



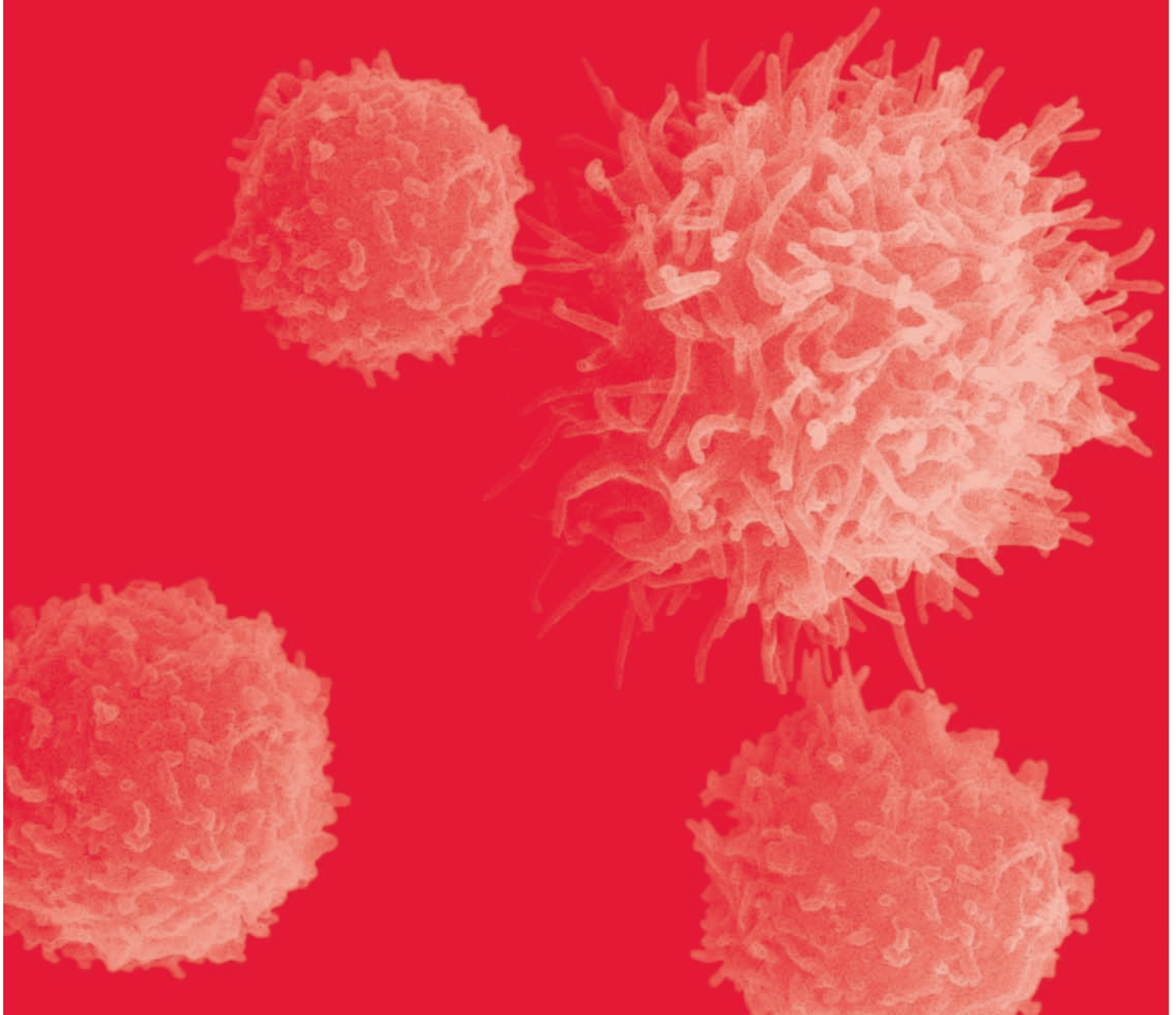
**The Leukemia &  
Lymphoma Society**<sup>®</sup>  
*Fighting Blood Cancers*

# Facts 2005-2006

LEUKEMIA

LYMPHOMA

MYELOMA



# Table of Contents

## 1 Executive Summary

## 2 About the Diseases

- 2 New Cases
- 2 Deaths
- 2 Survival
- 2 Treatment
- 4 New Approaches to Treatment

## 6 Leukemia

- 6 Living with Leukemia
- 6 New Cases
- 7 Incidence by Gender
- 7 Incidence by Race/Ethnicity
- 7 Incidence by Age Group
- 8 Signs and Symptoms of Leukemia
- 8 Possible Causes of Leukemia
- 8 Treatment of Leukemia
- 9 Survival
- 9 Deaths

## 10 Lymphoma

- 10 Hodgkin Lymphoma
- 10 Non-Hodgkin Lymphoma
- 10 Living with Lymphoma
- 10 New Cases
- 11 Incidence by Gender
- 11 Incidence by Race and Ethnicity
- 11 Incidence in Children
- 12 Incidence in Adults
- 12 Signs and Symptoms
- 12 Treatment
- 13 Survival for Adults
- 13 Survival for Children
- 13 Deaths

## 14 Myeloma

- 14 Living with Myeloma
- 14 New Cases
- 14 Signs and Symptoms
- 14 Possible Causes
- 14 Treatment
- 14 Survival
- 14 Deaths

## 15 Incidence Rates: Leukemia, Lymphoma and Myeloma

## 17 Notes

- 17 Notes, Definitions and Citations

## 18 About the Society

- 18 Research
- 19 Patient Services
- 20 Advocacy

## Figures

- 1 *Figure 1: Five-Year Relative Survival Rates 1960-63 v. 1995-2001*
- 2 *Figure 2: Estimated New Cases (%) of Blood Cancers in 2005*
- 7 *Figure 3: Estimated Proportion of New Cases (%) in 2005 for Each Type of Leukemia, Including Adults and Children*
- 8 *Figure 4: Age-Specific Incidence Rates for Acute Myelogenous Leukemia (All Races) 1998-2002*
- 8 *Figure 5: Five-Year Relative Survival Rates for All Ages, All Types of Leukemia 1974-2001*
- 9 *Figure 6: Five-Year Relative Survival Rates for Acute Lymphocytic Leukemia, in Children Under 15 Years of Age, 1964-2001*
- 11 *Figure 7: Age-Specific Incidence Rates for Hodgkin Lymphoma, 1998-2002*
- 12 *Figure 8: Age-Specific Incidence Rates for Non-Hodgkin Lymphoma, 1998-2002*
- 14 *Figure 9: Age-Specific Incidence Rates for Myeloma, 1998-2002*

## Tables

- 6 *Table 1: The Four Major Types of Leukemia*
- 6 *Table 2: Approximate U.S. Prevalence of the Four Major Leukemias as of January 1, 2002*
- 6 *Table 3: Total Estimated Number of New Leukemia Cases in the United States for 2005*
- 9 *Table 4: Estimated Deaths (All Age Groups) from All Types of Leukemia in 2005*
- 10 *Table 5: New Cases of Lymphoma by Gender, 2005*
- 13 *Table 6: Trends in Five-Year Relative Survival Rates by Race for Hodgkin Lymphoma and Non-Hodgkin Lymphoma*
- 13 *Table 7: Estimated Deaths by Gender from Hodgkin Lymphoma and Non-Hodgkin Lymphoma*
- 15 *Table 8: Incidence by Gender, All Races, Per 100,000 Population (1998-2002)*
- 15 *Table 9: Incidence Rates by Gender for Blacks, per 100,000 Population (1998-2002)*
- 15 *Table 10: Incidence Rates by Gender for Whites, per 100,000 Population, (1998-2002)*
- 16 *Table 11: Estimated New Cases of Blood Cancers by Site, by State, 2005*
- 16 *Table 12: Estimated Deaths from Blood Cancers by Site, by State, 2005*

# Executive Summary

*Facts 2005-2006* is an annual publication and is a compilation of the most recent data on leukemia, lymphoma and myeloma. The data within *Facts 2005-2006* reflect the most recent statistics available from SEER, the National Cancer Institute's Surveillance, Epidemiology and End Results Program, Cancer Statistics Review 1975-2002 (see Notes, page 17). This data was published online by SEER, [www.seer.cancer.gov](http://www.seer.cancer.gov), in April 2005. The next SEER Cancer Statistics Review is expected to be published online in April 2006.

Leukemia, lymphoma and myeloma are cancers that originate in the bone marrow or lymphatic tissues as the result of an acquired genetic injury to the DNA of a single cell, which becomes malignant and multiplies continuously. This abnormal accumulation interferes with the production of healthy blood cells.

