



LEUKEMIA &
LYMPHOMA
SOCIETY®

fighting blood cancers

Facts 2012

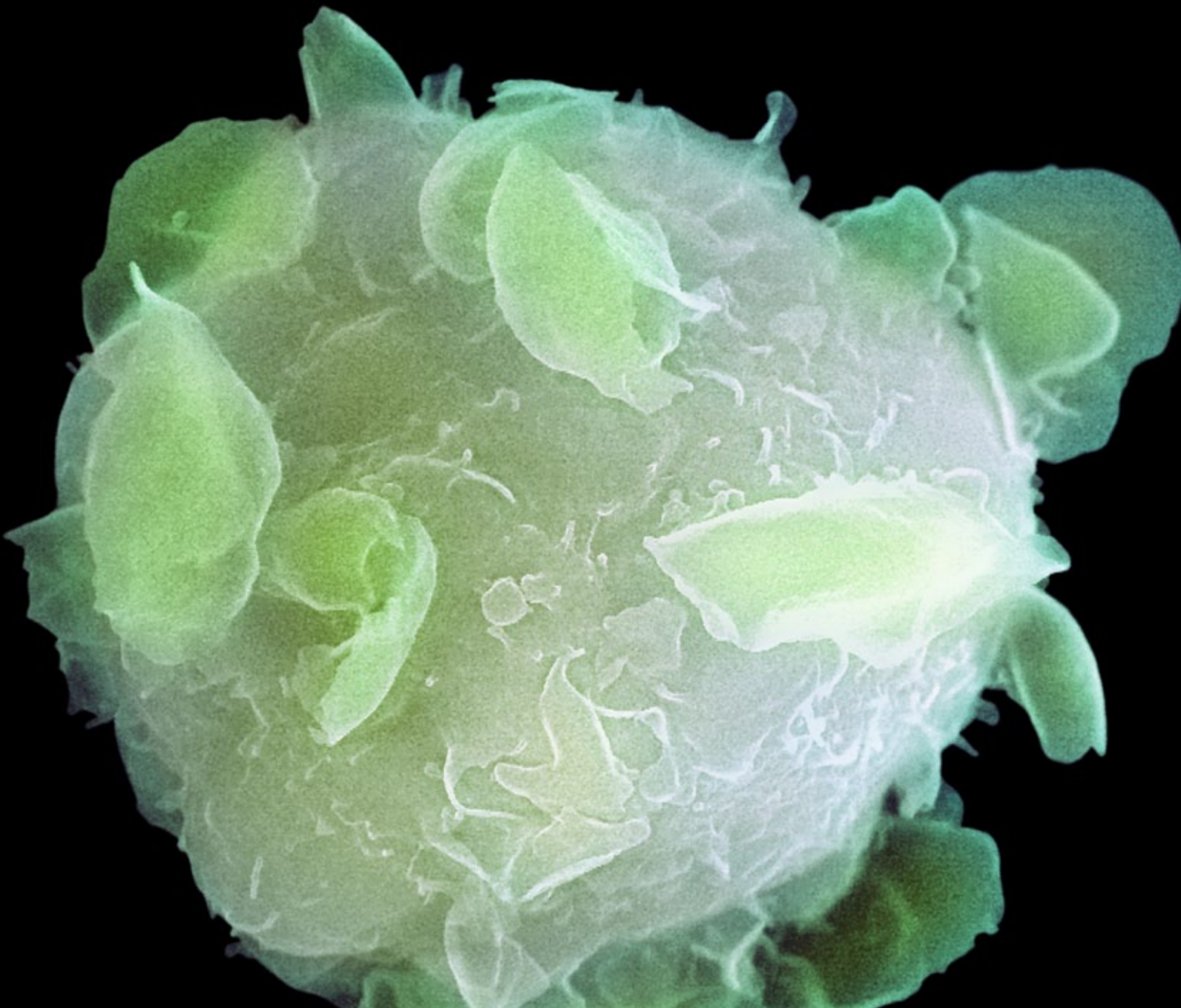


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Description: Stem cell, colored scanning electron micrograph (SEM). Stem cells can differentiate into any other cell type. There are three main types of mammalian stem cells: embryonic stem cells, adult stem cells, and cord-blood stem cells. The cell seen here is destined to become a blood cell. During blood cell development in adults, stem cells are formed through a process known as hematopoiesis. Blood cells have short lifespans and are therefore constantly produced by the bone marrow.

Executive Summary

Facts 2012 is an annual compilation of data available for leukemia, lymphoma, myeloma and myelodysplastic syndromes* (blood cancers). *Facts 2012* includes the estimated numbers of new blood cancer cases and deaths in 2011; the most recent statistics available for incidence, mortality and survival; and current and accurate information about symptoms, risk factors and treatment. Blood cancers 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.

*Data specified for "leukemia, lymphoma and myeloma" do not include data for myelodysplastic syndromes.

Highlights From *Facts 2012*

New Cases

Approximately every 4 minutes one person in the United States is diagnosed with a blood cancer.

- An estimated combined total of 140,310 people in the US are expected to be diagnosed with leukemia, lymphoma or myeloma in 2011.
- New cases of leukemia, lymphoma and myeloma are expected to account for 9.0 percent of the estimated 1,596,670 new cancer cases diagnosed in the US in 2011.

Incidence

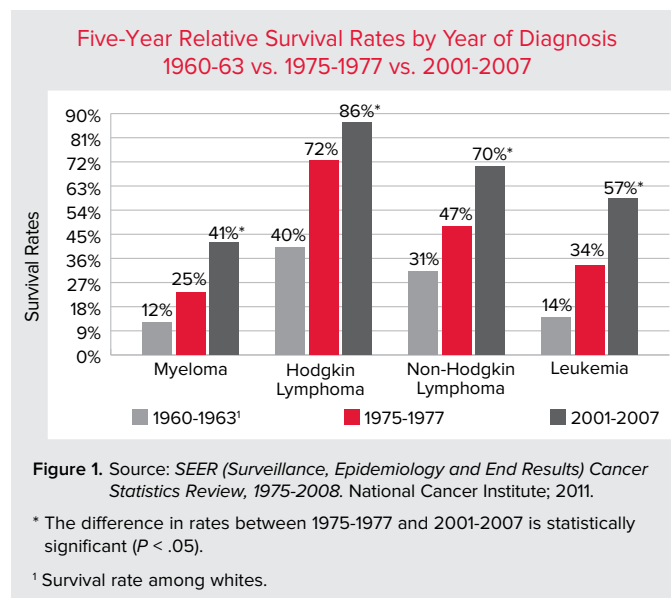
Incidence rates are the number of new cases in a given year, not counting the preexisting cases. The incidence rates are usually presented as a specific number per 100,000 population.

Overall incidence rates per 100,000 population reported in 2011 for leukemia, lymphoma and myeloma are close to or the same as data reported in 2010: leukemia 12.5, 2011 vs. 12.3, 2010; non-Hodgkin lymphoma (NHL) 19.8, 2011 vs. 19.6, 2010; Hodgkin lymphoma (HL) 2.8, 2011, same as 2010; myeloma 5.7, 2011 vs. 5.6, 2010.

Leukemia (27.2 percent), neoplasms of the brain and other nervous tissue (17.2 percent), HL (7.1 percent) and NHL (6.5 percent) are the most common types of cancer in children and adolescents 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. 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. Figure 1 shows the five-year relative survival rates for leukemia, lymphoma and myeloma during 1960-1963, 1975-1977 and 2001-2007.



An estimated 1,012,533 people in the US are living with, or are in remission from, leukemia, lymphoma or myeloma.

Deaths

Approximately every 10 minutes, someone in the US dies from a blood cancer. This statistic represents nearly 145 people each day or more than six people every hour.

- Leukemia, lymphoma and myeloma are expected to cause the deaths of an estimated 53,010 people in the US in 2011.
- These diseases are expected to account for nearly 9.3 percent of the deaths from cancer in 2011, based on the estimated total of 571,950 cancer deaths.
- In general, the likelihood of dying from most types of leukemia, lymphoma or myeloma decreased from 1999 to 2008 (the most recent data available).

Leukemia

- There are an estimated 274,930 people living with, or in remission from, leukemia in the US.
- In 2011, 44,600 people are expected to be diagnosed with leukemia.
- In 2011, 21,780 people are expected to die from leukemia.
- Approximately 31 percent more males are living with leukemia than females. More males than females are diagnosed with leukemia and die of leukemia.
- Leukemia causes almost one-third of all cancer deaths in children and adolescents younger than 15 years.

Hodgkin and Non-Hodgkin Lymphoma

- There are an estimated 662,789 people living with, or in remission from, lymphoma in the US.
- For HL, an estimated 159,846 people are living with the disease or are in remission.
- For NHL, an estimated 502,943 people are living with the disease or are in remission.
- In 2011, there are expected to be 75,190 new cases of lymphoma diagnosed in the US (8,830 cases of HL, 66,360 cases of NHL).
- In 2011, 20,620 people are expected to die from lymphoma (1,300 from HL, 19,320 from NHL).
- NHL is the seventh most common cancer in the US, and age-adjusted incidence rose by more than 82.5 percent from 1975 to 2008.

