white, Asian and Pacific Islander populations.
- Leukemia rates are substantially higher for children who are Hispanic, white, Asian, Pacific Islander, American Indian and Alaska Native than for black children.
- Hispanic children of all races under the age of 20 years have the highest rates of leukemia.

*Note: The incidence rate for all types of cancer among blacks in the SEER 17 region, from 2002 to 2006, was 493.6 per 100,000 population, averaging about 190,356 cases per year. The American Cancer Society estimates that about 150,090 of the expected 1.5 million new cancer cases in 2009 will be diagnosed in blacks.

Children. From 2002 to 2006, leukemia represented 27 percent of all of the types of cancer occurring among children younger than 20 years.

- Leukemia is the most common cancer in children less than 20 years old.
- In 2009, about 3,509 children less than 15 years old will be diagnosed with leukemia throughout the United States. About 33 percent of cancer cases in children aged 0 to 14 years are leukemia.
- In the 17 SEER regions of the United States, excluding Louisiana, from 2004 to 2006, there were 2,901 children under the age of 20 years diagnosed with leukemia, including 1,203 diagnosed with ALL.
- ALL is the most common cancer in children 1 to 7 years old.
- The incidence of ALL among 1- to 4-year olds is nearly eight times greater than the rate for young adults 20 to 24 years.

Adolescents and Young Adults. AML incidence is much higher in children from 0 to 14 years than it is in people aged 15 years through young adulthood.

- In 2002 to 2006, among 15- to 19-year olds, ALL incidence was almost twice that of AML.
- In 25- to 29-year olds, AML incidence was 29 percent higher than that of ALL
- From 1975 to 2006, the incidence of AML declined slightly for all age-groups.

Adults. CLL, AML and CML are most prevalent in the seventh, eighth and ninth decades of life. Incidence begins to increase significantly among people with

- CLL—at aged 50 years and older
- AML—at aged 55 years and older (see Figure 4)
- CML—at aged 55 years and older.

Age-Specific Incidence Rates for Acute Myelogenous Leukemia (All Races), 2002-2006

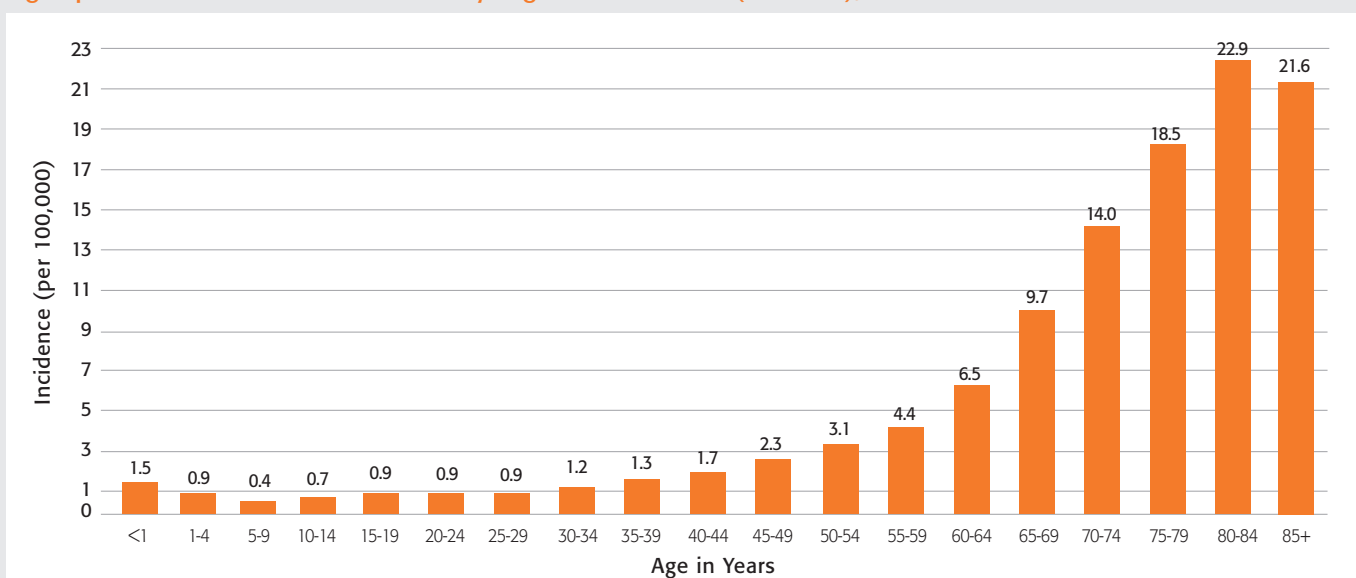


Figure 4. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009.

Signs and Symptoms

Signs of acute leukemia may include easy bruising or bleeding (because of platelet deficiency), paleness or easy fatigue (because of anemia), recurrent minor infections or poor healing of minor cuts (because of an inadequate white cell count). These signs are not unique to leukemia and may be caused by other more common conditions. Nonetheless, they do warrant medical evaluation. The diagnosis of leukemia requires specific blood tests, including an examination of cells in the blood and marrow. People who have chronic leukemia may not have major symptoms; they may be diagnosed as a result of a periodic physical examination and testing.

Possible Causes

Leukemia strikes males and females of all ages. The cause of leukemia is not known. Chronic exposure to benzene (primarily from tobacco smoke), extraordinary doses of radiation, and certain cancer therapies, can be causes of the disease. However, most cases are not explained by any of these causes.

Treatment

The goal of treatment for leukemia is to bring about a complete remission. Complete remission means that there is no evidence of disease and the individual returns to good health with normal blood and marrow cells. Relapsed leukemia indicates return of the cancer cells and the return of disease signs and symptoms. For acute leukemia, a complete remission that lasts five years after diagnosis often indicates long-term survival. Treatment centers report increasing numbers of people with leukemia who are in complete remission at least five years after diagnosis of their disease.

Survival

Relative survival rates vary according to a person's age at diagnosis, gender, race and type of leukemia. The overall five-year relative survival rate for leukemia has nearly quadrupled in the past 48 years. From 1960 to 1963, the five-year relative survival rate among whites with leukemia was 14 percent. From 1975 to 1977, the five-year relative survival rate for the total population with leukemia was 35 percent and from 1999 to 2005, the overall relative survival rate was 54 percent (see Figure 5). Thirty-one percent more males than females are living with leukemia.

From 1999 to 2005, the five-year relative survival rates overall were:

- CML—53.3 percent
- CLL—78.8 percent
- AML—23.4 percent overall and 60.2 percent for children younger than 15 years
- ALL—66.3 percent overall and 90.9 percent for children younger than 5 years.

Five-Year Relative Survival Rates for All Ages, All Types of Leukemia, 1975-2005

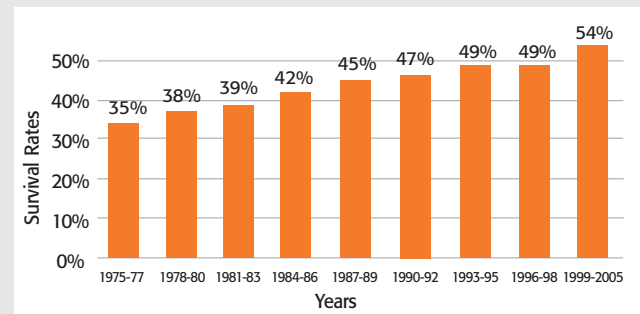


Figure 5. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2006. National Cancer Institute; 2009.

Figure 6 shows childhood ALL five-year survival rates have improved significantly over the past four decades. Most children with ALL younger than 19 years will become five-year survivors of the disease. However, significant treatment-related long-term morbidity and mortality for childhood cancer has been well established by several studies. Long-term treatment-related effects among ALL and other childhood cancer survivors may include any subsequent cancer, cardiac disease, pulmonary disease or other causes.