## Highlights from the Report Include:

- An estimated 747,465 Americans are living with blood cancers.
- Approximately every five minutes, someone is diagnosed; approximately 114,530 new cases are expected this year.
- Every 10 minutes, someone dies from blood cancers – an estimated 54,480 deaths in 2005.
- The likelihood of dying from leukemia, lymphoma or myeloma decreased from 1992 to 2002 (the last year data were available).

## Leukemia:

- There are 198,257 people in the United States living with or in remission from leukemia.
- Thirty percent more males are living with leukemia than females.
- In 2005, 34,810 people will be diagnosed with leukemia.
- In 2005, 22,570 people will die of leukemia.
- Leukemia causes more deaths than any other cancer among children and young adults under the age of 20.

## Lymphoma:

- There are 493,104 people living today with lymphoma: 127,804 have or are in remission from Hodgkin lymphoma; 365,300 have or are in remission from non-Hodgkin lymphoma (NHL).

- This year, 63,740 new cases of lymphoma will be diagnosed in the United States (7,350 cases of Hodgkin, 56,390 cases of non-Hodgkin).
- This year, 20,610 people will die of lymphoma (1,410 of Hodgkin, 19,200 of non-Hodgkin).
- Non-Hodgkin lymphoma is the fifth most common cancer in the United States, and its age-adjusted incidence rose 74 percent from 1975 to 2002.

## Myeloma:

- This year, 15,980 people will be diagnosed with myeloma.
- This year, 11,300 people will die from myeloma.
- From 1975 to 2002, the incidence of myeloma has increased 12.2 percent, and mortality from the disease has increased 31 percent.
- Eighty-six percent of myeloma cases occur in people over the age of 55.
- Americans of African descent have more than double the incidence of those of European descent.
- Incidence rates in men are 58 percent higher than in women.
- Survival from myeloma five years after diagnosis was only 32.4 percent in 1995-2001 (the most recent data), making it the most difficult blood cancer to treat successfully.
- Although newer treatments are expected to improve survival rates, even the most aggressive therapies rarely cure the disease.

## Five-Year Relative Survival Rates 1960-63 vs. 1995-2001

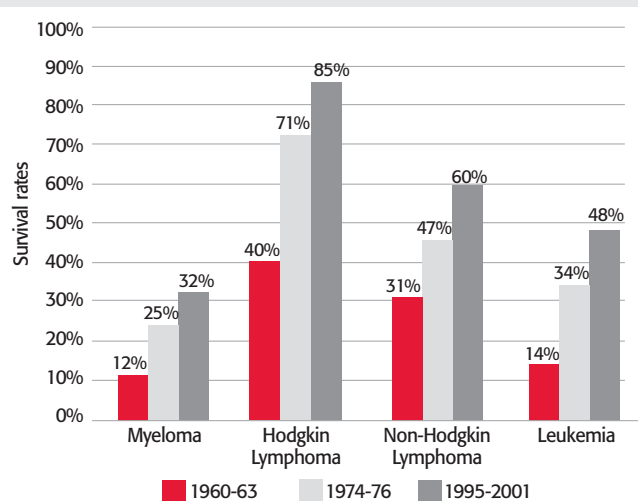


Figure 1: Sources: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2002, National Cancer Institute, 2005.

# About the Diseases

**Leukemia, Hodgkin and non-Hodgkin lymphoma and myeloma** are cancers that originate in the bone marrow or lymphatic tissues. They are considered to be related cancers because they involve the uncontrolled growth of cells with similar functions and origins. These diseases result from an acquired genetic injury to the DNA of a single cell, which becomes abnormal (malignant) and multiplies continuously. The accumulation of malignant cells interferes with the body's production of normal blood cells and can result in severe anemia, decreased ability to fight infections and a predisposition to bleeding.

## *New Cases*

An estimated 114,530 people in the United States will be diagnosed with leukemia, lymphoma and myeloma in 2005. New cases of leukemia, Hodgkin and non-Hodgkin lymphoma and myeloma will account for 8 percent of the 1,372,910 new cancer cases diagnosed in the United States this year.

## *Deaths*

Leukemia, lymphoma and myeloma will cause the deaths of an estimated 54,480 people in the United States this year. These blood cancers will account for nearly 9.6 percent of the deaths from cancer in 2005 based on the 570,280 total cancer-related deaths.

Every 10 minutes, another child or adult is expected to die from leukemia, lymphoma or myeloma. This statistic represents 149 people each day, or six people every hour. Leukemias are the leading fatal cancers in young men and women under age 20.

## *Survival*

An estimated 747,465 Americans are living with leukemia, Hodgkin and non-Hodgkin lymphoma and myeloma.

Estimated New Cases (%) of Blood Cancers in 2005

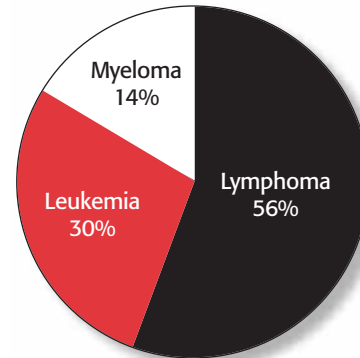


Figure 2: Source: *Cancer Facts and Figures, 2005*, American Cancer Society.

## *Treatment*

**Chemotherapy and Radiotherapy:** The use of chemotherapy (anti-cancer drugs), usually in combinations of two or more drugs, is largely responsible for the dramatic improvement in managing leukemia and lymphoma. Approximately 50 different drugs are now being used in the treatment of these diseases.

Patients with leukemia, myeloma or lymphoma are usually treated with chemotherapy. Patients with acute lymphocytic leukemia (ALL), with some types of Hodgkin lymphoma, with large localized areas of non-Hodgkin lymphoma or with special complications that are amenable to radiation therapy may receive both primary chemotherapy and ancillary radiation therapy.

**Blood and Marrow Stem Cell Transplantation:**

Stem cell transplantation from marrow was introduced approximately 35 years ago and is now standard therapy for selected patients with leukemia, lymphoma and myeloma. There are two major types of stem cell transplants: syngeneic and allogeneic. Syngeneic transplant describes the use of an identical twin as donor. An allogeneic transplant uses blood or marrow stem cells from a normal donor, usually a brother or sister with the same tissue type. If a sibling is not available, a search of the National Marrow Donor Program registry of tissue-typed volunteers could be made for a matched unrelated donor. In special instances, especially in young children, slightly mismatched donors may be used, such as a parent.

Autologous transplantation uses the patient's own marrow stem cells and is technically not transplantation since another person is not the donor. The technique is important, however. The blood or marrow stem cells are collected while the patient is in remission, and the harvested cells may be treated with chemotherapy agents or monoclonal antibodies to decrease the presence of contaminating tumor cells before being returned to the patient. The stem cells are frozen and later thawed and infused into the patient if intensive chemotherapy and/or radiotherapy is required for subsequent treatment.

The technique of harvesting stem cells from blood and cord blood has made transplantation available for more patients. Blood and cord blood transplants differ from marrow transplants principally in the source of the cells collected for transplant. Stem cells not only reside in the marrow but also circulate in the blood. Because blood, as well as marrow, is a source of stem cells for transplantation, these cells can be harvested from the blood of a donor, frozen and stored and later transplanted to the patient. To ensure there will be enough blood stem cells for successful transplantation, donors of blood stem cells require special treatment to mobilize sufficient stem cells from marrow into their blood before cells are harvested.

Stem cells also circulate in large numbers in fetal blood and can be recovered from umbilical cord and placental blood after childbirth. The harvesting, freezing and storing of cord blood has provided another source of stem cells for transplantation,

especially for children. The numbers of stem cells in cord blood are often insufficient for the needs of larger adult patients.

Cord blood stem cell transplantation provides an additional donor pool and the opportunity for greater ethnic diversity in the blood supply because of collection efforts in hospitals where children of underrepresented ethnic backgrounds are born.

“Non-ablative” allogeneic stem cell transplantation is the term applied to a technique of allogeneic transplant that uses lower doses of chemotherapy and/or radiotherapy to prepare the recipient to receive the donor's stem cells. This still experimental approach greatly lessens the early toxicity of transplantation and has extended the age at which recipients with leukemia, lymphoma or myeloma can have a transplant. It has been made possible by more effective immunosuppressive drugs that are capable of preventing rejection of the donor's cells without full intensity treatment of the patient's immune system. Over time the donor's cells take hold and the patient's leukemia, lymphoma or myeloma is attacked and suppressed by donor lymphocytes that form from the donor stem cells. This “graft versus leukemia or lymphoma effect” can suppress (cure) the malignancy and is a prolonged (indefinite) form of immunotherapy. In standard stem cell transplantation, ablation of the recipient's blood-cell-forming and immune cells was the price that had to be paid to eradicate the leukemia, lymphoma, or myeloma and permit the donor's cells to be accepted by the temporarily immunodeficient recipient. “Ablation” referred to wiping-out the recipient's cancer, marrow and immune system. In non-ablative transplantation, the recipient's blood cell and immune system are preserved, making the procedure more tolerable.