Myeloma

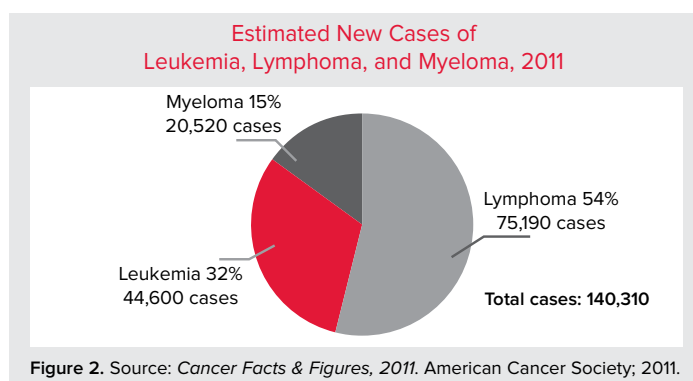
- There are 74,814 people living with, or in remission from, myeloma in the US.
- In 2011, 20,520 people are expected to be diagnosed with myeloma.
- The median age at diagnosis is 69 years; myeloma rarely occurs in people under age 45.
- In 2011, approximately 10,610 people are expected to die from myeloma.
- From 1975 to 2008, the incidence of myeloma increased by 18.3 percent.
- The incidence of myeloma in black males and females was 146 percent greater than myeloma incidence in white males and females in 2008.
- Overall, mortality from myeloma has been decreasing from 1995 to 2008 (the most recent data available).

Myelodysplastic Syndromes

- There were an estimated 12,577 new cases of myelodysplastic syndromes (MDS) diagnosed each year from 2004 to 2008.
- The estimated overall incidence rate of MDS is 4.4 cases per 100,000 population. White males have the highest MDS incidence rates (6.2 per 100,000 population).
- A possible cause of MDS (and acute myeloid leukemia) is repeated exposure to benzene. About half of the exposure to benzene in the US results from smoking tobacco or from exposure to tobacco smoke.
- Therapy-related MDS accounts for less than 2 percent of all cases.

About Blood Cancer Therapy

Leukemia, Hodgkin lymphoma (HL), 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 diseases are related cancers in the sense that they probably all result from acquired mutations to the DNA of a single lymph- or blood-forming stem cell. The mutated stem cell produces clones, which generate high numbers of abnormal cells (such as neutrophils, monocytes and lymphocytes). The abnormal cells multiply and survive without the usual controls that are in place for healthy cells. The accumulation of these cells in the marrow, blood and/or lymphatic tissue interferes with production and functioning of red cells, white cells and platelets. The disease process can lead to severe anemia, bleeding, an impaired ability to fight infection, or death. Figure 2 shows the percentage of estimated new cases for leukemia, lymphoma and myeloma in 2011.



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. Research has led to the growing understanding of the many subtypes for each of the blood cancers, and the differences in therapy required based on subtype. Thus, accurate diagnosis of the leukemia, lymphoma, myeloma or MDS subtype is critical. In the past decade, several new drugs (and new uses for established drugs) have greatly improved rates of blood cancer cure and remission. These drugs are often combined with chemotherapy. Combination therapy may result in certain cancer cells being less resistant to treatment. People living with some types and stages of cancer may also benefit from treatment with radiation.

When radiation therapy (RT) is used to treat a type of blood cancer, 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. Current methods of delivering RT are improved, so there is less “scatter” of radiation to nearby healthy tissues. In addition, radioimmunotherapy, a treatment that combines radiation therapy with immunotherapy (see page 5), is used to treat some types of NHL.

Newer classes of drugs include: 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 such as rituximab (Rituxan®); antibody-drug conjugates such as brentuximab vedotin (Adcetris®); 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.

These are some of the US Food and Drug Administration (FDA) approved drug therapies for blood cancers.

Alemtuzumab (Campath®) is indicated as a single agent for chronic lymphocytic leukemia (CLL) treatment.

All-trans-retinoic acid or ATRA (Tretinoin®) in combination with chemotherapy (anthracycline antibiotics) has significantly improved the remission rate and duration of remission for people with acute promyelocytic leukemia (APL), a type of acute myeloid 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.

Asparaginase Erwinia chrysanthemi (Erwinaze®) is a chemotherapy drug approved to treat patients with acute lymphoblastic leukemia (ALL) who have developed a hypersensitivity to *Escherichia coli* (E. coli) derived asparaginase and pegaspargase chemotherapy drugs used to treat ALL. The two E. coli derived asparaginase and

pegaspargase drugs approved to treat patients with ALL are asparaginase (Elspar®) and pegaspargase (Oncaspar®).

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 B-cell NHL that has progressed during or within six months of treatment with rituximab (Rituxan®) or a rituximab-containing regimen.

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

Brentuximab vedotin (Adcetris®) is indicated to treat HL after failure of autologous stem cell transplantation (ASCT) or after failure of at least two prior multi-agent chemotherapy regimens in patients who are not ASCT candidates, and to treat patients with systemic anaplastic large cell lymphoma (ALCL) after failure of at least one prior multi-agent chemotherapy regimen. This is the first new FDA-approved treatment for HL since 1977 and the first specifically indicated to treat ALCL.

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

Clofarabine (Clolar®) is approved to treat children with relapsed or refractory acute lymphoblastic leukemia (ALL) who have received at least two prior therapies.

Dasatinib (Sprycel®) is an approved oral drug for patients with newly diagnosed chronic-phase chronic myeloid leukemia (CML), for patients with CML who are no longer benefitting from, or did not tolerate, other treatment including imatinib mesylate (Gleevec®) and for patients with Philadelphia chromosome-positive acute lymphoblastic leukemia (Ph+ ALL) who no longer benefit from, or did not tolerate, other treatment.

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

Ibritumomab tiuxetan (Zevalin®) and *tositumomab and iodine I 131 tositumomab* (Bexxar®) are radioimmunotherapies (conjugated monoclonal antibodies) approved to treat individuals with certain types of NHL (see *Immunotherapy* on page 5). Zevalin is administered as part of a therapeutic regimen indicated for the treatment of patients with previously untreated follicular NHL who achieve a partial or complete response to first-line chemotherapy, or of patients with relapsed or refractory, low-grade or follicular B-cell NHL. Bexxar is indicated for the treatment of patients with CD20 antigen-expressing relapsed or refractory, low-grade, follicular or transformed NHL, including patients with rituximab-refractory NHL.

Imatinib mesylate (Gleevec®) is an oral drug indicated for the treatment of newly diagnosed adult and pediatric patients with CML in chronic phase, with CML in blast crisis, accelerated phase, or with chronic phase CML after failure of interferon-alfa therapy; of adult patients with relapsed or refractory Ph+ ALL; of adult patients with myelodysplastic/myeloproliferative diseases (MDS/MPD) associated with *PDGFR* (platelet-derived growth factor receptor) gene rearrangements; and of adult patients with chronic eosinophilic leukemia (CEL) who have the *FIP1L1-PDGFR α* fusion kinase (mutational analysis or FISH demonstration of *CHIC2* allele deletion) and/or the *FIP1L1-PDGFR α* fusion kinase negative or unknown.

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.

Nilotinib (Tasigna®) is an oral therapy approved to treat newly diagnosed CML patients and patients who do not respond to Gleevec, develop resistance to it or cannot tolerate its side effects (see *Imatinib mesylate*, above).

Ofatumumab (Arzerra®) is approved for the treatment of patients with CLL that is refractory to fludarabine (Fludara®) and Campath.

Pralatrexate (Folotyn®) is approved for the treatment of patients with relapsed or refractory peripheral T-cell lymphoma (PTCL). The National Comprehensive Cancer Network (NCCN) NHL Clinical Practice Guidelines and the Drug and Biologics Compendium includes Folotyn for the treatment of CTCL patients with mycosis fungoides and Sézary syndrome.

Rituximab (Rituxan®) is indicated for the treatment of patients with previously untreated follicular, CD20-

positive, B-cell NHL in combination with first-line chemotherapy and, in patients achieving a complete or partial response to Rituxan in combination with chemotherapy, as single-agent maintenance therapy; with nonprogressing (including stable disease), low-grade, CD20-positive, B-cell NHL, as a single agent, after first-line CVP¹ chemotherapy; with relapsed or refractory, low-grade or follicular, CD20-positive, B-cell NHL as a single agent; with previously untreated diffuse large B-cell, CD20-positive NHL in combination with CHOP² or other anthracycline-based chemotherapy regimens; and with previously untreated and previously treated CD20-positive CLL in combination with fludarabine and cyclophosphamide.

Romidepsin (Istodax[®]) is approved for the treatment of PTCL in patients who have received at least 1 prior therapy and for CTCL in patients who have received at least one prior systemic therapy.

Ruxolitinib (Jakafi[®]) is an oral medication approved for the treatment of intermediate and high risk myelofibrosis (MF), including primary myelofibrosis, post-polycythemia vera myelofibrosis and post-essential thrombocythemia myelofibrosis. Jakafi is the first approved JAK-inhibitor and is currently the only drug specifically approved to treat patients for this indication.

Thalidomide (Thalomid[®]), in combination with dexamethasone, is approved to treat newly diagnosed patients with myeloma.

Vorinostat (Zolinza[®]) is an agent that is approved to treat patients with CTCL following two systemic therapies, and is also being studied to treat people who have MDS.

Immunotherapy. Immunotherapy is based on the concept that laboratory-produced immune cells, capable of recognizing and killing cancer cells, can be given to patients to treat cancer. Immunotherapy is usually combined with chemotherapy or other cancer treatments. Monoclonal antibody therapy, cancer vaccines and donor lymphocyte infusion (DLI) are types of immunotherapy. These therapies generally result in less severe short-term side effects than chemotherapy.

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. A mAb can also be linked to a radioactive isotope to deliver radiation directly to the cancer cells. The conjugated mAbs Zevalin and 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 may be used to treat 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 expression) 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 Tassigna 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.)

Another gene therapy approach called “gene transfer therapy” involves removing patients’ cells, modifying them and then infusing the genetically engineered versions of the patients’ own T cells back into their bodies following chemotherapy. This approach has been studied in a very small group of advanced CLL patients, showing sustained remissions of up to a year. Studies for this approach are ongoing for CD19-positive tumors, including some subtypes of CLL, NHL and ALL.