Five-Year Relative Survival Rates for Acute Lymphocytic Leukemia in Children Under 15, Diagnosed 1964-2005

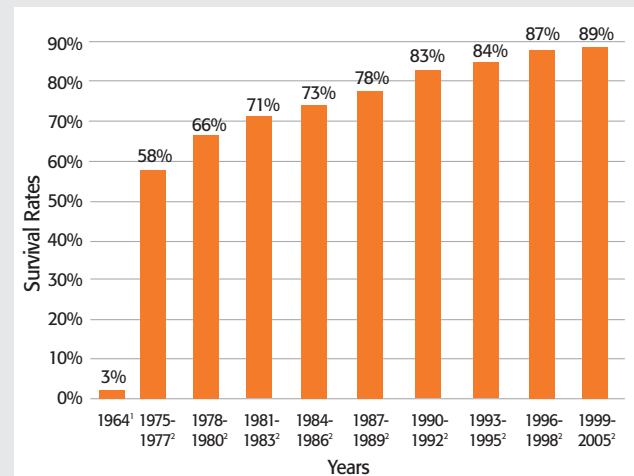


Figure 6. Sources: 1. Zuelzer WW. Implications of long-term survivals in acute stem cell leukemia of childhood treated with composite cyclic therapy. *Blood*. 1964;24:477-494. 2. SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2006. National Cancer Institute; 2009.

Deaths

In 2009, it is anticipated that approximately 21,870 deaths (12,590, males and 9,280, females) in the United States will be attributed to leukemia. Estimated deaths for the four major types of leukemia are:

- AML—9,000 deaths estimated, 2009
- CLL—4,390 deaths estimated, 2009
- ALL—1,400 deaths estimated, 2009
- CML—470 deaths estimated, 2009.

For other, unclassified forms of leukemia an additional 6,610 deaths are estimated for 2009.

In general, the likelihood of dying from most types of leukemia decreased from 1996 to 2005 (the latest year for which these data are available). However, the likelihood of dying from AML increased from 1996 to 2005.

Gender. In 2009, leukemia will be the fifth most common cause of cancer deaths in men and the seventh most common in women in the United States. The estimated number of deaths attributed to leukemia in the United States is nearly 36 percent higher for males than for females. Deaths from leukemia in 2009 are expected to be distributed by gender as shown in Table 4.

Race and Ethnicity. The highest rate of deaths from 2002 to 2006 was in whites, at 7.5 per 100,000 population, followed by blacks at 6.4 per 100,000.

- From 2002 to 2006, blacks diagnosed with leukemia between the ages of 25 and 64 years had a higher death rate than whites from the disease.
- In 2009, approximately 1,830 blacks (970 males and 860 females) are expected to die of leukemia.
- Leukemia is the seventh most common cause of cancer deaths in black males and the eighth most common in black females.

Children, Adolescents and Young Adults. The leukemia death rate for children from 0 to 14 years in the United States has declined 88 percent from 1969 to 2006.

- Despite this decline, leukemia causes more deaths than any other cancer among children and young adults less than age 20 years.
- In 2009, about 460 children under 15 years are expected to die from leukemia.

Estimated Deaths (All Age-Groups) from All Types of Leukemia, 2009

Type	Overall	Male	Female
Acute lymphocytic leukemia	1,400	740	660
Chronic lymphocytic leukemia	4,390	2,630	1,760
Acute myelogenous leukemia	9,000	5,170	3,830
Chronic myelogenous leukemia	470	220	250
Other, unclassified forms of leukemia	6,610	3,830	2,780
Total	21,870	12,590	9,280

Table 4. Source: *Cancer Facts & Figures 2009*, American Cancer Society; 2009.

Hodgkin and Non-Hodgkin Lymphoma

“Lymphoma” is a general term for many malignant diseases that originates in the lymphatic system. Lymphoma results when a lymphocyte (a type of white cell) undergoes a malignant change and multiplies out of control. Eventually, healthy cells are crowded out and malignant lymphocytes amass in the lymph nodes, liver, spleen and/or other sites in the body.

Living with Lymphoma

A total of 601,184 members of the US population are living with, or in remission from, lymphoma.

- There were 148,461 people living with Hodgkin lymphoma (active disease or in remission).
- There were 452,723 people living with non-Hodgkin lymphoma (active disease or in remission).

Hodgkin Lymphoma. Hodgkin lymphoma has characteristics that distinguish it from other diseases classified as lymphoma, including the presence of the Reed-Sternberg cell, a large, malignant cell found in Hodgkin lymphoma tissues.

- Hodgkin lymphoma will represent about 11.4 percent of all of types of lymphoma diagnosed in 2009.

Non-Hodgkin Lymphoma. Non-Hodgkin lymphoma (NHL) represents a diverse group of diseases that are distinguished by the characteristics of the cancer cells associated with each disease type. The designations “indolent” and “aggressive” are often applied to types of NHL. Each type has prognostic factors that categorize it as either more or less favorable.

- NHL is the ninth most common cause of cancer deaths in males and the sixth in females.

New Cases

About 74,490 people living in the United States will be diagnosed with lymphoma in 2009 (8,510 cases of Hodgkin lymphoma and 65,980 cases of NHL).

The incidence of Hodgkin lymphoma is consistently lower than that of NHL. Table 5 shows estimated new cases of lymphoma, in 2009, by gender.

New Cases of Lymphoma by Gender, 2009

Type	Male	Female	Total
Hodgkin lymphoma	4,640	3,870	8,510
Non-Hodgkin lymphoma	35,990	29,990	65,980
Total	40,630	33,860	74,490

Table 5. Source: *Cancer Facts & Figures 2009*, American Cancer Society; 2009.

Incidence

Gender. Incidence rates for Hodgkin lymphoma tend to be higher among males than among females. NHL is also more common in males than in females.

- NHL is the seventh most common cancer in males and females in the United States.
- The age-adjusted incidence of NHL rose by more than 76 percent from 1975 to 2006, an average annual percentage increase of about 2.5 percent.

Age-specific incidence rates, by gender, for NHL are as follows:

- At ages 20 to 24 years, 2.9 per 100,000 males and 1.9 per 100,000 females.
- By ages 60 to 64 years, 54.2 per 100,000 males and 39.5 per 100,000 females.

Race and Ethnicity. From 15 to 19 years, more non-Hispanic white children are diagnosed with Hodgkin lymphoma than children of other races or ethnic groups.

From ages 0 to 14 years, American Indian, Alaska Native, Asian and Pacific Islander children have the lowest rates of Hodgkin lymphoma.

In children, the highest incidence rates of NHL are in black children from ages 15 to 19 years (2.06 per 100,000). In children younger than 20

- Lymphoma is most commonly diagnosed in whites (24.3 per 1 million population), followed by black children (21.9 per 1 million population) and Hispanic children (20.6 per 1 million population).
- Lymphoma is least commonly diagnosed among American Indian and Alaska Native children (12.6 per 1 million population).

Blacks, from the mid-to-late teen years to the mid-50s, have higher incidence rates of NHL than whites. However, beginning at age 55 years, whites generally have considerably higher incidence rates of NHL than blacks.

NHL is the fifth most common cancer in Hispanics, comprising nearly 5 percent of all types of cancer cases. Among women, Hispanics of all races have the second highest incidence rates of NHL after whites.

Children. Lymphoma (Hodgkin lymphoma, 7.2 percent; NHL, 6.6 percent) is the third most common cancer in children.

- In 2009, children younger than 15 years will comprise more than 4.5 percent of all cases of Hodgkin lymphoma expected to be diagnosed and 0.7 percent of all NHL cases expected to be diagnosed. Note that the numbers of cases expected to be diagnosed in children younger than 15 years are similar: 461 for NHL and 386 for Hodgkin lymphoma.
- The incidence of Hodgkin lymphoma among young people under 20 years was 1.1 per 100,000 children in 2006. The incidence in this group decreased significantly between 1975 and 1995. It has remained fairly constant since 1999, decreasing slightly to 0.9 in 2005.

Adolescents and Young Adults. Older children and adolescents are more commonly diagnosed with Hodgkin lymphoma than young children.