## *New Approaches to Treatment*

Several areas of research have resulted in new approaches to the treatment of leukemia, lymphoma and myeloma.

**Development of New Drugs:** In the past decade, several important new drugs and new uses for existing drugs have greatly improved cure rates or remission duration for some patients with leukemia. Imatinib mesylate (Gleevec®) has been shown to normalize blood cell counts in nearly all patients with chronic myelogenous leukemia (CML). It works by blocking the oncogene-encoded protein product that instigates the transformation to a leukemic cell. The protein is an enzyme in the family of tyrosine kinases. Gleevec offers several dramatic advantages to patients: oral administration, decreased side effects, few adverse effects on normal tissues and a very high response rate. The effectiveness and tolerance of older patients and the projections from the first several years of clinical trials suggest that the drug will prolong the duration of hematological remission and life when compared to former therapy. Although a minority of patients have developed resistance to the drug, two new congeners are in clinical trials that can overcome this resistance in some cases.

Gleevec is not only a very important new agent in the treatment of CML, but it can also induce remissions in some cases of acute leukemia, chronic eosinophilic leukemia (formerly hypereosinophilic syndrome), occasional cases of chronic myelomonocytic leukemia and in systemic mastocytosis because they have a genetic abnormality that results in an abnormal tyrosine kinase that is blocked by imatinib (ABL, PDGFR or KIT).

New drugs targeting other abnormal tyrosine kinases are under study, such as FLT3 inhibitors. FLT3 is a gene that is present in about 30 percent of cases of acute myelogenous leukemia (AML). The treatment of hairy cell leukemia, a less common type of chronic lymphocytic leukemia (CLL), has improved dramatically with the introduction of two very useful agents: 2-deoxycoformycin and cladribine. Hairy cell leukemia was very resistant to treatment; however, these drugs have been very effective in producing very long-term remissions of the disease.

The remission rate and duration of remission of acute promyelocytic leukemia (APL) has been improved

significantly with the introduction of all-trans retinoic acid in combination with chemotherapy. Arsenic trioxide also adds to the drugs available to treat this subtype of acute leukemia.

Thalidomide can stop the progression of advanced myeloma in some patients. The U.S. Food and Drug Administration (FDA) has given thalidomide (Thalomid®) an “orphan drug” designation, which clears the way for researchers to use and evaluate thalidomide against myeloma and other cancers. Two additional drugs being studied in clinical trials have shown responses in a subset of patients with myeloma: the proteasome inhibitor bortezomib (Velcade®) and the immune modulator CC-5013 (Revlimid®). Velcade recently received FDA approval for treating people with myeloma who have had at least one prior therapy. Recent clinical trial results have shown a significant survival advantage for myeloma patients (who had received one to three prior therapies) treated with Velcade versus dexamethasone alone.

**Immunotherapy:** This is a treatment that uses immune cells or antibodies to fight the disease; suppresses the progression of leukemia, lymphoma or myeloma; and enhances the specificity of treatment to minimize toxic effects on normal tissues. Three types of immunotherapy are being explored: antibody treatment, vaccine development and immune cell administration.

Monoclonal antibodies are laboratory-produced proteins that can be infused into an appropriate patient. Some antibodies can be made to interact with a cell antigen and, in so doing, decrease the viability of the tumor cell, leading to its death. These antibodies are sometimes called “naked” antibodies, in contrast to antibodies that carry a radioactive agent or a toxin to kill the tumor cell.

Monoclonal antibodies have added to the arsenal of agents that can be used for the treatment of patients with lymphoma and leukemia. It is hoped that they can be added to chemotherapy without producing many toxic side effects.

Rituximab (Rituxan®) is an antibody directed at the target CD20 antigen on B cell lymphoma cells. Cell surface antigens have been given a cluster designation (CD) followed by a number, thus rituximab is an anti-CD20 antibody. Rituximab has become an important

agent to treat CD20-positive lymphocytic malignancies. Campath-1H is a monoclonal antibody directed against the antigen CD52 found on T and B lymphocytes. It is especially active against the lymphocytes in chronic lymphocytic leukemia (CLL).

Another antibody that has been approved for use by the FDA to treat certain patients with AML is linked to a chemical toxin called calicheamicin. This drug, with the trade name Mylotarg®, is approved for older patients with AML who relapse after initial treatment.

Monoclonal antibodies can also be linked to a radioactive isotope to target and kill specific cancer cells. These antibodies are injected into the patient in the hope that the antibodies will latch on to the antigen on the cancer cells and destroy the cells. These are called conjugated monoclonal antibodies. They deliver the toxic substance directly to the cancer cells. Examples of this treatment are the drugs Zevalin® and Bexxar®. These drugs have been approved to treat relapsed B-cell non-Hodgkin lymphoma.

In patients with CML who have relapsed after stem cell transplantation, the infusion of donor lymphocytes can re-induce remission. Patients with myeloma have also had remission re-induced by donor lymphocytes. 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 situations.

**Vaccines:** Vaccines are now used to treat certain types of lymphoma. Studies of patients with follicular or indolent lymphoma demonstrated an immune response in patients. Researchers are working on vaccines that could prevent cancer from recurring.

Many cancer vaccines under development are intended to induce antigen-specific antitumor immune responses. This means that the vaccine induces an immune response against the cancer cells present in the patient.

Some vaccines contain antigens or parts of antigens purified from cancer cells obtained from the patient or from the same type of cancer cells of another patient. DNA vaccines that contain the DNA that encodes the specific antigen are being tested. In some approaches, cells are isolated in the laboratory and start making antibodies after insertion of the cancer antigen. In each case, the basis for the vaccine is to make the cancer cells susceptible to immune attack by

heightening the recognition of markers on the cancer cells. Paradoxically, some vaccines are made from leukemic cells treated in test tubes to convert them to potent antigen-presenting cells.

These vaccine approaches are in clinical trials. The hope is that the immune system of the patient will inhibit the growth of cancer cells. Leukemias, lymphomas and myeloma are among the cancers for which vaccines are being developed.

**Reversal of Multidrug Resistance:** The malignant cells of patients have mechanisms that may allow them to escape the damaging effects of chemotherapy agents. These cells are, or become, less responsive to therapy. Approaches to reversing multidrug resistance are under study. The goal of several new agents being studied is to decrease resistance to an important chemotherapy drug used in leukemia. These agents are currently being tested in patients with AML and myeloma in the hope that they may decrease drug resistance and increase the rate of a prolonged response to therapy.

**Gene Therapy:** One approach to this type of treatment is to use “antisense” agents that block the encoding instructions of an oncogene so that it cannot direct the formation of the corresponding oncoprotein that causes the cell to transform into a malignant cell. These agents can act on the gene (DNA) or on RNA to prevent the formation of the gene product or protein (oncoprotein) that is the direct cause of transforming the cell into a malignant type.

In another approach, drugs are designed to interfere with the oncoprotein and prevent its effect on the cell. In studies of CML, gene therapy researchers are trying to modify an oncogene (BCR-ABL) that produces a protein that stimulates malignant cell growth. An alternative strategy called molecular targeted drug development targets the oncoprotein. Two new and potentially important approaches include a) the application of RNA interference, b) a modality that uses molecules of RNA to silence complementary (DNA) genes and aptamer treatment, a technique that prepares small molecules in the laboratory that have the ability to inactivate proteins that cause disease. If the gene in the former case is an oncogene or the protein in the latter case is an oncoprotein, new forms of cancer therapy may be developed.

# Leukemia

**Leukemia** is a malignant disease (cancer) of the bone marrow and blood. It is characterized by the uncontrolled accumulation of blood cells. Leukemia is divided into four categories: myelogenous or lymphocytic, each of which can be acute or chronic. The terms myelogenous or lymphocytic denote the cell type involved. Thus, the four major types of leukemia are:

Acute Lymphocytic Leukemia	Chronic Lymphocytic Leukemia
Acute Myelogenous Leukemia	Chronic Myelogenous Leukemia

**Table 1:** The Four Major Types of Leukemia

## Living with Leukemia

An estimated 198,257 people in the United States are living with leukemia.

Acute leukemia is a rapidly progressing disease that results in the accumulation of immature, functionless cells in the marrow and blood. The marrow often can no longer produce enough normal platelets, red blood cells and white blood cells. Anemia, a deficiency of red cells, develops in virtually all leukemia patients. The lack of normal white cells impairs the body's ability to fight infections. A shortage of platelets results in bruising and easy bleeding.