¹cyclophosphamide, vincristine, prednisone

²cyclophosphamide, hydroxydoxorubicin (doxorubicin), Oncovin (vincristine), prednisone

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 different subtypes of the same broad diagnosis; for example, diffuse large B-cell lymphoma (DLBCL). 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

The purpose of stem cell transplantation, for the treatment of patients with certain blood cancers, is to restore the function of the marrow. The patient’s marrow may be impaired due to the blood cancer and/or cancer treatment. Between 1970, when the International Bone Marrow Transplant Registry (IBMTR) began tracking data, and today, the number of successful stem cell transplants for people with blood cancer has increased from hundreds to several thousand each year.

The main types of stem cell transplantation are autologous transplantation and allogeneic transplantation. 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.

Autologous Stem Cell Transplantation involves the use of a patient’s own stem cells. The stem cells are collected from marrow or blood and then frozen. The thawed cells are returned to the patient after he or she has received intensive chemotherapy and/or radiation therapy for his or her underlying disease. Autologous transplantation requires that an individual have sufficient numbers of healthy stem cells in the marrow or blood. Drugs such as plerixafor (Mozobil®), administered with a white cell growth factor (see *Quality of Life, Physical Issues*, page 7), may be given to move stem cells from the marrow to the blood for collection and subsequent autologous transplantation.

Allogeneic Stem Cell Transplantation involves the use of donor stem cells. The stem cells are most often collected from the circulating blood, but may be collected from the marrow. The donated stem cells can come from a related or unrelated donor. Siblings have the potential

to match the patient most closely, because the patient and the donor received their genes from the same parents. However, siblings do not always have closely matched tissue types. Umbilical cord-blood is another source of stem cells for allogeneic transplantation, especially for children and smaller adults. A cord-blood unit needs to have the correct number of stem cells based on the recipient’s size; research is under way to improve the yield of cord-blood stem cells, and to examine the use of more than one cord-blood unit per transplant. Cord-blood transplants may require a lower level of matching between the donor and recipient. The term “matched unrelated donor” (MUD) is sometimes used to describe a donor who is not a blood relative. MUDs are found by searching registries of volunteer donors for an individual who happens to be identical or very similar in tissue type to the patient. The National Marrow Donor Program (NMDP) provides patients with access to nearly 9 million potential donors and more than 145,000 cord-blood units through its registry and through its agreements with international cooperative registries. Transplant doctors can test to determine the degree of compatibility before a decision is made to use a particular donor. Compatibility is assessed by laboratory tests that identify the tissue type of donor and recipient.

Before a standard allogeneic transplant, patients receive high doses of chemotherapy and sometimes radiation therapy. A reduced-intensity allogeneic transplant involves using less intense conditioning treatment to prepare for the transplant compared to that for a standard allogeneic transplant. With a standard allogeneic transplant, the pretransplant treatment destroys most of the cancer cells. A reduced-intensity allogeneic transplant relies on the donor immune cells to fight the disease. Reduced-intensity allogeneic transplants may be an option for certain patients who are older, who have major organ complications or are otherwise not healthy or strong enough to undergo standard allogeneic transplantation. However, reduced-intensity allogeneic transplants do carry many of the same risks as standard allogeneic transplants.

Haploidentical Transplantation. About 70 percent of patients who need an allogeneic stem cell transplant do not have a suitable donor in their family. Efforts are being made to develop methods to permit a transplant between individuals who are only partially matched. For example, the ability to transplant from parent to child would make the availability of transplantation nearly universal for childhood disorders. Children’s bodies are more tolerant of deviations from ideal matching, and it is hoped that with better control of the immune reactions involved, moderately mismatched transplants

may be feasible. Studies are under way to find a means to shorten immune system recovery for recipients of partially matched (haploidentical) donor cells. These approaches may involve donor vaccination and adding back T lymphocytes that are specific for certain infections after the transplanted cells have engrafted.

Quality of Life

Care for people with blood cancer includes providing good quality of life. Palliative care, also called “supportive care,” is given to prevent or treat psychosocial and physical aspects of disease and/or treatment.

Psychosocial Issues. Palliative care includes helping people with blood cancer who have depression, anxiety, a lack of information, a lack of 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. Common side effects of cancer treatment include hair loss, nausea, diarrhea and low blood cell counts. This is because rapidly dividing cells, such as hair follicle cells, cells that line the gastrointestinal tract and stem cells that produce blood and immune cells are the most affected by cancer therapies. These and other treatment side effects can be managed with supportive care.

Survivorship

The risk of long-term effects of anticancer therapy has been recognized for years. To reduce the risks of therapy, treatments continue to evolve, and 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 (LTLE). Survivors need physical examinations yearly or more often. Regular examinations include cancer screening and screening for LTLE 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.

Efforts are under way to develop tools and strategies for comanagement of cancer survivors among hematologist/oncologists and primary care providers. The American Society of Clinical Oncology (ASCO) has developed a generic treatment plan and summary template that can be customized for almost any cancer diagnosis, which may be helpful to improve documentation and

coordination of cancer treatment and survivorship care. Survivorship programs that foster implementation of survivorship care plans and focus on life after cancer exist at a number of 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; others follow both pediatric and 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). The implementation of these guidelines is intended to increase awareness of potential LTLE and to standardize and improve follow-up care provided to survivors of childhood cancers throughout their lives. 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 LTLE. 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 and characteristics of their disease, the treatments received, when the treatments were given and underlying risk factors independent of their cancer or its treatment. The NCCN has incorporated into its treatment guidelines (www.nccn.org) some recommendations for surveillance and management of common issues facing survivors.

Leukemia

“Leukemia” is the term used to describe the four major types of leukemia (see Tables 1 and 2).

The Four Major Types of Leukemia

Acute Lymphoblastic Leukemia (ALL)	Chronic Lymphocytic Leukemia (CLL)
Acute Myeloid Leukemia (AML)	Chronic Myeloid Leukemia (CML)

Table 1. Source: The Leukemia & Lymphoma Society.

The terms “myeloid” or “myelogenous” and “lymphoid,” “lymphocytic” or “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 274,930 people in the US 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, nonfunctional 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, 2008

Type	Prevalence
Acute Lymphoblastic Leukemia	58,854
Chronic Lymphocytic Leukemia	105,119
Acute Myeloid Leukemia	30,993
Chronic Myeloid Leukemia	26,359

Table 2. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. Prevalence database: “US Estimated 33-Year L-D Prevalence Counts on 1/1/2008.” National Cancer Institute; 2011.

New Cases

An estimated 44,600 new cases of leukemia are expected to be diagnosed in the US in 2011. (See Figure 3 and Table 3.) Cases of chronic leukemia account for 5.6 percent more cases than acute leukemia.

Estimated Proportion of New Cases in 2011 for Types of Leukemia, Adults and Children

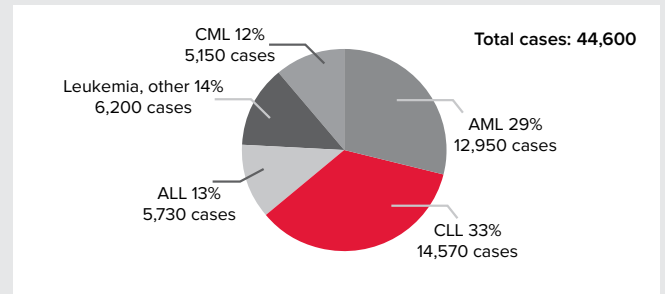


Figure 3. Source: Cancer Facts & Figures, 2011. American Cancer Society; 2011.

- Most cases of leukemia occur in older adults; the median age at diagnosis is 66 years.
- In 2011, leukemia is expected to strike more than 10 times as many adults (40,789) as children and adolescents (3,811, ages 0-14 years).
- The most common types of leukemia in adults are AML and CLL.
- The most common type of leukemia in children and adolescents (ages 0-19 years) is ALL.
- In 2008, the latest year for which data are available, ALL accounted for 76 percent of the new leukemia cases in children and adolescents ages 0 to 19 years.
- Most cases of CML occur in adults. About 2.9 percent of new cases of leukemia in children and adolescents (ages 0-19 years) are CML. Slightly more than 1 percent of all cases of CML are in adolescents ages 15 to 19 years.

Total Estimated Number of New Leukemia Cases in the United States for 2011

Type	Total	Male	Female
Acute Lymphoblastic Leukemia	5,730	3,320	2,410
Chronic Lymphocytic Leukemia	14,570	8,520	6,050
Acute Myeloid Leukemia	12,950	6,830	6,120
Chronic Myeloid Leukemia	5,150	3,000	2,150
Other Leukemia	6,200	3,650	2,550

Table 3. Source: Cancer Facts & Figures 2011. American Cancer Society; 2011.

Incidence

Gender. Incidence rates for all types of leukemia are higher among males than among females. In 2011, males are expected to account for nearly 57 percent of the new cases of leukemia.

Race and Ethnicity. Leukemia is the tenth most frequently occurring type of cancer in all races or ethnicities.

- Leukemia incidence is highest among whites (13.1 per 100,000 population); incidence is lowest among Asian and Pacific Islander populations (7.3 per 100,000 population) and American Indian and Alaska Native populations (7.6 per 100,000 population).
- While incidence rates for all types of cancer combined are 4.1 percent higher among blacks* than among whites, leukemia rates are higher among whites than among other races or ethnicities.
- From 1999 to 2008, incidence rates for leukemia have shown the greatest decline in Asian/Pacific Islander populations.
- Leukemia rates are higher for children and adolescents who are white, Hispanic, Asian, Pacific Islander, American Indian and Alaska Native than for black children and adolescents.
- Hispanic children and adolescents 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 2004 to 2008, was 491.2 per 100,000 population, averaging about 193,927 cases per year. As reported in Cancer Facts & Figures for African Americans 2011-2012, the American Cancer Society estimated that about 168,900 of the expected 1.6 million new cancer cases in 2011 would be diagnosed in blacks.*

Children. From 2004 to 2008, leukemia represented 27 percent of all of the types of cancer occurring among children and adolescents younger than 20 years.