- About 2.4 cases of NHL per 100,000 people occur in 20- to 24-year old individuals.

- The lymphoma rates (Hodgkin lymphoma and NHL) for the years from 1997 to 2006, were higher for the 20- to 24-year old age-group (7.4 per 100,000) than for the 15- to 19-year old age-group (4.7 per 100,000).
- There was an overall decrease in the incidence of lymphoma for people between the ages of 15 years and 39 years during the span of years from 1997 to 2006.

Adults. Hodgkin lymphoma incidence rates are lower in adults in their middle years than in young adults. Incidence increases in people between 60 and 84 years (see Figure 7).

The incidence of NHL increases with age (see Figure 8).

- From ages 60 to 64 years the rate increases more than 19 times to 46.5 cases per 100,000.
- From ages 80 to 84 years the rate increases more than 49-fold to 118.1 cases per 100,000 persons.

Age-Specific Incidence Rates for Hodgkin Lymphoma, 2002-2006

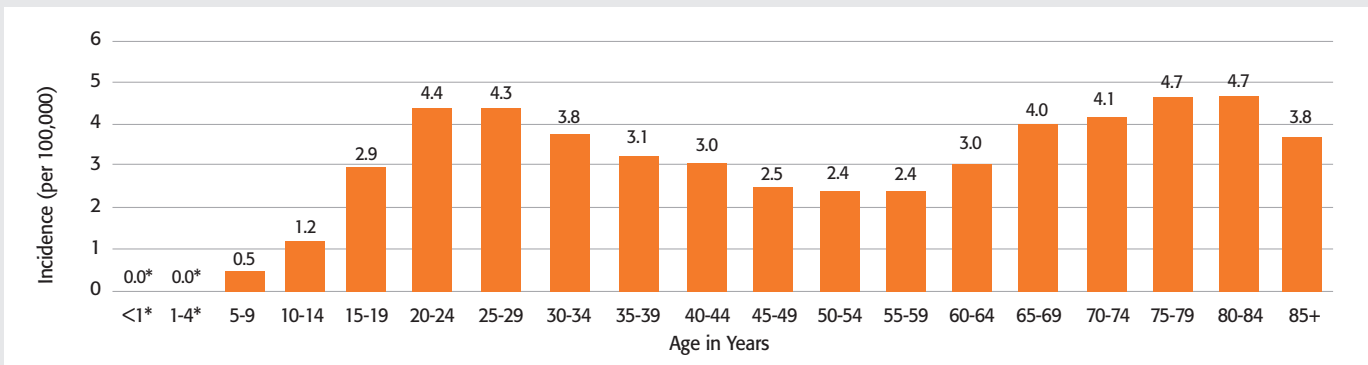


Figure 7. Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009. *<16 cases for each age and time interval, SEER 17 areas.

Age-Specific Incidence Rates for Non-Hodgkin Lymphoma, 2002-2006

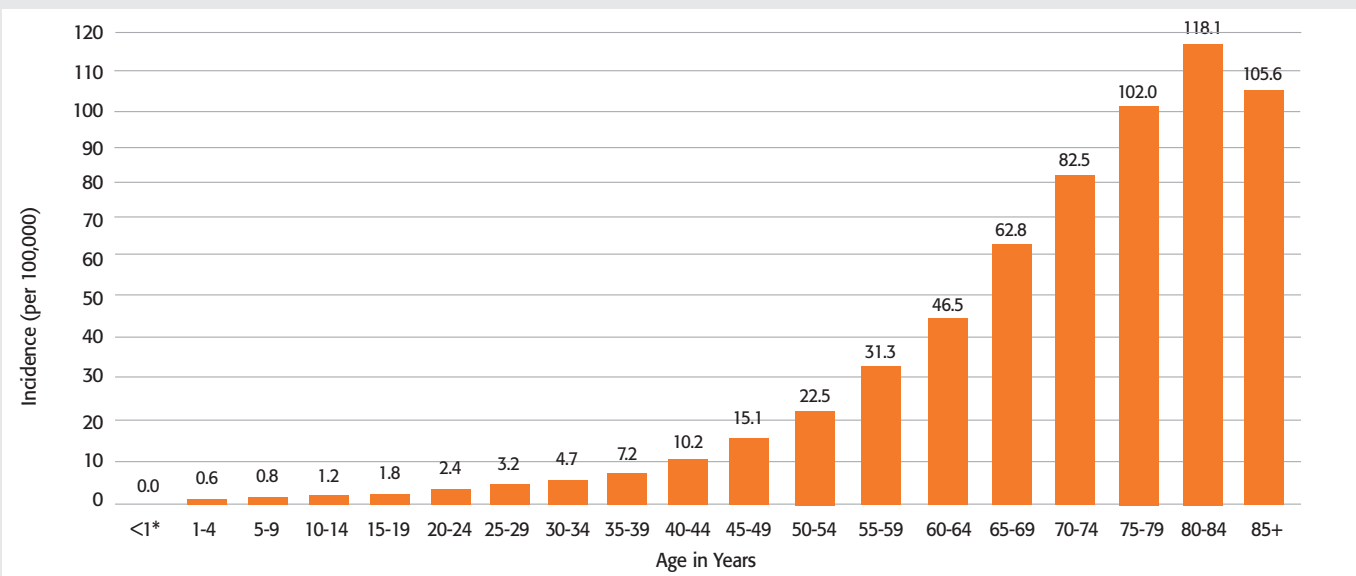


Figure 8. Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009. *<16 cases for each age and time interval, SEER 17 areas.

Signs and Symptoms

A common early sign of Hodgkin lymphoma or NHL is a painless enlargement of one or more lymph nodes. However, enlarged lymph nodes may be the result of inflammation in the body and are not necessarily a sign of cancer.

Other Hodgkin lymphoma signs and symptoms may include recurrent high fever, persistent cough and shortness of breath, drenching night sweats of the whole body, itching and weight loss.

Other signs and symptoms of NHL may include bone pain, cough, chest pain, abdominal pain, rash, fever, night sweats, enlarged spleen, unexplained fatigue or weight loss. Some individuals may have no symptoms and a diagnosis of NHL is made as a result of a periodic physical examination and testing.

Possible Causes

The results of certain studies about causes of Hodgkin lymphoma have not been definitive—many studies of links between Hodgkin lymphoma and environmental exposures have been conducted, with unclear results. Although Epstein-Barr Virus (EBV) has been associated with nearly half of Hodgkin lymphoma cases, EBV has not been conclusively established as a cause. Most cases of Hodgkin lymphoma occur in people who do not have identifiable risk factors; most people with identifiable risk factors do not develop Hodgkin lymphoma.

The reasons for the development of NHL are not known. Immune suppression plays a role in some cases. People infected with the human immunodeficiency virus (HIV) have a higher risk of developing lymphoma. Studies suggest that specific ingredients in herbicides and pesticides may be linked to NHL. Exposure to certain viruses, such as EBV and human T-lymphotropic virus (HTLV), are also associated with NHL. The bacterium *Helicobacter pylori* causes ulcers in the stomach and it is associated with the development of mucosa-associated lymphoid tissue (MALT) lymphoma in the stomach wall. About a dozen uncommon, inherited syndromes can predispose individuals to later development of NHL. These risk factors explain only a small proportion of cases.

Treatment

Cure is the goal of treatment for people who have Hodgkin lymphoma. “Involved field” radiation therapy with chemotherapy (sometimes called “combined modality therapy”) is the most common treatment approach for Hodgkin lymphoma. Involved field radiation therapy targets the evident Hodgkin lymphoma cell masses, and chemotherapy is used to kill neighboring lymphoma cells.

In general, the goal of treatment for NHL is to destroy as many lymphoma cells as possible and to induce a complete

remission. Treatment protocols vary according to the type of disease. Chemotherapy and radiation therapy are the two principal forms of treatment. Although radiation therapy is not often the sole or principal curative therapy, it is an important additional treatment in some cases. Stem cell transplantation and a watch-and-wait strategy are also used to treat some NHL subtypes. Immunotherapy is indicated to treat individuals with specific types of NHL.