Chronic leukemia progresses more slowly and allows greater numbers of more mature, functional cells to be made.

## Approximate U.S. Prevalence of the Four Major Leukemias as of January 1, 2002

Type	No. of 27-year Survivors
Chronic lymphocytic leukemia	70,315
Chronic myelogenous leukemia	16,877
Acute lymphocytic leukemia	43,983
Acute myelogenous leukemia	22,493

**Table 2:** Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.

## New Cases

An estimated 34,810 new cases of leukemia will be diagnosed in the United States this year. Acute leukemias account for nearly 11 percent more of the cases than chronic leukemias.

- Most cases of leukemia occur in older adults; more than half of all cases occur after age 67. Leukemia is expected to strike nearly nine times as many adults as children in 2005. (About 31,289 adults compared with 3,521 children, ages 0-19.)
- The most common types of leukemia in adults are acute myelogenous leukemia (AML) and chronic lymphocytic leukemia (CLL).
- About 35 percent of cancers in children ages 0-14 years are leukemia.
- Most cases of chronic myelogenous leukemia (CML) occur in adults. Only 2.6 percent of leukemias in children ages 0-19 are CML.
- The most common form of leukemia in children is acute lymphocytic leukemia (ALL). Nearly 62 percent (about 2,455) of the new cases of this disease will occur among children in 2005.

## Total Estimated Number of New Leukemia Cases in the United States for 2005

Type	Individuals	Male	Female
Acute lymphocytic leukemia	3,970	2,180	1,790
Chronic lymphocytic leukemia	9,730	5,780	3,950
Acute myelogenous leukemia	11,960	6,530	5,430
Chronic myelogenous leukemia	4,600	2,640	1,960
Other, unclassified forms of leukemia	4,550	2,510	2,040
Total	34,810	19,640	15,170

**Table 3:** Source: *Cancer Facts and Figures 2005*, American Cancer Society, 2005.

### Estimated Proportion of New Cases (%) in 2005 for Each Type of Leukemia Including Adults and Children

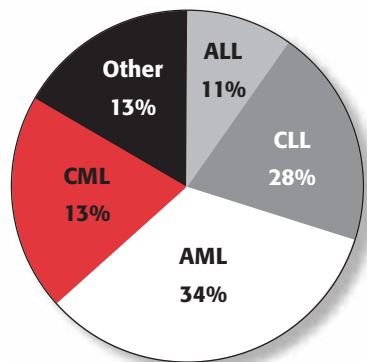


Figure 3: Source: *Cancer Facts and Figures 2005*, American Cancer Society, 2005. (Numbers do not add up to 100 because of rounding.)

### Incidence by Gender

Incidence rates\* for all types of leukemia are higher among males than among females and higher in Americans of European descent than among those of African descent. In 2005, males are expected to account for 56 percent of the new cases of leukemia.

*\*Note: Incidence rates are the number of new cases in a given year not counting the pre-existing cases. The incidence rates are usually presented as a specific number per 100,000 population.*

### Incidence by Race and Ethnicity

Incidence rates for all types of cancer are 7 percent higher among Americans of African descent than among those of European descent. The incidence rate for all cancers among African Americans, from 1973-2002, was 505.2 per 100,000 population, averaging about 175,093 cases per year.

Leukemia is one of the top 15 most frequently occurring cancers in minority groups. Leukemia incidence is highest among whites and lowest among American Indians/Alaskan natives.

Leukemia rates are substantially higher for white children than for black children.

Hispanic children of all races under the age of 20 have the highest rates of leukemia.

### Incidence by Age Group

Incidence rates by age differ for each of the leukemias. The leukemias represented 25 percent of all cancers occurring among children younger than 20 years from 1997-2002. In the 13 SEER areas of the United States, there were 1,490 children under the age of 20 diagnosed with leukemia from 1998-2002, including 1,113 with ALL. From these data, it is estimated that in 2005, 3,521 children will be diagnosed with leukemia throughout the United States. About 2,455 new cases of childhood ALL are expected to occur in 2005.

The most common form of leukemia among children under 19 years of age is ALL. The incidence of ALL among 1- to 4-year-old children is more than 10 times greater than the rate for young adults ages 20-24.

There is optimism within centers that specialize in the treatment of children because survival statistics have dramatically improved over the past 30 years. Most children with ALL are cured.

CLL and AML incidences increase dramatically among people who are over the age of 50, and CML incidence increases dramatically among people who are over the age of 60. These cancers are most prevalent in the seventh, eighth and ninth decades of life.

## Age-Specific Incidence Rates for Acute Myelogenous Leukemia (All Races), 1998-2002

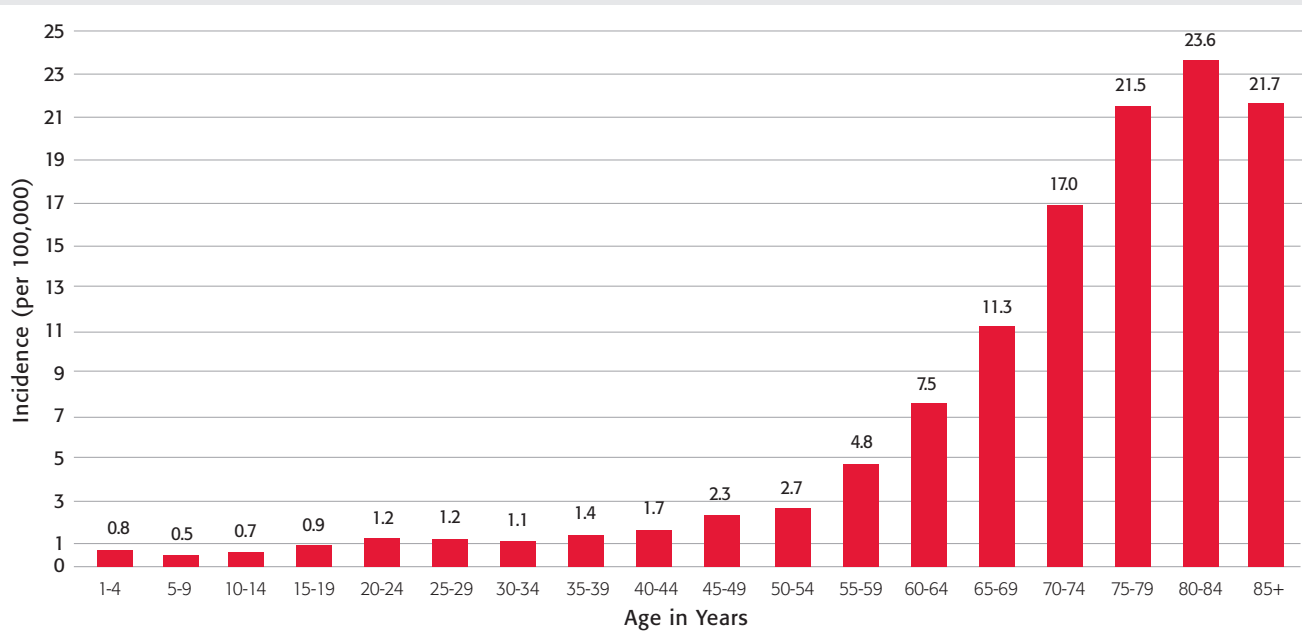


Figure 4: Sources: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.

### Signs and Symptoms of Leukemia

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 inadequate white cell count)

These signs are not specific to leukemia and may be caused by other disorders. They do warrant medical evaluation. The diagnosis of leukemia requires specific blood tests, including the examination of the cells in blood or marrow. A proportion of people with chronic leukemia may not have major symptoms and are diagnosed during a medical examination.

### Possible Causes of Leukemia

Anyone can get leukemia. Leukemia strikes all ages and both sexes. The cause of leukemia is not known. Although chronic exposure to benzene in the workplace and exposure to extraordinary doses of irradiation can be causes of the disease, neither explains most cases.

### Treatment of Leukemia

The aim of treatment is to bring about a complete remission. Complete remission means that there is no evidence of the disease and the patient returns to good health with normal blood and marrow cells. Relapse indicates a return of the cancer cells and the return of other signs and symptoms of the disease. For acute leukemia, a complete remission (no evidence of disease in the blood or marrow) that lasts five years after treatment often indicates cure. Treatment centers report increasing numbers of patients with leukemia who are in complete remission at least five years after diagnosis of their disease.