- Leukemia is the most common cancer in children and adolescents less than 20 years old.
- In 2011, about 3,811 children and adolescents less than 15 years old are expected to be diagnosed with leukemia throughout the US.
- About 34 percent of estimated cancer cases in children and adolescents ages 0 to 14 years are leukemia.
- In the 17 SEER regions of the US, excluding Louisiana,* from 2004 to 2008 there were 5,053 children and adolescents under the age of 20 years diagnosed with leukemia, including 3,841 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.

**Note: Due to the large migration of both cancer patients and populations from Louisiana into Texas, Alabama and Mississippi in the aftermath of Hurricane Katrina in September 2005, and to some hospital closures and the loss of many patient records in affected areas, the 2004-2008 SEER 17 statistics include only 4.5 years of data for Louisiana, from 2003 through June 2005 and all of 2006 through 2008, to avoid miscalculation of cancer rates.*

Adolescents and Young Adults. ALL incidence is higher in children and adolescents from 0 to 14 years than it is in people ages 15 years through young adulthood. AML incidence is lower in children and adolescents from 0 to 14 years than it is in people ages 15 years through young adulthood.

- In 2004 to 2008, among 15- to -19-year-olds, ALL incidence was more than twice that of AML.
- In 25- to -29-year-olds, AML incidence was 57 percent higher than that of ALL.
- From 1975 to 2008, the incidence of AML has remained the same overall. The 2008 rate (3.69 per 100,000 population) is slightly above the average rate of 3.45 per 100,000 population.

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 age 50 years and older
- AML – at age 50 years and older (see Figure 4)
- CML – at age 65 years and older.

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.

Age-Specific Incidence Rates for Acute Myeloid Leukemia (All Races), 2004-2008

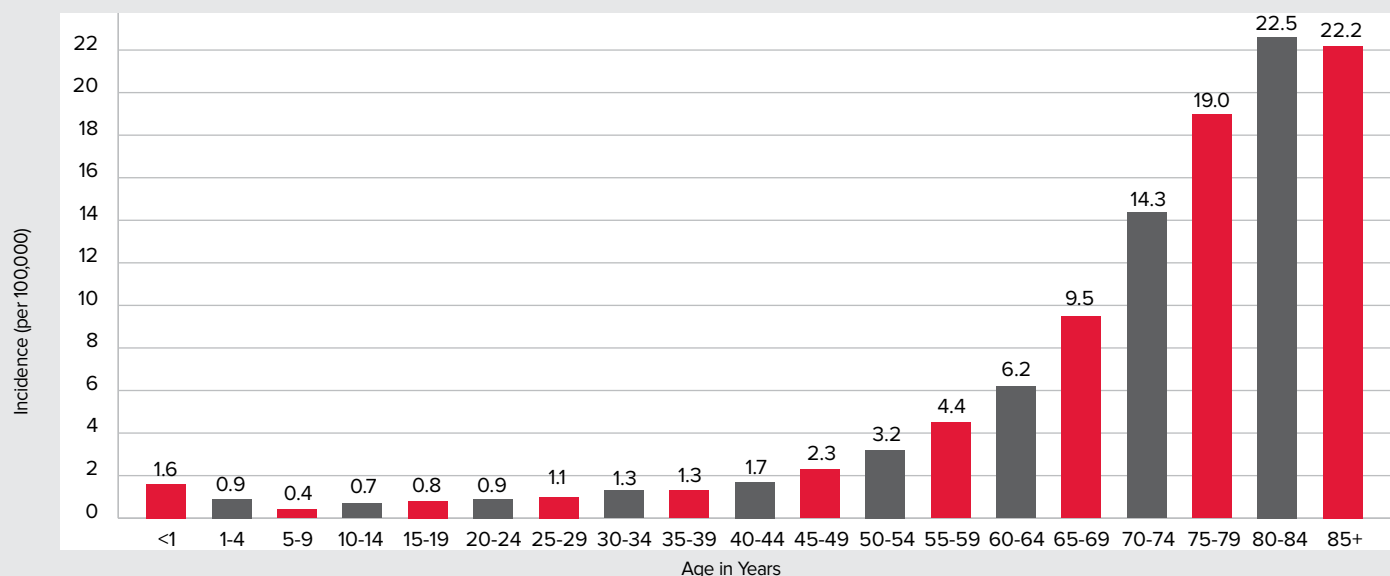


Figure 4. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

Possible Causes

Leukemia strikes males and females of all ages. The cause of most cases of leukemia is not known. Extraordinary doses of radiation and certain cancer therapies are possible causes. Repeated exposure to the chemical benzene may cause AML. Automobile exhaust and industrial emissions account for about 20 percent of the total national benzene exposure. About half of US benzene exposure results from tobacco smoking or from exposure to tobacco smoke. The average smoker is exposed to about 10 times the daily intake of benzene compared to nonsmokers.

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 50 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 34.4 percent, and from 2001 to 2007, the overall relative survival rate was 56.5 percent (see Figure 5; percentages in Figure 5 are rounded to the nearest integer). Thirty-one percent more males than females are living with leukemia.

From 2001 to 2007, the five-year relative survival rates overall were

- CML – 55.2 percent
- CLL – 80.8 percent
- AML – 23.6 percent overall and 63.6 percent for children and adolescents younger than 15 years
- ALL – 66.6 percent overall, 90.5 percent for children and adolescents younger than 15 years, and 91.5 percent for children younger than 5 years.

Five-Year Relative Survival Rates for All Ages, All Types of Leukemia, 1975-2007

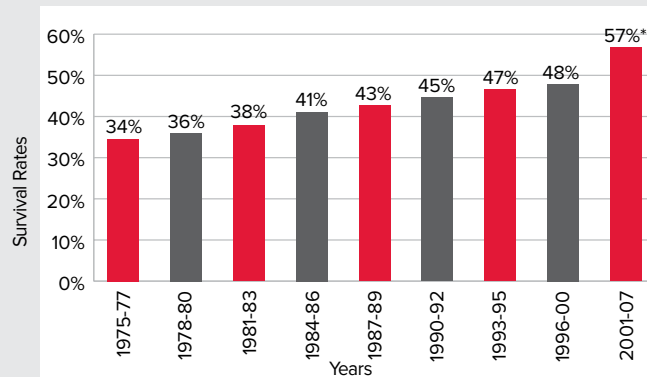
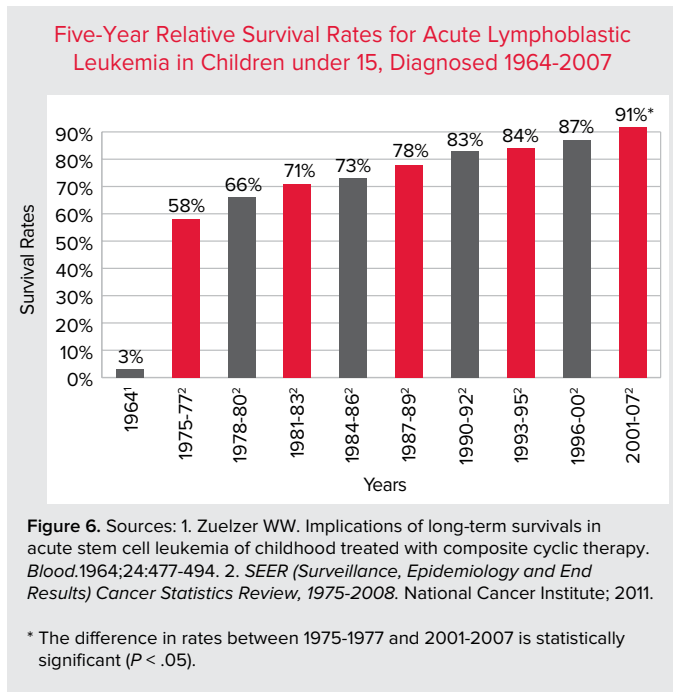


Figure 5. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

* The difference in rates between 1975-1977 and 2001-2007 is statistically significant ($P < .05$).

Figure 6 shows that childhood ALL five-year survival rates have improved significantly over the past five decades. Most children and adolescents younger than 20 years who have ALL are expected to 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.



Deaths

Approximately 21,780 deaths (12,740 males and 9,040 females) in the US are expected to be attributed to leukemia in 2011. Estimated deaths for the four major types of leukemia in 2011 are

- AML – 9,050 deaths
- CLL – 4,380 deaths
- ALL – 1,420 deaths
- CML – 270 deaths.

For other unclassified forms of leukemia, an additional 6,660 deaths in 2011 are estimated.

In general, the likelihood of dying from most types of leukemia decreased from 1999 to 2008 (the latest year for which these data are available).

Gender. In 2011, leukemia is expected to be the sixth most common cause of cancer deaths in men and the seventh most common in women in the US. The estimated number of deaths attributed to leukemia in the US is nearly 41 percent higher for males than for females. In 2011, deaths from leukemia are expected to be distributed by gender as shown in Table 4.

Estimated Deaths (All Age Groups) from All Types of Leukemia, 2011.			
Type	Total	Male	Female
Acute Lymphoblastic Leukemia	1,420	780	640
Chronic Lymphocytic Leukemia	4,380	2,660	1,720
Acute Myeloid Leukemia	9,050	5,440	3,610
Chronic Myeloid Leukemia	270	100	170
Other Leukemia	6,660	3,760	2,900
Total	21,780	12,740	9,040

Table 4. Source: *Cancer Facts & Figures 2011*. American Cancer Society; 2011.