Survival

Hodgkin lymphoma is now considered to be one of the most curable forms of cancer.

- The five-year relative survival rate for people with Hodgkin lymphoma has more than doubled from 40 percent in whites from 1960 to 1963, to just over 86 percent for all races from 1999 to 2005.
- Five-year relative survival rates are 91.8 percent for all people who were less than 45 years old at diagnosis.

The five-year relative survival rate for people with NHL has risen from 31 percent in whites from 1960 to 1963 to nearly 69 percent for all races from 1999 to 2005.

Race and Ethnicity. Table 6 shows the Hodgkin lymphoma and NHL five-year relative survival rates for all races, blacks and whites, spanning three decades.

Trends in Five-Year Relative Survival Rates by Race for Hodgkin Lymphoma and Non-Hodgkin Lymphoma

Hodgkin Lymphoma	1975-77	1981-83	1990-92	1999-2005
All races	74%	76%	83%	86%
Whites	74%	76%	84%	87%
Blacks	71%	73%	74%	81%
Non-Hodgkin Lymphoma	1975-77	1981-83	1990-92	1996-2005
All races	48%	53%	52%	69%
Whites	48%	53%	53%	70%
Blacks	49%	50%	42%	60%

Table 6. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009.

Children. Five-year relative survival is 95.5 percent for Hodgkin lymphoma in people younger than 20 years. Five-year relative survival is now 95.4 percent for Hodgkin lymphoma in children aged from 0 to 14 years.

In children aged from 0 to 19 years, five-year relative survival for NHL is now 84.4 percent. This represents a significant improvement in the rate of recovery. As recently as the mid-1970s, most children with NHL did not survive five years after they were diagnosed.

Subsequent Primary Cancers. The growing US survivor population has special needs for medical follow-up. Efforts are underway to provide information about survivors' risks for developing multiple primary cancers. The information will help physicians and patients discuss the risks and any established prevention and screening guidelines. Tables 8 and 9 show the observed-to-expected ratio (O/E) for subsequent primary cancer development in Hodgkin lymphoma and NHL survivors (see *Definitions*, page 25). Subsequent cancers among Hodgkin lymphoma survivors have been well-studied because of the high long-term survival rates and the relatively young age at diagnosis for many with this disease. NHL represents broad range of diseases, with varying risk factors and treatments; the relative risk for subsequent cancers depends on the NHL subtype and the treatment. The SEER data show that as a group, survivors of NHL have an increased O/E for developing subsequent cancers (O/E = 1.16), but their risk is lower than the risk of Hodgkin lymphoma survivors (O/E = 2.20).

Deaths

In 2009, an estimated 20,790 members of the US population will die from lymphoma (19,500, NHL and 1,290, Hodgkin

lymphoma). Overall, death rates have been declining for people with Hodgkin lymphoma for the last 30 years.

Estimated Deaths from Hodgkin Lymphoma and Non-Hodgkin Lymphoma, by Gender, 2009

Type	Overall	Male	Female
Hodgkin lymphoma	1,290	800	490
Non-Hodgkin lymphoma	19,500	9,830	9,670
Total	20,790	10,630	10,160

Table 7. Source: *Cancer Facts & Figures 2009*, American Cancer Society; 2009.

Gender. In men, death rates for Hodgkin lymphoma have been declining by 3 percent per year since 1997 and in women death rates for Hodgkin lymphoma have been declining 3.7 percent per year since 1998.

NHL is the ninth most common cause of cancer death in males and the sixth most common cause of cancer death in females in the United States (see Table 7).

Race and Ethnicity. NHL is the eighth most common cause of cancer death in Hispanic females and the seventh most common cause of cancer death in Hispanic males.

Observed-to-Expected Ratio for Developing Subsequent Primary Cancer after Hodgkin Lymphoma (HL) by Age at Diagnosis of HL, SEER 1973-2005

Second Primary Site	Birth to 19 (N=3,026)	20 to 39 (N=10,272)	40 to 59 (N=4,365)	60 and older (N=21,015)	All ages (N=21,015)	All ages		
						Observed	Expected	EAR**
Lung and bronchus	10.16*	5.07*	3.47*	1.78*	3.03*	365	120	11.34
Female breast	17.00*	2.99*	1.36*	1.04*	2.50*	307	123	8.54
Non-Hodgkin lymphoma	7.49*	6.54*	6.83*	3.78*	5.86*	225	38	8.66
ANLL***	31.86*	19.86*	18.16*	6.57*	15.24*	121	8	5.24
All subsequent cancers	7.80*	2.87*	2.11*	1.28*	2.20*	2,013	917	50.85

Table 8. Adapted with permission of the American Cancer Society, *Cancer Facts and Figures 2009*. American Cancer Society; 2009. *p<0.05 Figure is significant. **EAR = Estimated absolute risk (see *Definitions*, page 25). ***ANLL = Acute nonlymphocytic leukemia.

Observed-to-Expected Ratio for Developing Subsequent Primary Cancer after Non-Hodgkin Lymphoma (NHL) by Age at Diagnosis of NHL, SEER 1973-2005

Second Primary Site	Birth to 19 (N=3,026)	20 to 39 (N=10,272)	40 to 59 (N=4,365)	60 and older (N=21,015)	All ages (N=21,015)	All ages		
						Observed	Expected	EAR**
Lung and bronchus	—	2.37*	1.59*	1.18*	1.30*	1,449	1,115	6.52
Hodgkin lymphoma	4.13	5.65*	7.94*	3.85*	5.35*	99	18	1.57
ANLL***	23.94*	12.13*	5.51*	2.38*	3.34*	212	63	2.92
Melanoma	2.08*	1.61	1.42*	1.42*	1.44*	293	204	1.74
Kaposi sarcoma	—	15.31*	16.89*	2.34*	11.25*	119	11	2.12
All subsequent cancers	4.55*	2.14*	1.34*	1.05*	1.16	8,408	7,262	22.42

Table 9. Adapted with permission of the American Cancer Society, *Cancer Facts and Figures 2009*. American Cancer Society; 2009. *p<0.05 Figure is significant. **EAR = Estimated absolute risk (see *Definitions*, page 25). ***ANLL = Acute nonlymphocytic leukemia.

Myeloma

Myeloma is a cancer of the plasma cells (a type of white cell). Plasma cells are found primarily in the marrow. About 90 percent of people with myeloma have disease involving multiple sites at the time of diagnosis. Some individuals have myeloma that progresses very slowly (often referred to as “smoldering” or “indolent” myeloma).

In myeloma, a B lymphocyte (the cell-type that forms plasma cells) becomes malignant. Eventually, malignant plasma cells (myeloma cells) amass in the marrow and sometimes other sites in the body. The myeloma cells disrupt normal blood production, destroy normal bone tissue and cause pain. Healthy plasma cells produce immunoglobulins (antibodies) that protect the body against certain types of infection. The onset of myeloma interferes with antibody production, making people with myeloma susceptible to infection and other serious complications.

Living with Myeloma

An estimated 66,529 people in the United States were living with, or in remission from, myeloma.

New Cases

An estimated 20,580 new cases of myeloma (11,680 men and 8,900 women) are expected to be diagnosed in the United States in 2009.

Incidence

Gender. The incidence rate for the years 2002 to 2006 was 54 percent higher in men (7.1 per 100,000) than in women (4.6 per 100,000).

Race and Ethnicity. From 2002 to 2006, myeloma was the 10th most commonly diagnosed cancer among black men and women.

- The median age at diagnosis for blacks is 66.
- Blacks have more than double the incidence rate (11.7 per 100,000) of myeloma than whites (5.2 per 100,000).
- Black men who are 45 years and older have higher myeloma incidence rates than black women and white men and women.
- The highest incidence rates are found in black men 80 to 84 years of age (93.6 per 100,000).

Age. Figure 9 shows the age-specific incidence rates for myeloma for 2002-2006.