### Five-Year Relative Survival Rates for All Ages, All Types Leukemia, 1974-2001

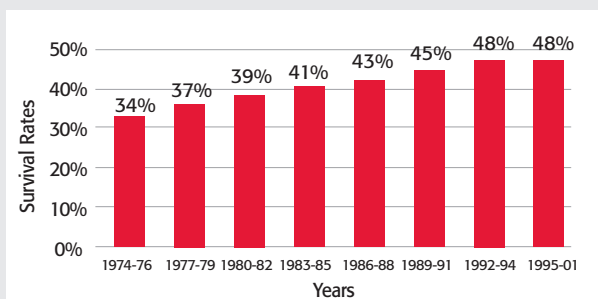


Figure 5: Sources: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.

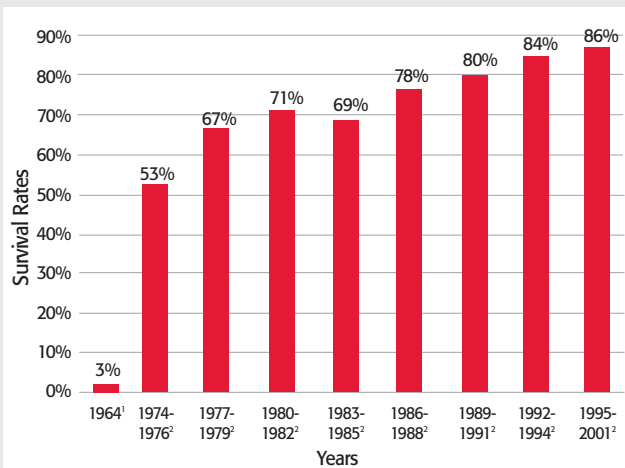
## Survival

Relative survival compares the survival rate of a person diagnosed with a disease with that of a person without the disease. The relative five-year survival rate has more than tripled in the past 45 years for patients with leukemia. In 1960-63, when compared to a person without leukemia, a patient had a 14 percent chance of living five years. By 1970-73, the five year relative survival rate had jumped to 22 percent, and in 1995-2001, the overall relative survival rate was nearly 48 percent. The relative survival rates differ by age of the patient at diagnosis, gender, race and type of leukemia.

During 1995-2001, relative survival rates overall were:

- Acute lymphocytic leukemia: 64.6 percent overall; 88.4 percent for children under 5
- Chronic lymphocytic leukemia: 74.2 percent
- Acute myelogenous leukemia: 19.8 percent overall; 52 percent for children under 15
- Chronic myelogenous leukemia: 39.3 percent

### Five-Year Relative Survival Rates for Acute Lymphocytic Leukemia, in Children Under 15 Years, 1964-2001



**Figure 6:** Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2002, National Cancer Institute. The graph shows childhood ALL five-year relative survival rates have improved significantly over the past 40 years. Sources: 1. Zuelzer WW. Implications of long-term survivals in acute stem cell leukemia of childhood treated with composite cyclic therapy. *Blood* 1964; 24: 477-94. 2. *Surveillance, Epidemiology and End Results (SEER) Program, Cancer Statistics Review, 1975-2002*, National Cancer Institute, 2005.

## Deaths

It is anticipated that approximately 22,570 deaths in the United States will be attributed to leukemia in 2005: 12,540 males and 10,030 females.

There will be an estimated 4,600 deaths from CLL and 1,490 deaths from ALL. There will be an estimated 9,000 deaths from AML and 850 deaths from CML. Unclassified forms of leukemia will account for 6,630 additional deaths.

The estimated numbers of deaths attributed to leukemia in the United States are about 25 percent higher for males than for females. In 2005, deaths from leukemia are expected to be distributed in the following numbers:

### Estimated Deaths (All Age Groups) from All Types of Leukemia in 2005

Type	Overall	Male	Female
Acute lymphocytic leukemia	1,490	850	640
Chronic lymphocytic leukemia	4,600	2,520	2,080
Acute myelogenous leukemia	9,000	5,040	3,960
Chronic myelogenous leukemia	850	430	420
Other, unclassified forms of leukemia	6,630	3,700	2,930
<b>Total</b>	<b>22,570</b>	<b>12,540</b>	<b>10,030</b>

**Table 4:** Source: *Cancer Facts and Figures 2005*, American Cancer Society.

Leukemia is the fifth most common cause of cancer deaths for men and the sixth most common cause of cancer deaths for women. The leukemia death rate for children 0-14 years of age in the United States has declined 60 percent over the past three decades. Despite this decline, leukemia causes more deaths than any other cancer among children under age 20.

Approximately 413 children from 0-14 years of age are expected to die from leukemia in 2005.

# Lymphoma

**Lymphoma** is a general term for a group of cancers that originates in the lymphatic system. Lymphoma results when a lymphocyte (a type of white blood cell) undergoes a malignant change and begins to multiply, eventually crowding out healthy cells and creating tumors that enlarge the lymph nodes or other sites in the body. Fifty-six percent of the blood cancers diagnosed are lymphomas.

## *Hodgkin Lymphoma*

Hodgkin lymphoma is a specialized form of lymphoma and will represent about 11.5 percent of all lymphomas diagnosed in 2005. Hodgkin lymphoma has characteristics that distinguish it from all other cancers of the lymphatic system, including the presence of an abnormal cell called the Reed-Sternberg cell (a large, malignant cell found in Hodgkin lymphoma tissues); incidence rates higher in adolescents and young adults than adults in their middle years; and long-term survival rates of more than 85 percent.

## *Non-Hodgkin Lymphoma*

Non-Hodgkin lymphoma represents a diverse group of cancers with the distinctions between types based on the characteristics of the cancerous cells. The groups are often classified as indolent or aggressive or low, intermediate and high grade. Each histologic grouping is diagnosed and treated differently, and each has prognostic factors that categorize it as more or less favorable. It is the eighth most common cause of cancer deaths in males and the seventh most common cause of cancer deaths in females.

## *Living with Lymphoma*

In the United States in 2005, there are 127,801 people living with Hodgkin lymphoma (active disease or in remission) and 365,300 people living with non-Hodgkin lymphoma, for a total of 493,101 members of the U.S. population who are living with lymphoma.

## *New Cases*

About 63,740 Americans will be diagnosed with lymphoma in 2005 (7,350 cases of Hodgkin lymphoma and 56,390 cases of non-Hodgkin lymphoma). The incidence of Hodgkin lymphoma is consistently lower than that of non-Hodgkin lymphoma.

Non-Hodgkin lymphoma is the sixth most common cancer in males and the fifth most common cancer in females in the United States. The age-adjusted incidence of non-Hodgkin lymphoma rose by 74 percent from 1975 to 2002, an average annual percentage increase of 2.7 percent.

### **New Cases of Lymphoma by Gender, 2005**

Type	Male	Female	Total
Hodgkin Lymphoma	3,980	3,370	7,350
Non-Hodgkin Lymphoma	29,070	27,320	56,390
Total	33,050	30,690	63,740

**Table 5:** Source: *Cancer Facts and Figures 2005*, American Cancer Society, 2005.

Age-specific incidence rates of non-Hodgkin lymphoma are 3.0/100,000 at ages 20-24 for males and 1.9/100,000 for females. By ages 60-64, they are 51.5/100,000 for males and 37.5/100,000 for females. Twelve percent of all cases of Hodgkin lymphoma diagnosed in 2005 will be in children under 20 years of age, while only about 2 percent of all cases of non-Hodgkin lymphoma will be diagnosed in children this year.

The reasons for the development of non-Hodgkin lymphoma are not certain. Immune suppression plays a role in some patients. Persons infected with the human immunodeficiency virus (HIV) have a much higher risk of developing lymphoma. The Epstein-Barr virus causes Burkitt lymphoma in Africa. The bacterium *Helicobacter pylori* is associated with the development of lymphoma in the stomach wall. These risk factors explain only a small proportion of cases.

### Incidence by Gender

Table 5 illustrates the breakdown of incidence of lymphoma by gender. After the age of 25, incidence rates for Hodgkin lymphoma tend to be higher among males than among females. In aggregate, both lymphomas are more common in males than in females.

### Incidence by Race and Ethnicity

Although blacks in their mid 20s to late 40s have higher incidence rates of non-Hodgkin lymphoma than whites, in general whites have higher incidence rates than blacks. After 50-54 years of age, incidence rates for non-Hodgkin lymphoma are higher in Americans of European descent than among those of African descent. Among women, Hispanics of all races have the second highest incidence rates after whites. Non-Hodgkin lymphoma is the seventh most common cancer in Hispanics, comprising nearly 5 percent of all cancers diagnosed and is the eighth most common cause of cancer death in that group.

### Incidence in Children

The incidence of Hodgkin lymphoma among people under 20 years of age was 1.2 per 100,000 children in 2002. The incidence in this group has been decreasing steadily and significantly between 1975 and 2002.