Race and Ethnicity. For leukemia, the highest rate of deaths from 2004 to 2008 was in whites, at 7.4 per 100,000 population, followed by blacks at 6.3 per 100,000 population.

- From 2004 to 2008, black males between the ages of 25 and 64 years had a higher death rate from leukemia than white males.
- As reported in *Cancer Facts & Figures for African Americans 2011-2012*, the American Cancer Society estimated that approximately 1,830 blacks (980 males and 850 females) are expected to die from leukemia.
- Leukemia is the seventh most common cause of cancer deaths in black males and the ninth most common in black females.

Children, Adolescents and Young Adults. The leukemia death rate for children and adolescents ages 0 to 14 years in the US has declined 77 percent from 1969 to 2007. Despite this decline, leukemia causes more deaths than any other cancer among children, adolescents and young adults less than age 20 years.

- In 2011, about 440 children and adolescents under 15 years are expected to die from leukemia.

Hodgkin and Non-Hodgkin Lymphoma

“Lymphoma” is a general term for many blood cancers that originate 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

An estimated total of 662,789 individuals in the US population are living with, or in remission from, lymphoma.

- There are 159,846 people living with Hodgkin lymphoma (active disease or in remission).
- There are 502,943 people living with non-Hodgkin lymphoma (active disease or in remission).

Hodgkin Lymphoma. Hodgkin lymphoma (HL) represents 11.7 percent of all types of lymphoma diagnosed in 2011. This disease 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 HL lymphoma tissues.

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 is associated with factors that categorize the prognosis as either more or less favorable. NHL is the sixth most common cause of cancer deaths in males and the seventh in females.

New Cases

About 75,190 people living in the US are expected to be diagnosed with lymphoma in 2011 (8,830 cases of HL and 66,360 cases of NHL).

The incidence of HL is consistently lower than that of NHL. Table 5 shows estimated new cases of lymphoma in 2011, by gender.

New Cases of Lymphoma by Gender, 2011			
Type	Total	Male	Female
Hodgkin Lymphoma	8,830	4,820	4,010
Non-Hodgkin Lymphoma	66,360	36,060	30,300
Total	75,190	40,880	34,310

Table 5. Source: *Cancer Facts & Figures 2011*. American Cancer Society; 2011.

Incidence

Gender. Incidence rates for HL and NHL tend to be higher among males than among females.

- NHL is the seventh most common cancer in males and females in the US.
- The age-adjusted incidence of NHL rose by 82.5 percent from 1975 to 2008, an average annual percentage increase of 2.4 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, 54.7 per 100,000 males and 39 per 100,000 females.

Race and Ethnicity. From ages 15 to 19 years, more non-Hispanic whites are diagnosed with HL than adolescents of other races or ethnic groups.

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

In children and adolescents younger than 20 years,

- Lymphoma is most commonly diagnosed in non-Hispanic whites (2.64 per 100,000 population) and whites (2.44 per 100,000 population), followed by non-Hispanic blacks (2.43 per 100,000 population) and blacks (2.34 per 100,000 population) and Hispanics (1.96 per 100,000 population)
- Lymphoma is least commonly diagnosed among American Indian and Alaska Native children and adolescents (0.69 per 100,000 population)

- The highest incidence rates of NHL are in non-Hispanic black adolescents ages 15 to 19 years (2.22 per 100,000 population) and black adolescents ages 15 to 19 years (2.11 per 100,000 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, constituting approximately 4.8 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 (HL, 7.1 percent; NHL, 6.5 percent) is the third most common cancer in children and adolescents 0 to 19 years of age.

- In 2011, children and adolescents younger than 15 years will constitute 4 percent of all cases of HL expected to be diagnosed and 4 percent of all NHL cases expected to be diagnosed. The number of cases expected to be diagnosed in children and adolescents younger than 15 years is 448 for NHL and 448 for HL.
- The incidence of HL among children and adolescents under 20 years was 1.2 per 100,000 population in 2008.
- The incidence of HL in people younger than 20 years has remained fairly constant between 1975 and 2008, with the exception of a significant decrease in incidence in 1995 and 2005 (0.9 percent, each of these years).

Adolescents and Young Adults. Older children and adolescents are more commonly diagnosed with HL than younger children.

- In 2004 to 2008, 2.4 cases of NHL per 100,000 population occurred in 20- to 24-year-old individuals.
- The lymphoma rates (HL and NHL), for the years from 1999 to 2008, were higher for the 20- to 24-year-old age-group (7.6 per 100,000 population) than for the 15- to 19-year-old age-group (4.8 per 100,000 population).
- There was an overall increase in the incidence of lymphoma for people between the ages of 15 years and 39 years during the span of years from 1999 to 2008.

Adults. HL 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 age 20 to 24 years the rate of NHL is about 2.4 cases per 100,000 population.
- From age 60 to 64 years the rate increases more than 19 times to 46.5 cases per 100,000 population.
- From age 80 to 84 years the rate increases more than 50-fold to 120.4 cases per 100,000 population.

Signs and Symptoms

A common early sign of HL 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 HL 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.

Age-Specific Incidence Rates for Hodgkin Lymphoma, 2004-2008

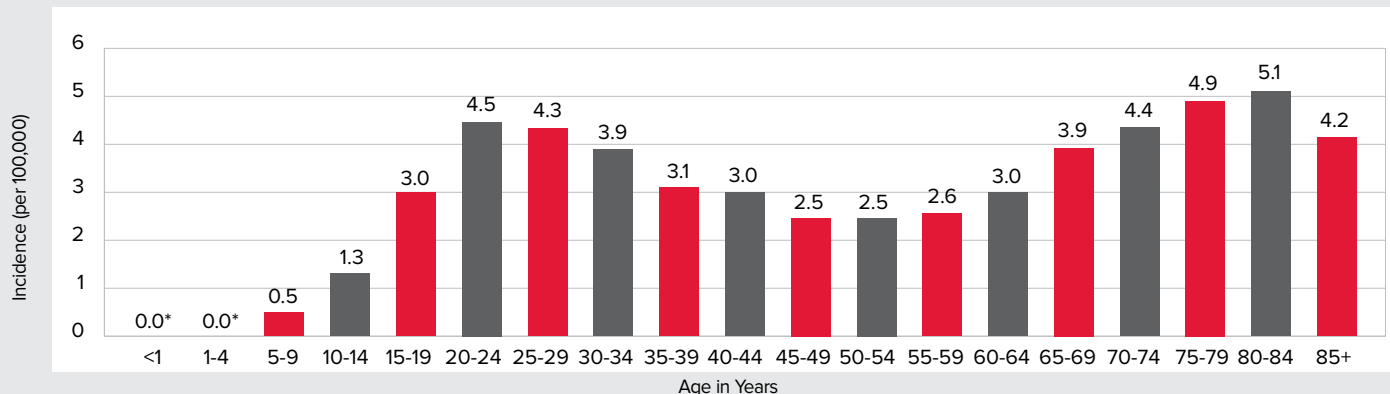


Figure 7. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011. *<16 cases for each age and time interval, SEER 17 areas.

Age-Specific Incidence Rates for Non-Hodgkin Lymphoma, 2004-2008

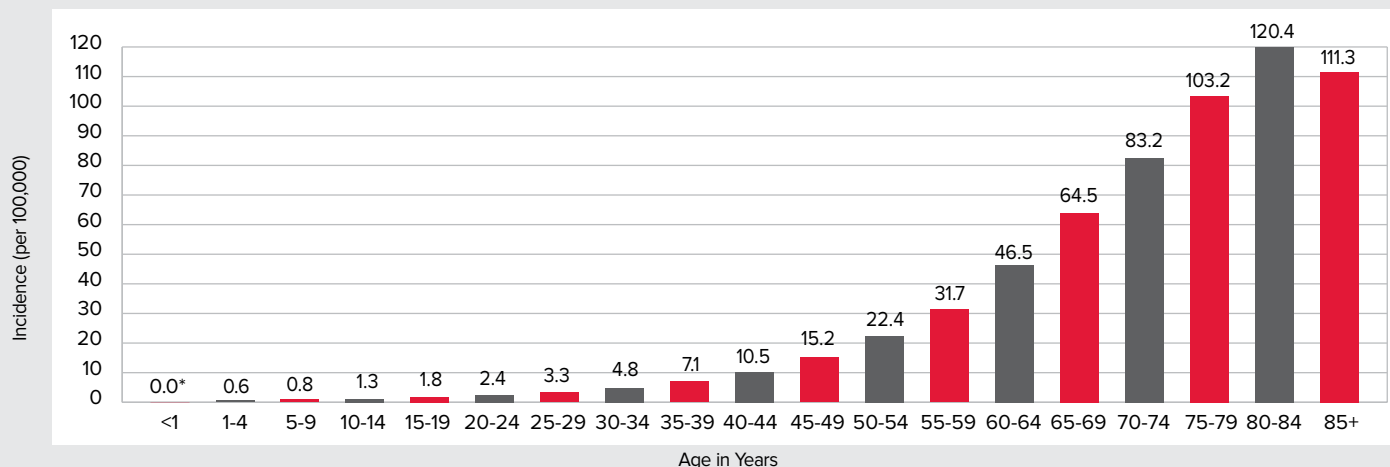


Figure 8. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011. *<16 cases for each age and time interval, SEER 17 areas.

Possible Causes

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

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 HL. “Involved field” radiation therapy with chemotherapy (sometimes called “combined modality therapy”) has been the most common treatment approach for HL. Involved field radiation therapy targets the evident HL cell masses, and chemotherapy is used to kill neighboring lymphoma cells. Clinical trials are under way comparing

chemotherapy with radiation to chemotherapy-only to treat patients with stage IA and IIA nonbulky Hodgkin lymphoma.