Age-Specific Incidence Rates for Myeloma, 2002-2006

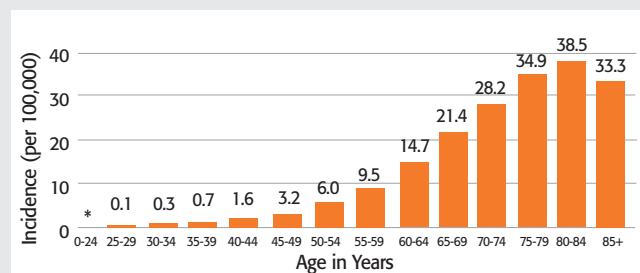


Figure 9. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009. * <16 cases for each age and time interval, SEER 17 areas.

Signs and Symptoms

The first symptom of myeloma is often bone pain from the effects of myeloma cells on the marrow. Fractures may occur as a result of the weakened bones. Anemia, recurrent infections or numbness or pain in the hands and/or feet (caused by a condition called “peripheral neuropathy”) can also be early signs of the disease. People with myeloma may have no symptoms or they may tire more easily and feel weak.

Possible Causes

The cause of myeloma is unknown in most cases. Long-term exposure to certain chemicals seems to increase risk for developing myeloma, but most people who have myeloma do not have any history of such exposure, indicating that other factors must play major roles.

Treatment

The goals of treatment for people with myeloma are to reduce symptoms, to slow disease progression and to provide prolonged remissions. There have been significant treatment advances in recent years. The approach for treating each person is customized, based on the extent of disease and the rate of disease progression. People who have a slow-growing myeloma and no symptoms, may not need treatment immediately. Some people need only supportive care to reduce symptoms of anemia, high blood calcium levels, infections and/or bone damage or osteoporosis. Patients who require myeloma-specific therapies may receive combination drug therapy, high-dose chemotherapy with stem cell transplant (autologous, allogeneic or reduced-intensity allogeneic), radiation therapy for local disease and/or new and emerging drug therapies as part of clinical trials.

Survival

Current statistical databases show that overall, five-year relative survival in people with myeloma has improved significantly since the 1960s.

- Five-year relative survival has increased from 12 percent in 1960-1963 (for whites) to 37.1 percent from 1999 to 2005 (for all races and ethnicities).
- Five-year survival for white males (40.1 percent) increased the most.
- The three-year survival rate as of January 1, 2006 was nearly 56 percent.

Deaths

Approximately 10,580 deaths from myeloma are anticipated this year.

Gender. Myeloma was the seventh most common cause of cancer death for black women and the twelfth most common cause of cancer death for white women from the years 2002 to 2006.

Race and Ethnicity. In 2009, approximately 3 percent of all cancer-related deaths among blacks is expected to be from myeloma.

- The mortality rate for myeloma from 2001 to 2005 for black men was nearly double the rate for white men (8.3 per 100,000 vs. 4.3 per 100,000). For black women, it was more than twice the rate for white women (6.0 per 100,000 to 2.8 per 100,000).
- The US median age at death from myeloma is 74 years. It is between 70 and 71 years for blacks and is 70 years for Hispanics.

Myelodysplastic Syndromes

Myelodysplastic syndromes (MDS) are a group of diseases of the blood and marrow, with varying degrees of severity and life expectancy. MDS begins with a change to a normal stem cell in the marrow. The marrow becomes filled with an increased number of developing blood cells. However, the blood is usually deficient in cells because the cells in the marrow die before they can be released into the blood. Normally, immature cells known as “blasts” make up less than 5 percent of all cells in the marrow. In MDS, blasts often constitute more than 5 percent of the cells. (A person with AML has more than 20 percent blasts in the marrow.) MDS has been known as “smoldering leukemia,” or “preleukemia.” These terms may be misleading because they imply that MDS is only serious and problematic if it evolves into AML; this is not the case.

Living with Myelodysplastic Syndromes

The most common specific MDS subtypes are refractory anemia (RA), 15 percent, and refractory anemia with excess blasts (RAEB), 14 percent.

- People diagnosed with MDS, not otherwise specified (MDS NOS) comprise 52 percent of all MDS cases.
- People diagnosed with therapy-related MDS comprise less than 2 percent of all reported cases.

New Cases

For the five-year period from 2002 to 2006 there were approximately 56,841 cases of MDS throughout the United States, averaging an estimated 11,368 cases per year.

Incidence

The overall incidence rate for MDS is estimated at four cases per 100,000 population (see Table 10).

Gender. For the five-year period from 2002 to 2006 there were a total of approximately 31,202 cases in males (averaging 6240 per year) and a total of 25,639 cases in females (averaging 5,128 per year). This results in an incidence rate of 5.4 per 100,000 population for males and a much lower 3.1 per 100,000 population in females.

Race and Ethnicity. White males have the highest incidence rates (5.6 per 100,000 population), while American Indian and Alaska Native females and Asian and Pacific Islander females have the lowest incidence rate (2.3 per 100,000 population for each population group).

Age. According to SEER data for 2002 to 2006, MDS is most commonly diagnosed in males aged 70 years and older.

Myelodysplastic Syndromes Incidence Rates, 2002-2006

By Race

Race	Rate per 100,000 population (Both genders)
All Races	4.0
White	4.1
Black	3.6
Asian/Pacific Islander	2.9
American Indian/Alaska Native	2.3
Hispanic (of all races, excluding Alaska Native Registry)	3.0

By Age

Age in Years	Rate per 100,000 population (Both genders)
<40	0.2
40 – 49	0.8
50 – 59	2.3
60 – 69	8.5
70 – 79	24.8
80+	43.9

Table 10. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, Age-Adjusted for 17 SEER Geographic Areas, 1975-2006. National Cancer Institute; 2009.

Signs and Symptoms

Most often, people diagnosed with MDS first seek medical attention because they are experiencing fatigue and shortness of breath (from anemia). Some individuals have no symptoms and a diagnosis of MDS is made as a result of a periodic physical examination and testing.

Possible Causes

MDS may be a primary diagnosis or the diagnosis may be secondary to treatment with chemotherapy and radiation therapy for certain other types of cancer. Most people with MDS have primary MDS, which usually has no clear-cut triggering event. A possible cause of MDS is repeated exposure to the chemical benzene. Tobacco smoke is now the most common known cause of benzene exposure. Benzene is also found in certain industrial settings, but regulation has reduced workplace exposure.

Treatment

The goal of therapy for a person with lower-risk MDS is to manage the disease by reducing transfusion needs and infection risk. Currently, the only potentially curative therapy is high-dose chemotherapy with allogeneic stem cell transplantation. This may be a practical option for certain younger people with higher-risk MDS (individuals whose life expectancy without successful treatment warrants the risk

associated with transplantation). Other general approaches to treatment (used alone or in combination) include: transfusion; a watch-and-wait strategy; administration of blood cell growth factors; drug therapy with newer agents or chemotherapy of the type used to treat AML.

Survival

On January 1, 2005, there were 25,473 people in the United States living with, or in remission from, MDS. Because the SEER program only recently began maintaining statistics for MDS, this is a four-year prevalence figure, as opposed to the 31-year prevalence figures reported for other types of cancer. Prevalence and mortality statistics were not reported by SEER for MDS in 2009 at the time of this publication.

Deaths

Data for the number and rates of deaths from MDS are not yet available.

Incidence Rates: Leukemia, Lymphoma, Myeloma and Myelodysplastic Syndromes

Tables 11, 12 and 13 show incidence rates for leukemia, Hodgkin lymphoma, NHL, myeloma and myelodysplastic syndromes using data figures from 2002 to 2006 (the most recent available). Rates are per 100,000 population and are age-adjusted to the 2000 population.

Incidence Rates by Gender, All Races, per 100,000 Population, 2002-2006

Type	Overall	Male	Female
Leukemia	12.2	15.8	9.5
Non-Hodgkin lymphoma	19.5	23.5	16.4
Hodgkin lymphoma	2.8	3.1	2.5
Myeloma	5.6	7.1	4.6
Myelodysplastic syndromes	4.0	5.4	3.1

Table 11. Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009. (Based on SEER 17 areas.)