In the United States, about 12,156 children under the age of 20 are expected to be diagnosed with cancer in 2005. Lymphomas (Hodgkin lymphoma, 8.7 percent,

and non-Hodgkin lymphoma, 4.7 percent) are the third most common cancer in children, following leukemia (24 percent) and neoplasms of the central nervous system (17 percent). Among very young children a diagnosis of non-Hodgkin lymphoma is more prevalent, whereas adolescents are more commonly diagnosed with Hodgkin lymphoma.

In children less than 20 years of age, lymphomas are most commonly diagnosed in whites (24.4/one million population), followed closely by Hispanic children of all races (19.9/one million population). It is rarest among American Indian/Alaskan native children.

The most common type of Hodgkin lymphoma in children is nodular sclerosis, accounting for 98 percent of Hodgkin cases. Other types include mixed cellularity, lymphocytic predominance, not specified and lymphocytic depletion.

Burkitt lymphoma is the third most common type of lymphoma in children ages 0-19, after Hodgkin and non-Hodgkin lymphomas.

### Age-Specific Incidence Rates for Hodgkin Lymphoma, 1998-2002

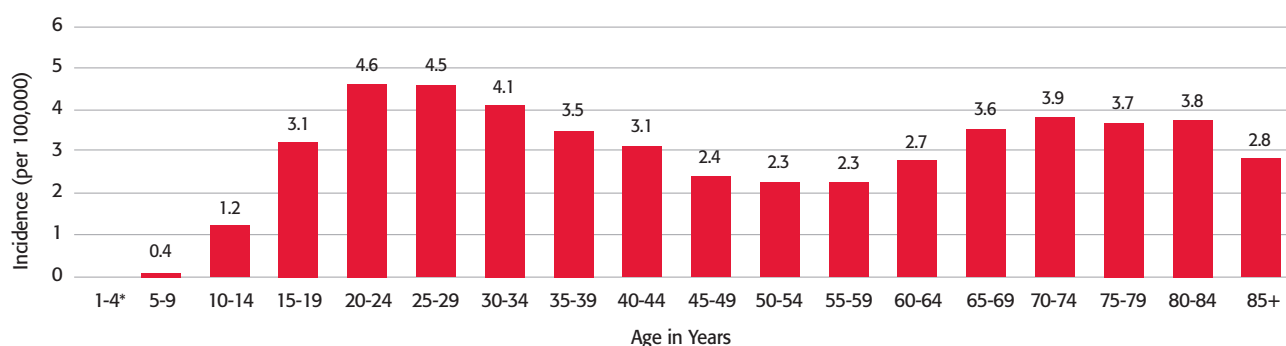


Figure 7: Sources: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.  
\* < 25 cases for time interval.

### Age-Specific Incidence Rates for Non-Hodgkin Lymphoma, 1998-2002

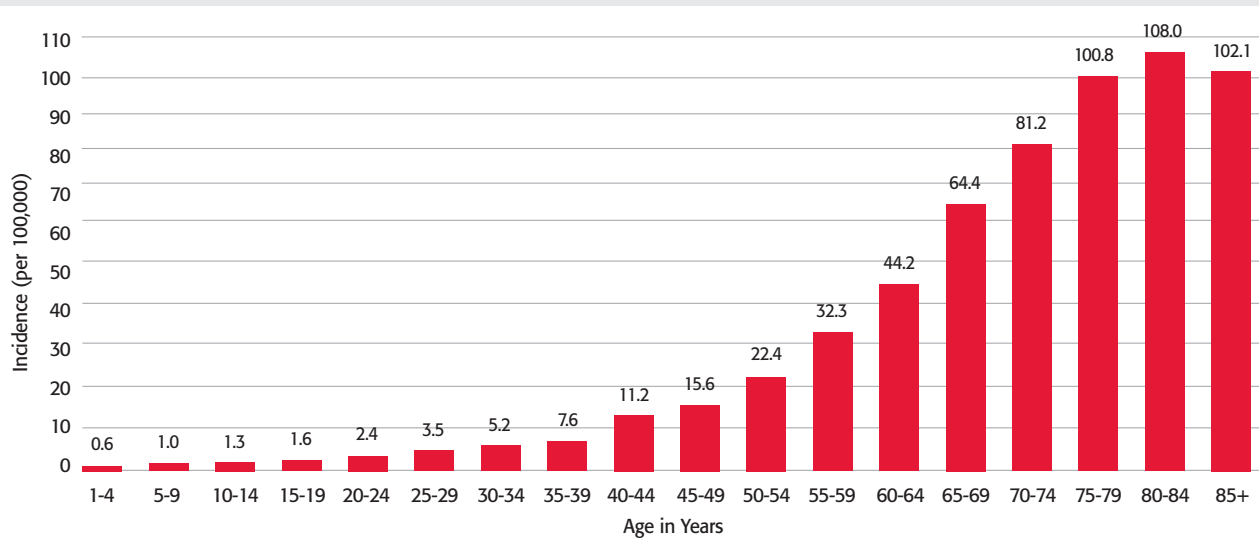


Figure 8: Sources: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.

#### Incidence in Adults

The incidence of non-Hodgkin lymphomas increases with age. About 2.4 cases per 100,000 people occur in 20-24-year-old individuals. The rate increases more than 18 times to 44.2 cases per 100,000 by age 60, and 40-fold to more than 100 cases per 100,000 persons after age 75.

#### Signs and Symptoms

Symptoms of Hodgkin lymphoma include painless swelling of lymph nodes in the neck, armpit or groin, persistent fatigue, recurrent high fever, sweating at night, troublesome itching and weight loss.

The most common early symptom of other forms of lymphoma is also painless swelling of the lymph nodes—usually in the neck, armpit, groin or in the abdomen. Other symptoms often include fever, night sweats, excessive tiredness, indigestion and abdominal pain, loss of appetite and bone pain.

#### Treatment

Hodgkin lymphoma is often treated with radiation and chemotherapy.

Early stage, localized non-Hodgkin lymphoma is sometimes treated with radiation; widespread disease requires chemotherapy or chemotherapy and/or monoclonal antibody therapy with radiation, depending on the tumor size, cell type and location of the lymphoma. Treatment for non-Hodgkin lymphoma sometimes includes vaccines and other forms of immunotherapy.

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

Hodgkin Lymphoma	1974-76	1980-82	1989-91	1995-2001
All races	71%	75%	82%	85%
Whites	72%	75%	83%	86%
African Americans	69%	71%	73%	80%

Non-Hodgkin Lymphoma	1974-76	1980-82	1989-91	1995-2001
All races	47%	51%	51%	60%
Whites	48%	52%	52%	61%
African Americans	48%	51%	44%	52%

**Table 6:** Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.

### Survival for Adults

Hodgkin lymphoma is now considered to be one of the most curable forms of cancer. Radiation, chemotherapy or both may result in cures for most patients with Hodgkin lymphoma.

The five-year relative survival rate for patients with Hodgkin lymphoma has more than doubled from 40 percent in whites in 1960 to 86 percent in 2001.

The five-year relative survival rate for non-Hodgkin lymphoma patients has risen from 47.3 percent in 1974 to 60.2 percent in 2001.

### Survival for Children

Five-year relative survival is 93 percent for Hodgkin lymphoma in people under 20 years of age.

In children 0-19 years of age, five-year relative survival for non-Hodgkin lymphoma is now 76.3 percent. This represents a significant improvement in the rate of recovery; even in the 1970s, the majority of children with non-Hodgkin lymphoma did not live five years after diagnosis.

### Deaths

An estimated 20,610 persons will die of lymphoma in the United States in 2005 (19,200 from non-Hodgkin lymphoma; 1,410 from Hodgkin lymphoma). Death rates have been decreasing for Hodgkin lymphoma patients since the mid-1970s.

### Estimated Deaths by Gender from Hodgkin Lymphoma and Non-Hodgkin Lymphoma

Type	Overall	Male	Female
Hodgkin Lymphoma	1,410	780	630
Non-Hodgkin Lymphoma	19,200	10,150	9,050
<b>Total</b>	<b>20,610</b>	<b>10,930</b>	<b>9,680</b>

**Table 7:** Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.

# Myeloma

**Myeloma** is a cancer of the plasma cells, a type of white blood cell found in many tissues of the body, but primarily in the bone marrow. In myeloma, a B lymphocyte, the cell that forms plasma cells, becomes malignant. It grows continuously and forms masses of plasma cells, especially in the marrow, destroying normal bone tissue, causing pain and crowding out normal blood cell production.

Malignant plasma cells produce an abnormal protein called monoclonal immunoglobulin. Immunoglobulins (or antibodies) are an important part of the body's natural defense against infection because they recognize microbes that invade the body and permit them to be removed and destroyed. The onset of myeloma interferes with normal production of antibodies and makes myeloma patients susceptible to infections.