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

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

- The five-year relative survival rate for people with HL has more than doubled, from 40 percent in whites from 1960 to 1963 to 86.3 percent for all races from 2001 to 2007.
- Five-year relative survival rates are 92.8 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 69.5 percent for all races from 2001 to 2007.

Race and Ethnicity. Table 6 shows the HL and NHL five-year relative survival rates, rounded to the nearest integer, for all races and for blacks and for whites, spanning four decades.

Trends in Five-Year Relative Survival Rates by Race for Hodgkin Lymphoma and Non-Hodgkin Lymphoma				
Hodgkin Lymphoma	1975-1977	1981-1983	1990-1992	2001-2007
All Races	72%	74%	82%	86%*
Whites	72%	75%	83%	88%*
Blacks	70%	72%	74%	81%*
Non-Hodgkin Lymphoma	1975-1977	1981-1983	1990-1992	2001-2007
All Races	47%	51%	51%	70%*
Whites	47%	51%	52%	71%*
Blacks	48%	50%	42%	62%*

Table 6. Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

* The difference between 1975-1977 and 2001-2007 is statistically significant ($P < .05$).

Children. Five-year relative survival is 96 percent for HL in adolescents ages 15 to 19 years. Five-year relative survival is 95.6 percent for HL in children and adolescents ages 0 to 14 years.

In children and adolescents ages 0 to 19 years, five-year relative survival for NHL is 84.7 percent. This represents a significant improvement in the rate of recovery. As recently as the mid-1970s, most children and adolescents with NHL did not survive five years after they were diagnosed.

Subsequent Primary Cancers. The growing US cancer survivor population has special needs for medical follow-up. Efforts are under way 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 7 and 8 show the observed-to-expected ratio (O/E) for subsequent primary cancer development in HL and NHL survivors (see *Definitions*, page 27). Subsequent cancers among HL 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 a 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 = 1.19), but their risk is lower than the risk of HL survivors (O/E = 2.17).

Observed-to-Expected Ratio for Developing Subsequent Primary Cancer after Hodgkin Lymphoma (HL)
by Age at Diagnosis of HL, SEER 1973-2008

Second Primary Site	Birth to 19 (N=3,318)	20 to 39 (N=11,352)	40 to 59 (N=4,949)	60 and older (N=3,728)	All Ages (N=23,347)	All Ages		
						Observed	Expected	EAR**
Lung and Bronchus	9.11*	5.13*	3.17*	1.82*	3.00*	440	147	11.4
Female Breast	13.77*	3.02*	1.25	1.1	2.51*	390	155	19.77
Non-Hodgkin Lymphoma	6.65*	6.58*	6.40*	4.57*	5.95*	288	48	9.32
Acute Non-Lymphocytic Leukemia (ANLL)	27.40*	17.33*	15.79*	5.93*	13.51*	131	10	4.72
All Sites Excluding Non-Melanoma Skin	7.02*	2.81*	1.97*	1.33*	2.17*	2,499	1,150	52.46

Table 7. Source: SEER (Surveillance, Epidemiology and End Results). SEER*Stat Database: Incidence - SEER 9 Regs Research Data, Nov 2010 Sub (1973-2008) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2008 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2011, based on the November 2010 submission.

*P < .05

** EAR=Estimated absolute risk (see Definitions, page 27.)

Observed-to-Expected Ratio for Developing Subsequent Primary Cancer after Non-Hodgkin Lymphoma (NHL)
by Age at Diagnosis of HL, SEER 1973-2008

Second Primary Site	Birth to 19 (N=2,524)	20 to 39 (N=10,784)	40 to 59 (N=32,085)	60 and older (N=62,454)	All Ages (N=107,847)	All Ages		
						Observed	Expected	EAR**
Lung and Bronchus	0	2.36*	1.60*	1.20*	1.32*	1,802	1,365	6.99
Hodgkin Lymphoma	5.48*	7.87*	9.59*	4.49*	6.58*	151	23	2.05
Acute Non-Lymphocytic Leukemia (ANLL)	22.36*	12.83*	5.83*	2.68*	3.69*	286	78	3.33
Melanoma of the Skin	1.46	1.44	1.34*	1.42*	1.40*	384	275	1.75
Kaposi Sarcoma	0	14.92*	16.08*	2.56*	10.78*	126	12	1.83
All Sites Excluding Non-Melanoma Skin	4.86*	2.06*	1.35*	1.09*	1.19*	10,622	8,934	26.97

Table 8. Source: SEER (Surveillance, Epidemiology and End Results). SEER*Stat Database: Incidence - SEER 9 Regs Research Data, Nov 2010 Sub (1973-2008) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2008 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2011, based on the November 2010 submission.

*P < .05

** EAR=Estimated absolute risk (see Definitions, page 27.)

Deaths

In 2011, an estimated 20,620 members of the US population are expected to die from lymphoma (19,320 NHL and 1,300 HL). Overall, death rates have been declining for people with HL since 1975.

Gender. In males, death rates for HL have been declining by 2.3 percent per year, on average, since 1999, and in females death rates for HL have been declining 2.6 percent per year, on average, since 1999.

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 US (see Table 9).

Estimated Deaths from Hodgkin Lymphoma and Non-Hodgkin Lymphoma, by Gender, 2011

Type	Total	Male	Female
Hodgkin Lymphoma	1,300	760	540
Non-Hodgkin Lymphoma	19,320	9,750	9,570
Total	20,620	10,510	10,110

Table 9. Source: Cancer Facts & Figures 2011. American Cancer Society; 2011.

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.

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 (sometimes 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 74,814 people in the US are living with, or in remission from, myeloma.

New Cases

An estimated 20,520 new cases of myeloma (11,400 males and 9,120 females) are expected to be diagnosed in the US in 2011.

Incidence

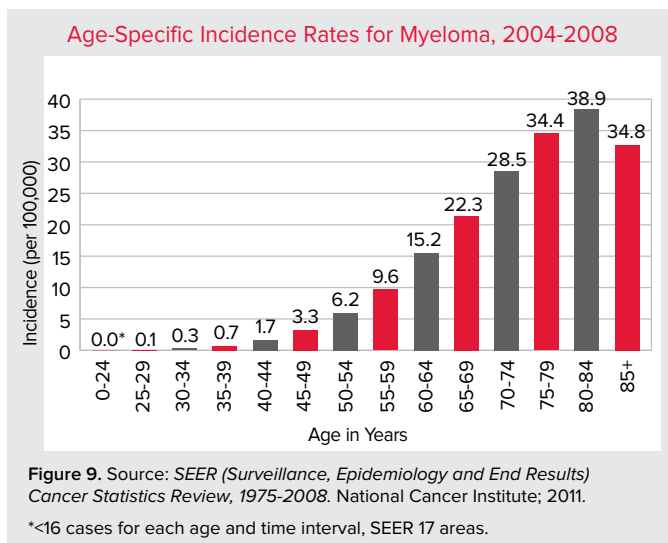
Gender. The incidence rate for the years 2004 to 2008 was 56.5 percent higher in males (7.2 per 100,000 population) than in females (4.6 per 100,000 population).

Race and Ethnicity. From 2004 to 2008, myeloma was the eleventh most commonly diagnosed cancer among black males and the eighth most commonly diagnosed cancer among black females.

- The median age at diagnosis for blacks is 66 years.
- Blacks have more than twice the incidence rate (11.9 per 100,000 population) of myeloma than whites (5.3 per 100,000 population).

- Black males who are 45 years and older have higher myeloma incidence rates than black females and white males and females who are age 45 years and older.
- The highest incidence rates are found in black males 85 years of age and older (118.6 per 100,000 population).

Age. Figure 9 shows the age-specific incidence rates for myeloma for 2004-2008.



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 also 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 the risk of 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 transplantation (autologous, allogeneic or reduced-intensity allogeneic), radiation therapy for local disease and/or new and emerging drug therapies as part of clinical trials.

- The mortality rate for myeloma from 2004 to 2008 for black males was nearly double the rate for white males (8.2 per 100,000 population vs. 4.2 per 100,000 population).
- For black females, it was more than twice the rate for white females (5.6 per 100,000 population vs. 2.6 per 100,000 population).
- The US median age at death from myeloma is 74 years. It is 71 years for blacks and 68 years for Hispanics.

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 41.1 percent from 2001 to 2007 (for all races and ethnicities).
- Five-year survival from 2001 to 2007 is highest for white males (43 percent) compared to 39.4 percent for white females, 41.4 percent for black males and 40 percent for black females.
- The three-year survival rate as of January 1, 2008, is 55.6 percent.

Deaths

Approximately 10,610 deaths from myeloma are anticipated in 2011.

Gender. Myeloma was the seventh most common cause of cancer death for black females and the twelfth most common cause of cancer death for white females from 2004 to 2008.

Race and Ethnicity. As reported in *Cancer Facts & Figures for African Americans 2011-2012*, the American Cancer Society estimated that approximately 3 percent of all cancer-related deaths among blacks are expected to be caused by myeloma.

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 acute myeloid leukemia [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 MDS subtype is refractory anemia with excess blasts (RAEB), 14.1 percent, followed by refractory anemia (RA), 12.4 percent.

- People diagnosed with MDS, not otherwise specified (MDS NOS) constitute 54.7 percent of all MDS cases.
- People diagnosed with therapy-related MDS constitute less than 2 percent of all reported cases.

New Cases

For the five-year period from 2004 to 2008 there were approximately 62,886 new cases of MDS throughout the US, averaging an estimated 12,577 cases per year.

Incidence

The overall incidence rate for MDS is 4.4 cases per 100,000 population (see Table 10).

Gender. For the five-year period from 2004 to 2008 there were a total of approximately 35,058 cases in males (averaging 7,012 per year) and a total of 27,828 cases in females (averaging 5,566 per year). This results in an incidence rate of 6.1 per 100,000 population for males and 3.4 per 100,000 population for females.