Incidence Rates by Gender, for Blacks, per 100,000 Population, 2002-2006

Type	Overall	Male	Female
Leukemia	9.8	12.7	7.8
Non-Hodgkin lymphoma	14.8	18.3	12.2
Hodgkin lymphoma	2.6	2.9	2.3
Myeloma	11.7	14.3	10.0
Myelodysplastic syndromes	3.6	4.3	3.2

Table 12. Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009. (Based on SEER 17 areas.)

Incidence Rates by Gender, for Whites, per 100,000 Population, 2002-2006

Type	Overall	Male	Female
Leukemia	12.8	16.5	9.9
Non-Hodgkin lymphoma	20.4	24.4	17.2
Hodgkin lymphoma	3.0	3.3	2.7
Myeloma	5.2	6.6	4.1
Myelodysplastic syndromes	4.1	5.6	3.1

Table 13. Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2006, National Cancer Institute; 2009. (Based on SEER 17 areas.)

LEUKEMIA

LYMPHOMA

MYELOMA

Estimated New Cases and Estimated Deaths by State

Estimated New Cases of Blood Cancers by Site, by State, 2009

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	590	950	340	110
Alaska	70	110	*	*
Arizona	810	1,250	320	150
Arkansas	420	680	210	90
California	4,570	7,140	2,150	980
Colorado	720	920	250	140
Connecticut	540	920	270	130
Delaware	120	190	60	*
Dist. of Columbia	50	90	60	*
Florida	3,180	4,640	1,430	570
Georgia	1,080	1,560	570	250
Hawaii	160	260	70	*
Idaho	250	330	80	50
Illinois	1,940	2,900	890	400
Indiana	930	1,420	400	170
Iowa	590	750	260	90
Kansas	380	600	180	50
Kentucky	690	980	310	130
Louisiana	660	960	360	130
Maine	270	360	100	50
Maryland	640	1,120	400	120
Massachusetts	1,000	1,610	440	250
Michigan	1,690	2,470	730	320
Minnesota	890	1,130	350	50
Mississippi	360	540	210	*
Missouri	880	1,250	400	180
Montana	170	240	70	*
Nebraska	290	400	120	50
Nevada	380	480	140	60
New Hampshire	210	310	90	*
New Jersey	1,380	2,160	640	350
New Mexico	310	360	120	50
New York	3,140	4,540	1,520	680
North Carolina	1,150	1,730	640	250
North Dakota	110	140	50	*
Ohio	1,950	2,800	820	140
Oklahoma	580	820	250	100
Oregon	490	910	250	140
Pennsylvania	2,200	3,330	950	450
Rhode Island	180	260	70	50
South Carolina	590	870	330	110
South Dakota	140	180	60	*
Tennessee	1,000	1,370	430	90
Texas	3,470	4,530	1,600	650
Utah	330	440	110	60
Vermont	100	140	50	*
Virginia	840	1,450	470	200
Washington	990	1,540	420	180
West Virginia	290	420	130	50
Wisconsin	980	1,310	370	150
Wyoming	70	110	*	*
Total	44,790	65,980	20,580	8,510

Table 14. Sources: *Cancer Facts & Figures 2009*. American Cancer Society, 2009 and American Cancer Society, Inc., Surveillance Research. Used with permission. **Note:** These estimates are offered as a rough guide and should be interpreted with caution. They cannot be compared with estimates prior to 2007 to determine cancer incidence trends. The method of derivation, which was new for 2007, is described by Pickle et al., *CA: A Cancer Journal for Clinicians*, January/February 2007. State estimates may not add to US total due to rounding and exclusion of state estimates fewer than 50 cases. Numbers are rounded to the nearest 10. * <50 cases

Estimated Deaths from Blood Cancers by Site, by State, 2009

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma§
Alabama	340	290	220	
Alaska	*	*	*	
Arizona	410	350	210	
Arkansas	250	200	110	
California	2,200	1,900	1,080	
Colorado	300	230	150	
Connecticut	270	220	150	
Delaware	70	50	*	
Dist. of Columbia	50	*	*	
Florida	1,650	1,560	720	
Georgia	550	460	300	
Hawaii	80	80	*	
Idaho	120	80	50	
Illinois	950	770	440	
Indiana	520	420	250	
Iowa	300	280	120	
Kansas	200	180	120	
Kentucky	320	300	170	
Louisiana	310	310	150	
Maine	110	90	60	
Maryland	390	300	230	
Massachusetts	490	430	240	
Michigan	820	710	420	
Minnesota	370	320	200	
Mississippi	220	180	110	
Missouri	530	430	240	
Montana	90	70	*	
Nebraska	150	130	60	
Nevada	140	130	80	
New Hampshire	100	60	50	
New Jersey	610	610	290	
New Mexico	120	110	60	
New York	1,380	1,430	620	
North Carolina	640	530	370	
North Dakota	50	*	*	
Ohio	890	740	480	
Oklahoma	290	240	120	
Oregon	290	330	160	
Pennsylvania	1,080	1,090	520	
Rhode Island	90	70	*	
South Carolina	330	310	150	
South Dakota	60	70	*	
Tennessee	480	440	270	
Texas	1,430	1,300	700	
Utah	130	130	70	
Vermont	60	*	*	
Virginia	500	410	290	
Washington	450	410	200	
West Virginia	140	180	70	
Wisconsin	500	400	220	
Wyoming	*	*	*	
Total	21,870	19,500	10,580	

Table 15. Sources: *Cancer Facts & Figures 2009*. American Cancer Society, 2009. Additional data supplied by the American Cancer Society based on data from the US Mortality Public Use Data Tapes, 1969-2006, National Center for Health Statistics, Centers for Disease Control and Prevention, 2009. Used with permission. **Note:** These estimates are offered as a rough guide and should be interpreted with caution. State estimates may not add to US total due to rounding and exclusion of estimates that are less than 50. Numbers are rounded to the nearest 10. * <50 deaths § Deaths could not be calculated due to small numbers.

LEUKEMIA

LYMPHOMA

MYELOMA

About LLS

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to funding blood cancer research and providing education and patient services. LLS offers a wide variety of programs and services in support of its mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual and corporate contributions to advance its mission.

Research and Professional Education

LLS research programs are based on the belief that all scientifically sound approaches toward a cure for, or control of, leukemia, lymphoma, myeloma and myelodysplastic syndromes (blood cancer) should be encouraged worldwide. Since the first funding in 1954, LLS has awarded more than \$600 million in research funding.

LLS administers two integrated research-funding programs—the *Research Grant Program* and the *Therapy Acceleration Program*—to support its mission. With advisory input from world-renowned biomedical research experts, these programs support the entire research continuum relevant to improved outcomes for blood cancer patients, from basic laboratory science to clinical trials of new agents and from investigator-initiated research to multidisciplinary academic collaborations and private-sector drug development alliances, all aimed at effective discovery and development of new therapies to treat people with blood cancer.