## Living with Myeloma

An estimated 56,104 people in the United States are living with myeloma. Seventy-one percent of those were diagnosed with the disease within the previous five years.

## New Cases

An estimated 15,980 (8,600 men and 7,380 women) new cases of myeloma will be diagnosed in the United States in 2005.

- The median age at diagnosis is 70 years of age, and it rarely occurs in people under age 45.
- The median age at diagnosis for African Americans is 67.
- Americans of African descent have a much higher incidence rate (11.1/100,000) of myeloma than those of European descent (5.3/100,000). The highest rates are found in black men 80-84 years of age and older (93.8/100,000).
- In 2005, it is estimated that approximately 2.5 percent of all new cancer cases among African-American women will be myeloma.
- From 1992-2002, myeloma was the ninth most commonly diagnosed cancer among African-American women.
- Incidence rates in men (7.1/100,000) are 58 percent higher than for women (4.5/100,000) for all racial and ethnic groups.

## Signs and Symptoms

Often the first symptom of myeloma is bone pain caused by the effects of myeloma cells in the marrow. Patients may have anemia, tire more easily and feel weak. Fractures may occur as a result of the weakened bones. Recurrent infections may be an early sign of the disease.

## Possible Causes

The cause of myeloma is not known.

## Treatment

Chemotherapy for myeloma has led to sustained remissions in some patients. At times, two or three drugs are used simultaneously. Bortezomib (Velcade) has been approved for treating myeloma in patients who have had at least two prior therapies. Thalidomide and its derivatives have been added to the drug arsenal and found to be very useful. Treatment may include intensive chemotherapy followed by stem cell transplantation to restore normal blood cell production. Usually, the patient's own stem cells are used (autologous stem cell infusion). Treatment is aimed at slowing progress of the disease.

## Survival

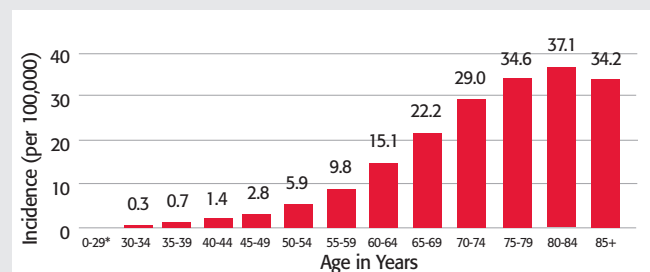
Current statistical databases show that overall five-year survival in patients with myeloma has shown a modest improvement since the 1970s: 24.5 percent in 1974-76 to 32.4 percent from 1995-2001. Total survival for males, especially, has been increasing.

Although newer treatments are expected to improve survival rates, even the most aggressive therapies rarely cure the disease.

## Deaths

Approximately 11,300 deaths from myeloma are anticipated this year. Myeloma will be the ninth most common cause of cancer deaths for women in 2005. Approximately 3 percent of all cancer-related deaths among African Americans in 2005 will be from myeloma. The mortality rates from myeloma for people of African descent is more than double the rates for whites (7.4/100,000 to 3.5/100,000). The U.S. median age at death from multiple myeloma is 74. It is 71 for African Americans.

## Age-Specific Incidence Rates for Myeloma, 1998-2002



**Figure 9:** Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005.  
\* < 25 cases for each age interval.

# Incidence Rates: Leukemia, Lymphoma and Myeloma

The following tables showing incidence rates for leukemia, Hodgkin and non-Hodgkin lymphoma and myeloma use figures from 1998-2002, the most recent available. Rates are per 100,000 population and are age-adjusted to the 2000 population.

**Incidence Rate by Gender, All Races, Per 100,000 Population (1998-2002)**

Type	Overall	Male	Female
Leukemia	12.4	16.3	9.6
Non-Hodgkin Lymphoma	19.4	23.6	16.1
Hodgkin Lymphoma	2.8	3.1	2.5
Myeloma	5.6	7.1	4.5

**Table 8:** Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005. (Based on SEER nine areas).

**Incidence Rate by Gender, for Blacks, Per 100,000 Population (1998-2002)**

Type	Overall	Male	Female
Leukemia	9.6	12.4	7.8
Non-Hodgkin Lymphoma	14.1	17.3	11.6
Hodgkin Lymphoma	2.4	2.9	2.0
Myeloma	11.1	13.1	9.8

**Table 9:** Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005. (Based on SEER nine areas).

**Incidence Rate by Gender, for Whites, Per 100,000 Population (1998-2002)**

Type	Overall	Male	Female
Leukemia	13.1	17.1	10.1
Non-Hodgkin Lymphoma	20.4	24.6	16.9
Hodgkin Lymphoma	3.0	3.3	2.7
Myeloma	5.3	6.9	4.1

**Table 10:** Source: SEER (*Surveillance, Epidemiology and End Results*) Cancer Statistics Review 1975-2002, National Cancer Institute, 2005. (Based on SEER nine areas).

### Estimated New Cases of Blood Cancers by Site, by State, 2005

State	Leukemia	Non-Hodgkin Lymphoma	Hodgkin Lymphoma	Myeloma
Alabama	560	940	100	300
Alaska	50	90	*	*
Arizona	620	1060	160	270
Arkansas	400	650	100	170
California	3,380	5,700	780	1,540
Colorado	460	880	100	200
Connecticut	400	730	100	200
Delaware	120	210	*	*
District of Columbia	50	90	*	60
Florida	2,620	3,470	470	780
Georgia	820	1,380	160	450
Hawaii	120	260	50	60
Idaho	150	210	50	60
Illinois	1,620	2,200	360	720
Indiana	820	1,410	100	370
Iowa	480	760	50	200
Kansas	350	650	50	160
Kentucky	490	970	160	250
Louisiana	540	1,060	100	230
Maine	150	260	*	100
Maryland	680	1,030	160	310
Massachusetts	770	1,260	210	370
Michigan	1,250	2,140	160	660
Minnesota	660	1,380	100	280
Mississippi	370	530	100	160
Missouri	830	1,530	210	340
Montana	140	210	*	60
Nebraska	250	380	100	100
Nevada	260	440	50	110
New Hampshire	170	320	50	70
New Jersey	1,100	1,760	210	510
New Mexico	170	320	50	110
New York	2,170	2,940	570	990
North Carolina	990	1,760	160	540
North Dakota	110	180	*	*
Ohio	1510	1970	310	650
Oklahoma	460	680	100	180
Oregon	420	1000	100	230
Pennsylvania	1630	2,880	360	820
Rhode Island	120	290	*	60
South Carolina	510	940	100	300
South Dakota	110	230	*	60
Tennessee	760	1,350	160	400
Texas	2,250	3,050	520	1,100
Utah	220	380	50	100
Vermont	90	180	*	*
Virginia	830	1,170	210	450
Washington	720	1,410	100	380
West Virginia	220	500	50	110
Wisconsin	770	1,120	160	270
Wyoming	60	90	50	*
Total U.S.**	34,810	56,390	7,290	15,840

**Table 11:** Source: American Cancer Society, *Cancer Facts and Figures 2005* and additional data supplied by the American Cancer Society.

\* Estimate is 50 or fewer cases.

\*\* State estimates may not add up to U.S. total because of rounding to nearest 10.

### Estimated Deaths from Blood Cancers by Site, by State, 2005

State	Leukemia	Non-Hodgkin Lymphoma	Hodgkin Lymphoma	Myeloma
Alabama	360	320	*	210
Alaska	*	*	*	*
Arizona	400	360	*	190
Arkansas	260	220	*	120
California	2,190	1,940	150	1,090
Colorado	300	300	*	140
Connecticut	260	250	*	140
Delaware	80	70	*	*
District of Columbia	*	*	*	*
Florida	1,700	1,180	90	550
Georgia	530	470	*	320
Hawaii	80	90	10	*
Idaho	100	70	*	*
Illinois	1050	750	70	510
Indiana	530	480	*	260
Iowa	310	260	*	140
Kansas	230	220	*	110
Kentucky	320	330	*	180
Louisiana	350	360	*	160
Maine	100	90	*	70
Maryland	440	350	*	220
Massachusetts	500	430	*	260
Michigan	810	730	*	470
Minnesota	430	470	*	200
Mississippi	240	180	*	110
Missouri	540	520	*	240
Montana	90	70	*	*
Nebraska	160	130	*	70
Nevada	170	150	*	80
New Hampshire	110	110	*	50
New Jersey	710	600	*	360
New Mexico	110	110	*	80
New York	1,410	1,000	110	700
North Carolina	640	600	*	380
North Dakota	70	60	*	*
Ohio	980	670	60	460
Oklahoma	300	230	*	130
Oregon	270	340	*	160
Pennsylvania	1,060	980	70	580
Rhode Island	80	100	*	*
South Carolina	330	320	*	210
South Dakota	70	80	*	*
Tennessee	490	460	*	280
Texas	1,460	1,040	100	780
Utah	140	130	*	70
Vermont	60	60	*	*
Virginia	540	400	*	320
Washington	470	480	*	270
West Virginia	140	170	*	80
Wisconsin	500	380	*	190
Wyoming	*	*	*	*
Total U.S.**	22,570	19,200	660	10,940

**Table 12:** Source: American Cancer Society, *Cancer Facts & Figures 2005* and additional data from the American Cancer Society, based on data from U.S. Mortality Public Use Data Tapes, 1969-2002, National Center for Health Statistics, Centers for Disease Control & Prevention, 2004. Rounded to nearest 10.