Race and Ethnicity. White males have the highest incidence rates (6.2 per 100,000 population), while the

lowest rates occur among American Indian and Alaska Native males (2.5 per 100,000 population) and Asian and Pacific Islander females (2.4 per 100,000 population).

Age. According to SEER data for 2004 to 2008, MDS is most commonly diagnosed in males ages 80 years and older.

Myelodysplastic Syndromes Incidence Rates, 2004-2008
(Rates per 100,000 population)

By Race	Rate
All Races	4.4
White	4.5
Black	3.8
Asian/Pacific Islander	3.3
American Indian/Alaska Native*	2.6
Hispanic**	3.3
By Age	Rate
Ages <40	0.2
Ages 40-49	0.8
Ages 50-59	2.5
Ages 60-69	9.2
Ages 70-79	27.1
Ages 80+	49.8

Table 10. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

* Incidence data for American Indians/Alaska Natives are based on the CHSDA (Contract Health Service Delivery Area) counties.

** Hispanics are not mutually exclusive from whites, blacks, Asian/Pacific Islanders and American Indians/Alaska Natives. Incidence data for Hispanics are based on NAACCR Hispanic Identification Algorithm (NHIA) and exclude cases from the Alaska Native Registry.

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. Automobile exhaust and industrial emissions account for about 20 percent of the total national exposure to benzene.

About half of the exposure to benzene in the US results from smoking tobacco or from exposure to tobacco smoke. The average smoker is exposed to about 10 times the daily intake of benzene compared to nonsmokers.

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

The SEER program only recently began maintaining statistics for MDS. Prevalence and mortality statistics were not reported by SEER for MDS in 2011 at the time of this publication.

Deaths

Mortality rates were not reported by SEER for MDS in 2011 at the time of this publication.

Incidence Rates: Leukemia, Lymphoma, Myeloma and Myelodysplastic Syndromes

Tables 11, 12 and 13 show incidence rates for leukemia, HL, NHL, myeloma and MDS using data figures from 2004 to 2008 (the most recent available). Rates are per 100,000 population and are age-adjusted to the 2000 US Standard population.

Incidence Rates by Gender, All Races, per 100,000 Population, 2004-2008			
Type	Total	Male	Female
Leukemia	12.5	16.1	9.7
Non-Hodgkin Lymphoma	19.8	24.0	16.5
Hodgkin Lymphoma	2.8	3.1	2.6
Myeloma	5.7	7.2	4.6
Myelodysplastic Syndromes	4.4	6.1	3.4

Table 11. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

Incidence Rates by Gender, for Blacks, per 100,000 Population, 2004-2008			
Type	Total	Male	Female
Leukemia	9.8	12.9	7.8
Non-Hodgkin Lymphoma	14.8	17.9	12.3
Hodgkin Lymphoma	2.8	3.2	2.4
Myeloma	11.9	14.5	10.2
Myelodysplastic Syndromes	3.8	4.8	3.4

Table 12. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

Incidence Rates by Gender, for Whites, per 100,000 Population, 2004-2008			
Type	Total	Male	Female
Leukemia	13.1	16.8	10.2
Non-Hodgkin Lymphoma	20.7	25.0	17.3
Hodgkin Lymphoma	3.0	3.3	2.8
Myeloma	5.3	6.8	4.1
Myelodysplastic Syndromes	4.5	6.2	3.4

Table 13. Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2008. National Cancer Institute; 2011.

Estimated New Cases and Estimated Deaths by State

Estimated New Cases of Blood Cancers by Site, by State, 2011

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	590	960	330	110
Alaska	80	130	*	*
Arizona	780	1,220	340	130
Arkansas	420	650	220	90
California	4,760	7,070	2,040	970
Colorado	710	970	260	150
Connecticut	520	880	250	120
Delaware	120	200	60	*
Dist. of Columbia	70	100	50	*
Florida	3,440	4,720	1,380	590
Georgia	1,130	1,670	590	260
Hawaii	170	230	70	*
Idaho	240	310	90	*
Illinois	1,870	2,640	890	400
Indiana	970	1,390	400	190
Iowa	580	770	230	110
Kansas	430	620	180	*
Kentucky	650	1,040	290	120
Louisiana	620	930	350	120
Maine	260	370	110	50
Maryland	700	1,130	390	120
Massachusetts	970	1,550	440	250
Michigan	1,630	2,330	730	330
Minnesota	820	1,140	340	*
Mississippi	370	550	210	60
Missouri	880	1,300	420	170
Montana	170	240	70	*
Nebraska	290	430	130	60
Nevada	290	440	140	*
New Hampshire	210	330	90	*
New Jersey	1,360	2,140	660	340
New Mexico	320	370	120	60
New York	3,070	4,650	1,620	670
North Carolina	1,230	1,930	640	250
North Dakota	100	150	*	*
Ohio	1,690	2,660	780	370
Oklahoma	590	850	260	90
Oregon	560	940	260	140
Pennsylvania	2,090	3,340	990	450
Rhode Island	160	250	70	50
South Carolina	640	960	340	120
South Dakota	140	190	60	*
Tennessee	930	1,410	420	170
Texas	3,280	4,520	1,550	670
Utah	320	440	120	70
Vermont	100	160	*	*
Virginia	940	1,520	480	210
Washington	1,060	1,610	430	190
West Virginia	300	480	130	60
Wisconsin	960	1,390	380	200
Wyoming	70	120	*	*
United States	44,600	66,360	20,520	8,830

Table 14. Source: American Cancer Society, Inc. The sum of the state estimates may not equal the US total due to rounding. Numbers are rounded to the nearest 10.

*Fewer than 50 cases.

Estimated Deaths from Blood Cancers by Site, by State, 2011

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	350	310	220	*
Alaska	*	*	*	*
Arizona	420	340	220	*
Arkansas	240	190	100	*
California	2,200	2,050	1,080	150
Colorado	300	290	150	*
Connecticut	260	220	130	*
Delaware	60	50	*	*
Dist. of Columbia	*	*	*	*
Florida	1,570	1,310	680	80
Georgia	560	500	280	*
Hawaii	80	90	*	*
Idaho	120	90	50	*
Illinois	900	680	420	50
Indiana	520	420	230	*
Iowa	300	290	120	*
Kansas	300	190	120	*
Kentucky	320	300	150	*
Louisiana	300	270	130	*
Maine	110	80	60	*
Maryland	390	300	220	*
Massachusetts	470	360	230	*
Michigan	820	660	370	*
Minnesota	390	310	200	*
Mississippi	220	190	110	*
Missouri	510	450	240	*
Montana	90	80	*	*
Nebraska	140	140	70	*
Nevada	100	150	80	*
New Hampshire	100	60	50	*
New Jersey	610	630	290	*
New Mexico	120	120	50	*
New York	1,350	1,470	610	100
North Carolina	660	550	380	*
North Dakota	50	*	*	*
Ohio	910	830	450	60
Oklahoma	290	280	120	*
Oregon	280	320	160	*
Pennsylvania	1,080	1,090	520	70
Rhode Island	90	50	*	*
South Carolina	330	300	170	*
South Dakota	70	80	*	*
Tennessee	490	470	280	*
Texas	1,410	1,060	720	90
Utah	140	100	70	*
Vermont	60	*	*	*
Virginia	500	440	280	*
Washington	490	430	190	*
West Virginia	140	190	70	*
Wisconsin	480	390	220	*
Wyoming	*	50	*	*
United States	21,780	19,320	10,610	1,300

Table 15. Source: American Cancer Society, Inc. The sum of the state estimates may not equal the US total due to rounding. Numbers are rounded to the nearest 10.

*Fewer than 50 cases.

About the LLS Mission

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to developing better outcomes for blood cancer patients. 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 research, patient services and advocacy professionals work together to provide professional and patient education, patient services and support, and to represent patients' healthcare concerns and medical research interests to government policy makers. LLS is a nonprofit organization that relies on the generosity of individual and corporate contributions to realize these important goals.

Research and Professional Education

LLS research programs are based on the belief that scientifically sound approaches toward cures for, or control of, blood cancers should be supported worldwide. Since 1954, LLS has awarded more than \$814 million to outstanding research projects. Two major integrated research-funding programs—the *Research Grant Program* and the *Therapy Acceleration Program*—have advisory input from world-renowned biomedical research experts. Together these programs

- Support the entire research continuum needed to improve 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
- Are aimed at the effective discovery and development of new and better therapies for people with blood cancer, and through a research initiative launched in 2009, support the development of measures to prevent or significantly reduce potential long-term and late toxicities of today's curative therapies.

Research Grant Program

The *Research Grant Program* provides grant funding to support scientific studies at academic centers in the United States and throughout the world, 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 up to \$110,000 a year for a total of up to \$550,000 over five years
 - *Special Fellows* are awarded up to \$65,000 a year for a total of up to \$195,000 over three years
 - *Fellows* are awarded up to \$55,000 a year for a total of up to \$165,000 over three years
 - Clinical Research
 - *Scholars in Clinical Research* are awarded up to \$110,000 a year for a total of up to \$550,000 over five years
 - *Special Fellows in Clinical Research* are awarded up to \$65,000 a year for a total of up to \$195,000 over three years
2. The *Translational Research Program (TRP)* supports outstanding investigations deemed by our expert advisors as 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 up to \$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 up to \$1 million over five years to facilitate new drug discovery or advances in diagnosis or prevention. In 2011, LLS actively requested proposals to help stimulate more academic research in three underdeveloped yet important areas of research. The research topics emphasized were the malignant stem cell in acute myeloid leukemia and myelodysplastic syndromes; noncutaneous T-cell leukemias and lymphomas; and high-risk myeloma cases. In addition, a request for research that focused on long-term and late effects of blood cancer therapies was extended into a second year. Progress in these research areas is

deemed likely to improve outcomes for patients with particularly urgent needs.