Research Grant Program

The *Research Grant Program* provides grant funding to support scientific studies at academic centers in the United States and 13 other countries, through three grant mechanisms:

1. The *Career Development Program (CDP)* provides stipends to investigators of exceptional promise in the early stages of their careers, helping them to devote their careers to leukemia, lymphoma and/or myeloma research. This program is stratified into two separately reviewed programs in basic or clinical research:
 - Basic Research
 - *Scholars* are awarded \$110,000 a year for a total of \$550,000 over five years.
 - *Special Fellows* are awarded \$65,000 a year for a total of \$195,000 over three years.
 - *Fellows* are awarded \$55,000 a year for a total of \$165,000 over three years.
 - Clinical Research
 - *Scholars in Clinical Research* are awarded \$110,000 a year for a total of \$550,000 over five years.
 - *Special Fellows in Clinical Research* are awarded \$65,000 a year for a total of \$195,000 over three years.
2. The *Translational Research Program (TRP)* supports outstanding investigations deemed by our expert advisors most likely to translate basic biomedical discoveries into new, safe and effective treatments, ultimately prolonging and enhancing patients' lives. *Translational Research Awards* are made for an initial three-year period. Awards up to \$200,000 per year for three years, for a total of \$600,000, are granted each year. Funding for two additional years may be provided for highly promising projects that are entering phase 1 clinical trials. Thus, research reaching a clinical trial can receive \$1 million over five years to facilitate new drug discovery or advances in diagnosis or prevention.
3. The *Marshall A. Lichtman Specialized Center of Research Program (SCOR)* encourages multidisciplinary research by teams of leading-edge academic investigators that hastens the discovery and development of better treatments for people who have blood cancer. These grants are awarded to a cluster of at least three research groups that interact to foster advances in the diagnosis, treatment or prevention of blood cancer. The program is expected to generate new knowledge and breakthrough discoveries, leading to better survival rates and prevention measures. Each *SCOR* group is funded up to \$1.25 million per year over a five-year period, to a total cost of \$6.25 million. The *SCOR* program brings together research teams working in complementary areas, each focused on the discovery of new approaches to benefit patients or those at risk for developing leukemia, lymphoma and myeloma. Awards go to those groups that best demonstrate the synergy that will occur from their close interaction. The participating scientists may be at different institutions or from any country.

The Grant Review Process for the Research Grant Program. Scientists and physician-scientists who are

experts in the field of blood cancer research constitute four review subcommittees. They are:

- *CDP*—basic research
- *CDP*—clinical research
- *TRP*
- *SCOR*.

These committees evaluate all grant applications in those programs and select those applicants with the most innovative and important projects to advance the mission of LLS. Guidelines, instructions and applications for the three LLS research programs may be obtained by visiting www.LLS.org or by or emailing researchprograms@LLS.org.

Therapy Acceleration Program (TAP)

The *Therapy Acceleration Program (TAP)* is a strategic LLS initiative launched in 2007 with \$4 million in seed funding. The program accelerates new and better treatments and clinical tests into preclinical development and clinical trials. Working in concert with academic investigators, medical centers and companies, TAP is further bridging the gap between discovery and human applications to increase the likelihood that novel, possibly breakthrough, treatments will be made available to patients as soon as possible.

TAP encompasses three innovative efforts:

1. The *Academic Concierge Division* identifies current LLS-funded research with the greatest clinical promise and provides the funding and support needed to advance selected projects to the product stage.
2. The *Clinical Trial Division* partners LLS with some of the country's leading clinical trial centers to accelerate the testing of new blood cancer therapies in clinical trials.
3. The *Biotechnology Accelerator Division* allies LLS with companies to combine scientific and financial resources and accelerate the development of potential therapies that otherwise would not be prioritized by the company.

The *TAP* project-review process involves due diligence by an LLS staff team of drug development specialists in concert with a panel of leading biotechnology and pharmaceutical company executives and intellectual property and business development experts.

Professional Education

LLS serves the continuing education needs of the medical and research community through professional symposia offered throughout the year. The education program offers varying formats to facilitate the exchange of information

and ideas on the newest developments in cancer research and treatment. The Annual Research Symposium, sponsored by LLS, is held each December on the Friday immediately before the American Society of Hematology meeting. LLS funds several Focused Workshops each year on important topics relevant to hematologic malignancies.

Other meetings are held for LLS grantees. These include the Stohlman Scholar Symposium, the Translational Research Grant Progress Review Meeting and the *SCOR* Progress Review Meeting.

In addition to the highly focused scientific meetings, LLS also sponsors education meetings for primary care physicians and other professionals at meetings such as the American Academy of Family Physicians and American College of Physicians. LLS is an accredited provider of continuing education credit for nurses and social workers.

Patient Services

LLS is the world's foremost source of information about blood cancer. Patient Services at LLS is committed to improving access to information and quality of life, and to promoting health-seeking behaviors and coping skills, for all people touched by blood cancer. At the home office and in the chapter offices throughout the United States and Canada, Patient Services staff help people to connect with the many services and programs. LLS volunteers generously provide their time, talents and professional guidance to help implement LLS programs and to raise vitally needed funds.

National Programs and Services

Information Resource Center (IRC). The IRC is a global connection for people living with blood cancer and for healthcare professionals. It is staffed with master's level oncology professionals (Information Specialists) who offer guidance for coping with a blood cancer diagnosis and provide current disease information. Information specialists address treatment questions, conduct individual clinical trials searches and help people discuss the potential benefits of treatment in a clinical trial with their doctors. Information Specialists can be called at (800) 955-4572, Monday through Friday, 9 a.m. to 6 p.m. ET. The IRC can be contacted by e-mail at infocenter@LLS.org and individuals may chat online with an Information Specialist, from 10 a.m. to 5 p.m. ET, at www.LLS.org (click "Live Help").

TrialCheck®—A Clinical Trial Search Service Provided by LLS. Web visitors can locate clinical trials near them through LLS-supported TrialCheck®, a clinical trial search service that offers immediate access to listings of leukemia, lymphoma, myeloma and other blood cancer clinical trials.

Co-Pay Assistance Program. People with certain blood cancers who find it difficult or impossible to afford drug co-pays or health insurance monthly payments may be eligible for assistance from LLS. Eligibility for this program is also based on fund availability for specific blood cancer diagnoses and is subject to change. A current list of available funds by blood cancer diagnosis is available at www.LLS.org/copay or at (877) 557-2672.

Teleconferences and Webcasts. LLS hosts more than 25 free education programs and Webcasts each year where medical experts share the latest disease, treatment and research information with patients, survivors, families and healthcare professionals around the world. Information on registration for these free events can be accessed at www.LLS.org. Audio, podcast, Webcast and written transcript archives of these programs are available at www.LLS.org/programs.

LLS Web Site. Education, information and support are also delivered on the dynamic LLS site at www.LLS.org. Up-to-date and comprehensive disease and treatment content, news about LLS programs and services and the opportunity to sign up for free monthly electronic news updates and podcasts are some of the site's important features. Visitors can access archived national education programs and use interactive Web-based education programs and tools. The LLS discussion boards, the interactive *Personal Journeys* series, online support groups and tools such as *My CML Tracker*, for personal management of medical information, put people living with blood cancer front and center on the site.

Free Education Materials. An extensive collection of education materials is offered free to people living with blood cancer and to healthcare professionals. Each year, LLS distributes more than 1 million detailed and basic booklets, coloring books, brochures and DVDs through the IRC, the local chapters and the Web site. Visitors to the Web site can view and download materials at www.LLS.org/freematerials.

Chapter Programs and Services

Family Support Groups. LLS has developed more than 480 chapter-based Family Support Groups. Each group is guided by two volunteer oncology health professionals. The groups provide information and support and encourage communication among patients, families, friends and healthcare professionals.

First Connection. This program links a person who is newly diagnosed and a trained peer volunteer who has experienced a similar diagnosis and is in remission. The peer volunteer phones the newly diagnosed person to share information and support.

The Patient Financial Aid Program. For more than 33 years, LLS has helped people in need who have blood cancer to cover a portion of their treatment costs. Through this program, LLS continues to provide a limited amount of financial assistance to help people who are under a doctor's care for a confirmed blood cancer diagnosis. Patient financial aid funds are subject to availability.

The Trish Greene Back to School Program for Children with Cancer. This program is designed to increase communication among healthcare professionals, parents, patients and school personnel to assure youngsters a smooth transition from active treatment to a return to school. Printed literature, videos and other materials to aid the process are available through all local chapters.

Chapter-Based Education Programs. LLS offers a number of education programs for people with blood cancer and healthcare professionals, including:

Welcome Back: Facilitating the Return to School for Children with Cancer, a part of *The Trish Greene Back to School Program*. This education program discusses possible emotional and cognitive short- and long-term effects that children may experience after treatment, and offers numerous resources that can assist childhood cancer survivors to flourish in the school post treatment.