3. The *Marshall A. Lichtman Specialized Center of Research Program (SCOR)* encourages multidisciplinary research by leading-edge academic investigators in teams of at least three research groups that interact to foster advances in the diagnosis, treatment and/or prevention of blood cancers. Each *SCOR* group is funded up to \$1.25 million per year over a five-year period, with a total amount of up to \$6.25 million. Awards go to those groups that best demonstrate synergistic expertise in complementary areas. 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 volunteer their services to constitute peer-review subcommittees for Basic Research *CDP*, Clinical Research *CDP*, *TRP* and *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 emailing researchprograms@LLS.org.

Therapy Acceleration Program

The *Therapy Acceleration Program (TAP)* is a strategic LLS initiative launched in 2007 with \$4 million in seed funding. The program accelerates new and potentially 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 would be made available to patients as soon as possible.

TAP encompasses three innovative efforts:

- 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
- The *Clinical Trials Division* partners LLS with one of the country's leading clinical-trial centers to accelerate the testing of new blood cancer therapies in clinical trials

- 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 volunteer panel of leading biotechnology and pharmaceutical company executives and intellectual property and business development experts.

The Learning Collaborative

In 2011, LLS began a unique collaboration with the University of Kansas Cancer Center and the National Institutes of Health to accelerate the development of potential therapies for rare blood cancers. This collaboration, known as *The Learning Collaborative*, brings together proven expertise in blood cancer research as well as drug discovery and development to rapidly advance promising new therapies from the bench to the bedside. If successful, *The Learning Collaborative's* novel model will demonstrate that government, academia, disease philanthropy and industry can successfully partner to safely and efficiently advance new or repurposed drug therapies to patients.

Annual Research Symposium and Academic Research Meetings

LLS serves the continuing education needs of the medical and research community through professional symposia offered throughout the year. The education programs offer varying formats to facilitate the exchange of information and ideas on the newest developments in blood 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 also funds selected academic research meetings each year on important topics relevant to blood cancers. Other meetings are held for LLS grantees, including the Stohlman Scholar Symposium, the Translational Research Grant Progress Review Meeting and the *SCOR* Progress Review Meeting.

Information and Services for Patients and Healthcare Professionals

LLS is the world's foremost source of current and accurate information about blood cancer. Patient Services at LLS is committed to improving access to information and enhancing 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 LLS services and programs and with other local and national resources. LLS volunteers generously provide their time, talents and professional guidance to help implement LLS programs and to raise vitally needed funds. In 2011, LLS had more than seven million contacts with patients, caregivers, healthcare professionals and the public.

National Education Programs and Services

Information Specialists

LLS Information Specialists provide a global connection for people living with blood cancer and for healthcare professionals. The staff members are master's level oncology professionals who offer guidance for coping with a blood cancer diagnosis and provide current disease information. Information Specialists address treatment questions and conduct individual clinical-trial searches (see TrialCheck®, below). Information Specialists can be contacted by phone at (800) 955-4572, Monday through Friday, 9 a.m. to 6 p.m. ET and by email at infocenter@LLS.org. Individuals may chat online with an Information Specialist from 10 a.m. to 5 p.m. ET, at www.LLS.org (click "LiveChat").

TrialCheck® — A Clinical-Trial Search Service

Visitors to the LLS website can locate clinical trials near them through LLS-supported TrialCheck®, a blood cancer-specific clinical-trial search tool that offers immediate access to customized listings of blood cancer clinical trials. LLS Information Specialists assist patients, family members and healthcare professionals by conducting individual clinical-trial searches and helping patients and caregivers discuss with doctors the potential benefits of treatment in a clinical trial.

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 funds by blood cancer diagnosis is available at www.LLS.org/copay or at (877) 557-2672.

Telephone and Web Education Programs

LLS provides a series of free telephone-and web-based education programs each year, where medical experts share the latest disease, treatment and research information with patients, survivors, caregivers and healthcare professionals around the world. For information on registration for these free programs or to access past programs, visit www.LLS.org/programs.

LLS is an accredited provider of continuing education credit for nurses and social workers, and partners with continuing medical education providers to offer education programs for physicians.

LLS Website

Education, information and support are also delivered on the LLS website 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, the LLS discussion boards, online chats and tools such as *My CML Tracker* for personal management of medical information, all of which 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, their families and healthcare professionals. Each year, LLS distributes detailed and basic information through LLS Information Specialists, the local chapters and the website. Visitors to the website can view and download materials at www.LLS.org/resourcecenter.

Chapter Programs and Services

Family Support Groups

LLS has chapter-based Family Support Groups led by volunteer oncology health professionals. The groups provide information and support, and encourage communication among patients, family members, friends and healthcare professionals.

Patti Robinson Kaufmann First Connection Program

This program links a patient with a trained peer volunteer who has experienced a similar diagnosis and is in remission. The peer volunteer contacts the patient to share information and support.

Patient Financial Aid Program

For more than 35 years, LLS has helped people who have blood cancer to cover a portion of their treatment costs. LLS continues to provide a limited amount of financial assistance to help people with significant financial need who are under a doctor's care for a confirmed blood cancer diagnosis. Patient financial aid funds are subject to availability.

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 children, adolescents and young adults a smooth transition from active treatment to their 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, their family members and healthcare professionals, including

Staying Connected—Facilitating the Learning Experience During and After Cancer Treatment a part of the *Trish Greene Back to School Program*. This education program addresses cancers that affect children, adolescents and young adults (AYAs), side effects, long-term and late effects of childhood/AYA cancer treatment, challenges for survivors throughout their education, laws that protect childhood/AYA cancer survivors' rights, strategies to help meet the students' short- and long-term education needs and resources that support schools and families

Myeloma Today—Diagnosis, Treatment & Side Effects Management, a complete overview of myeloma, including current and emerging drug therapies and stem cell

transplantation, disease and treatment-related side effects, clinical trial options and quality of life issues and resources. This program is supported by grants from Celgene Corporation and Millennium Pharmaceutical, Inc.

Cancer Treatment—How to Make Informed Choices about Standard Care and Clinical Trials, which discusses steps to take to help you make treatment decisions; questions to ask about benefits and risks of standard treatments and treatments under study in clinical trials; new blood cancer treatment development; clinical-trial myths and facts; and how to locate clinical trials. This program is supported by grants from Celgene Corporation and Millennium Pharmaceuticals, Inc.

Public Policy 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 60,000 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
- Oral chemotherapy coverage
- Cord-blood banking.

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 over \$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 \$32 million through 2011, 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. LLS state-advocacy efforts have focused on ensuring coverage of routine care for patients enrolled in cancer clinical trials. Since 2008, LLS has been the catalyst in increasing the number of states requiring clinical-trial coverage from 19 to 33. In 2011, LLS advocates successfully

- Led efforts to increase patient access to oral cancer treatments in New York and Illinois by requiring insurance companies to provide coverage for oral chemotherapy at a cost equal to what is charged for intravenous (IV) treatment. This coverage is now required by 14 states and the District of Columbia. LLS advocates are leading similar efforts in South Carolina and Wisconsin
- Advocated for passage of legislation in Florida that requires physicians and hospitals to inform expectant mothers of the importance of cord-blood banking and donation. Passage of this and similar bills will increase umbilical cord-blood resources, and LLS advocates continue to lead coalition efforts to pass this legislation in states around the country to expand the resources, available for stem cell matching and transplantation for the treatment of blood cancer patients.

Notes and Definitions

Notes

The data within *Facts 2012* reflect the most recent statistics from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, *Cancer Statistics Review (CSR) 1975-2008*. The CSR reports cancer incidence, mortality, survival, prevalence and lifetime risk statistics. Incidence, prevalence and survival data were updated online by SEER, www.seer.cancer.gov, on April 15, 2011. Mortality data were updated online by SEER on October 20, 2011. Additional updates to Hispanic data were made by SEER on October 28, 2011. The next SEER *Cancer Statistics Review* is expected to be published online in the spring of 2012.

The SEER Program's 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 US does not have a nationwide reporting system or registry for blood cancer, so the exact number of cancer cases is not known. The data presented in the report are an extrapolation from or estimate of the number of cases reported by the 17 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 2011 referenced SEER report reflect data updates from the NCHS from 1969 to 2008, made available in 2011. The American Cancer Society projects 2011's estimated cancer cases based on incidence rates for 1995 to 2007 from 46 states and the District of Columbia (approximately 95 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 25.8 percent of the US population. The data can be extrapolated for the entire US 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. Owing to the large migration

of both cancer patients and populations from Louisiana into Texas, Alabama and Mississippi in the aftermath of Hurricane Katrina in September 2005, and to some hospital closures and the loss of many patient records in affected areas, the 2004-2008 SEER 17 statistics include only 4.5 years of data for Louisiana, from 2003 through June 2005 and all of 2006 through 2008, to avoid miscalculation of cancer rates. The data also include a population correction for the effects of Hurricane Rita.

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.

Limited myelodysplastic syndromes (MDS) data were included in the SEER statistics as separate entities beginning in 2007.

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 cases (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. Therefore, 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 “33-year limited duration” prevalence figures, based on the “first invasive tumor for each cancer site diagnosed during the previous 33 years (1975-2008),” as per SEER Table 1.21. The specified date is January 1, 2008, for the prevalence estimates. The prevalence counts in this year’s *Facts* publication are adjusted for race, sex and age.

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 (see below) 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 two 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. The EAR represents the number of excess cancers per 10,000 PYAR (for example, a population of 10,000 cancer survivors followed for one year or 1,000 cancer survivors followed for 10 years).

Citations and Acknowledgements

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