Living With Myeloma: An Overview of Diagnosis and Treatment, a complete overview of myeloma, including emerging therapies and finding emotional support. This program is supported by unrestricted educational grants from Celgene Corporation and Millennium: The Takeda Oncology Company.

Getting the Best Cancer Care at 55 and Older, an overview of the many factors (not age alone) that healthcare professionals need to assess to determine an appropriate cancer treatment plan for older adults.

New Directions for Blood Cancer Therapies, a clear description of clinical trials, how cancer drugs are developed and what the emerging treatment options are for leukemia, lymphoma and myeloma. This program is supported by unrestricted educational grants from Millennium: The Takeda Oncology Company and Bristol-Myers Squibb Company.

Advocacy

Since 1994, LLS advocacy has been a strong voice in Washington, DC, representing the healthcare quality concerns and medical research interests of patients and their families to policy makers at all levels of government. LLS volunteers and staff visit Capitol Hill regularly to lobby Congress in support of issues that impact research and patient care. Working through chapters across the country, local volunteers and staff are building a grassroots advocates' network to rally patients and their families to promote common goals related to cancer research and treatment. That network now numbers more than 43,000 and has become a potent voice in public policy deliberations.

LLS has identified key issues that currently shape its advocacy agenda, including

- Insurance coverage of patient-care costs in clinical trials.
- Ready access for all people in the United States to quality cancer care.
- Increased funding for the National Institutes of Health and National Cancer Institute (NCI).
- Increased funding for blood cancer research at other federal institutions.
- Federal funding for patient education and support programs.

LLS successfully lobbied Congress in 2001 to institute a blood cancer research initiative as part of the US Department of Defense medical research program. To date, that program has funded some \$30 million in additional blood cancer research.

In 2002, LLS successfully lobbied Congress for legislation that authorizes a new blood cancer research effort at the NCI and creates a new blood cancer education program for patients and the public under the Centers for Disease Control and Prevention (CDC). The patient education program was funded at \$27 million through 2009, providing additional support for blood cancer patients and their families nationwide.

LLS expanded its advocacy program beyond Washington in 2007 to include the representation of patient interests in state capitals. Guided by the 2008-2011 LLS Strategic Plan, LLS state-advocacy efforts have focused on ensuring coverage of routine care for patients enrolled in cancer clinical trials. Following successful campaigns in Maryland and California, LLS launched campaigns in New York, Pennsylvania, Ohio and Iowa.

Notes and Definitions

Notes

The National Cancer Institute's SEER Cancer Statistics Review (CSR) presents statistics by age, sex, race and ethnicity. These distinctions, while definitely useful, should not be thought of as absolute. Statistics for these categories reflect a blend of biological and cultural factors. Additionally, data reported by race and ethnicity represent both the diversity and the mixed heritage of the US population.

The United States does not have a nationwide reporting system or registry for blood cancer, so the exact number of cases is not known. The data presented in the report are an extrapolation or estimate of the number of cases reported by the 17 Surveillance, Epidemiology and End Results Program (SEER) regions (or, in some cases fewer than 17 SEER regions) and mortality data from the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). These numbers are extrapolated to the entire 17 SEER regions by dividing the number of cancer cases or deaths in a specific region by the US Bureau of the Census 2000 population data for that region. Mortality data reflected in the 2009 referenced SEER report reflect data updates from the National Center for Health Statistics from 1969 to 2006, made available in 2009. The American Cancer Society projects this year's estimated cancer cases based on incidence rates for 1995 to 2005 from 41 states and the District of Columbia (approximately 85 percent of the estimated US population*), as reported by the North American Association of Central Cancer Registries.

The SEER (17 region) data cover only about 25.2 percent of the US population. The data can be extrapolated for the entire United States by multiplying by the population ratio, but these figures do not take into account differences in geography, race and ethnicity in various regions and region-specific health risks. This year's data include a population correction for the effects of Hurricanes Katrina and Rita.

Because of changes in the information—such as racial classification—gathered in the 2000 US Census, estimates of cancer incidence, survival and mortality have been revised, mostly upward, in comparison to the 2002 SEER report.

Beginning in 2007, the American Cancer Society changed its method of estimating cancer incidence. This change means that from 2007 on, incidence estimates are not comparable with previous estimates for determining cancer incidence trends. The description of the methods used was published in Pickle et al., *CA: A Cancer Journal for Clinicians*, January/February 2007. As a result of this change in method, state-by-state incidence data for Hodgkin lymphoma have not been available since 2007 (because these numbers are so small).

Data on American Indians and Alaska Natives (AI/AN) should be interpreted with care because the data reflect statistics from Indian

Health Service (IHS) Contract Health Service Delivery Area (CHSDA) counties only. Many AI/ANs do not reside in such counties, and other AI/AN individuals are not members of federally recognized tribes and cannot avail themselves of IHS services.

Myelodysplastic syndromes (MDS) were included in the SEER statistics as separate entities beginning in 2007. Little data are available on MDS.

Definitions

Age-adjusted rate is an incidence or death rate that has been adjusted to reduce the bias of age in the makeup of the populations being compared, thereby providing a more reliable rate for comparison. Incidence or death rates can be adjusted for any demographic factor or any combination of factors, such as age (the most common), sex and race.

Incidence is the number of newly diagnosed cases for a specific cancer or for all cancers combined during a specific time period. When expressed as a rate, it is the number of new cases per standard unit of population during the time period. Incidence rates can be calculated based on a number of factors, such as age, race or sex.

Prevalence is the estimated number of people alive on a certain date in a population who previously had a diagnosis of the disease. It includes new (incidence) and preexisting cases and is a function of both past incidence and survival. Prevalence may be calculated in a number of different ways, especially in looking at populations in which individuals have had more than one type of cancer. In some prevalence statistics, only the first diagnosed cancer counts. Thus, if a person is initially diagnosed with melanoma and later develops leukemia, his or her survival with leukemia may not be counted in leukemia prevalence statistics. Thus, prevalence numbers reported may vary depending upon the method used to determine them.

In this report, complete prevalence is reported as defined by SEER as “an estimate of the number of persons (or the proportion of population) alive on a specified date who had been diagnosed with the given cancer, no matter how long ago that diagnosis was.” We are using the “31-year limited duration” prevalence figures, based on the “first invasive tumor for each cancer site diagnosed during the previous 31 years (1975-2005),” as per SEER Table I-21. The specified date is January 1, 2006 for the prevalence estimates.

Relative survival rate is an estimate of the percentage of patients who would be expected to survive the effects of the cancer. This rate is calculated by adjusting the observed survival rate so that the effects of causes of death other than those related to the cancer in question are removed. The relative survival rate is a comparison of survival to that of a person who is free of the

disease. (Observed survival is the actual percentage of patients still alive at some specified time after diagnosis of cancer. It considers deaths from all causes, cancer or otherwise.)

Observed-to-expected ratio (O/E) is the observed number of cancers in a population of cancer survivors divided by the number of cancers expected. The number of cancers expected is calculated using cancer rates from the general population and person-years-at-risk (PYAR) of the survivor population under study. The risk of developing subsequent cancers varies by the type of first cancer diagnosed, age at first diagnosis, environmental exposures, genetic factors, treatment and other factors.

Person-years-at-risk (PYAR) is counted from the date 2 months after the diagnosis of the first cancer (to exclude multiple primaries diagnosed at the same time) until the date of last known vital status or death, and allocated by age, sex, race, and calendar year. All second and later (third, fourth, etc.) cancer diagnoses are included.

Estimated absolute risk (EAR) is calculated by subtracting the expected number of cancer cases from the observed number, dividing by the PYAR, and multiplying by 10,000 [$((O-E)/PYAR) \times 10,000$]. The EAR represents the number of excess cancers per 10,000 PYAR (for example, a population of 10,000 cancer survivors followed for 1 year or 1,000 cancer survivors followed 10 years).

Citations and Acknowledgments

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