\* Estimate is 50 or fewer deaths.

\*\* State estimates may not add up to U.S. total because of rounding.

# Notes

## *Notes, Definitions and Citations*

### **Notes**

The United States does not have a nationwide reporting system or registry for blood cancers, so the exact number of cases is not known. The data presented in this report are an extrapolation or estimate of the number of cases reported by the 13 Surveillance, Epidemiology and End Results Program (SEER) regions (or, in some cases fewer than 13 SEER regions) and death data from the National Center for Health Statistics. These numbers are extrapolated to the entire 13 SEER regions by dividing the number of cancer cases or deaths in a specific region by the U.S. Bureau of the Census' 2000 population data for that region.

Because of changes in the information – such as racial classification – gathered in the 2000 U.S. Census, estimates of cancer incidence, survival and mortality have been revised, mostly upward, in comparison to the 2002 SEER report. Because of reporting delays from some of the SEER regions, the data presented in the 2005 SEER report placed online on April 15, 2005, may be incomplete in some cases.

The SEER data cover only about 14 percent of the U.S. population. The data can be extrapolated for the entire United States by multiplying by the population ratio, but these figures do not take into account differences in geography, race and ethnicity in various regions and region-specific health risks.

### **Definitions**

*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.

*Age-adjusted rate* is an incidence or mortality rate that has been adjusted to reduce the effects of differences in the age distributions of the populations being compared.

*Relative survival rate* is an estimate of the percentage of patients that 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 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.)

*Prevalence* is the estimated number of people alive on a certain date in a population who previously had a diagnosis of the disease. It includes new (incidence) and pre-existing 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, their survival with leukemia may not be counted in leukemia prevalence statistics. Thus, prevalence numbers reported may vary depending upon the method used to determine them.

In this report, prevalence is reported as defined by SEER as the “first invasive tumor for each cancer site diagnosed during the previous 27 years (1975-2001)” as per SEER table I-17.

### **Source Citations**

*Cancer Facts & Figures 2005*. Atlanta: American Cancer Society, 2005.

*Cancer Facts & Figures for African Americans, 2005-2006*. Atlanta: American Cancer Society, 2005.

“Cancer Immunity Hits Multiple Myeloma.” Knuth, A. *Blood* Vol. 105, No. 10, May 15, 2005, pp.3765-3766.

*SEER Cancer Statistics Review, 1975-2002*. Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Mariotto A, Feuer EJ, Edwards BK (eds). National Cancer Institute. Bethesda, MD.

([http://seer.cancer.gov/csr/1975\\_2002/](http://seer.cancer.gov/csr/1975_2002/)), based on November 2004 SEER data submission, posted to the SEER Web site 2005.

U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 2001 Incidence and Mortality*. Atlanta: Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2004.

# About the Society

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

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

## Research

### Research Grant Programs

The Leukemia & Lymphoma Society's research programs are based on the belief that all scientifically sound approaches toward a cure for, or control of, leukemia, Hodgkin and non-Hodgkin lymphoma and myeloma should be encouraged on a worldwide basis. Since the first funding in 1954, the Society has awarded \$411 million in research grants. Now about \$50 million annually, the Society's grant programs are among the most prestigious in the fields of hematology and oncology.

Research grants are awarded in three program areas: Career Development, Translational Research and the Specialized Center of Research (SCOR).

### Career Development Program

The *Career Development Program* supports promising young scientists (Scholars, Special Fellows and Fellows) pursuing careers in basic or clinical research:

- Scholars and Scholars in Clinical Research are awarded \$110,000 a year for a total of \$550,000 over five years.
- Special Fellows are awarded \$55,000 a year for a total of \$165,000 over three years.
- Fellows are awarded \$45,000 a year for a total of \$135,000 over three years.

### Translational Research Program

The *Translational Research Program* provides early-stage support for research on leukemia, Hodgkin and

non-Hodgkin lymphoma and myeloma that is intended to advance treatment, diagnosis or prevention in the near term.

*Translational Research Awards* are made for an initial three-year period; funding for two additional years may be provided for highly promising projects. Awards up to \$150,000 are granted each year.

As of June 30, 2005 the Society will have 336 active grantees at 108 institutions in the United States and abroad. This support should advance the understanding, treatment and prevention of leukemia, Hodgkin and non-Hodgkin lymphoma and myeloma.

### The Specialized Center of Research (SCOR) in Leukemia, Lymphoma and Myeloma

These center grants are awarded to a cluster of at least three research groups that interact to foster advances in the diagnosis, treatment or prevention of leukemia, lymphoma or myeloma. The *SCOR* grants also support scientific core laboratories to provide access to innovative technology if required by the participating research programs. The program is expected to generate new knowledge and breakthrough discoveries, leading to better survival rates and prevention measures for patients. Each *SCOR* is funded up to \$1 million – \$1.5 million annually over a five-year period, to a total cost of \$5 million – \$7.5 million over five years.

The *SCOR* program brings together research teams working in complementary areas, each focused on the discovery of new approaches to benefit patients or those at risk for developing leukemia, lymphoma or myeloma. Awards go to those groups that best demonstrate the synergy that will occur from their close interaction. The participating scientists may be at different institutions or from any country.

Experts in the field of leukemia, lymphoma and myeloma research carefully evaluate all grant applications.

Guidelines and applications for the Society's three research programs may be obtained by contacting the Research Department at (914) 949-5213, faxing to (914) 949-6691 or emailing [researchprograms@LLS.org](mailto:researchprograms@LLS.org). Detailed instructions for proposal submissions are posted on the Society's Web site, [www.LLS.org](http://www.LLS.org).

## Professional Education

The Society serves the continuing educational needs of the medical and research community through professional symposia offered throughout the year. The educational program offers varying formats to facilitate the exchange of information and ideas on the newest developments in cancer research and treatment. The Annual Research Symposium, sponsored by the Society, is held each December on the Friday immediately before the American Society of Hematology meeting. Other meetings are held for the Society's grantees. These include the Stohlman Scholar Symposium, the Translational Research Grant Progress Review Meeting and the SCOR Progress Review Meeting.

## Patient Services

The Society has a network of 64 chapters throughout the United States, with additional branches in Canada, that conducts life-enhancing patient services, including support groups, peer counseling and patient financial aid. The Society also hosts numerous teleconferences and Webcasts, where medical professionals share the latest research findings.

## Information Resource Center

The Society strives to be the world's foremost source of information on leukemia, lymphoma and myeloma. The Information Resource Center is a nationwide link to information and resources useful to patients, their families and healthcare professionals. Information specialists are oncology social workers, nurses and health educators who provide callers with current information on blood cancer, treatments, clinical trials and offer guidance on coping. They are available to talk one-on-one from Monday through Friday, 9 a.m. to 6 p.m. ET. Patients, families and professionals may call the Information Resource Center toll free at (800) 955-4572 in addition to corresponding by email at [infocenter@LLS.org](mailto:infocenter@LLS.org). You may also chat online with an information specialist on the Society's Web site, [www.LLS.org](http://www.LLS.org), and click on "Live Help."

## The Society's Web Site

The Society's Web site, [www.LLS.org](http://www.LLS.org), serves a wide variety of education and information needs. Initiated in 1996, the site has undergone explosive growth and is continually being updated and expanded to support and promote the Society's mission.

The user has the opportunity to create personalized pages with identified interests. The site features a comprehensive overview of blood cancers, the Society's programs and services, Family Support Group locations, information about our peer-to-peer program First Connection and other programs.

## Chapter Programs:

- Family Support Groups. The Society has developed more than 400 Family Support Groups at 64 chapters throughout the country. Guided by two volunteer oncology health professionals, groups provide information and support, and encourage greater communication among patients, families, friends and healthcare professionals.
- First Connection. This program links newly diagnosed patients to a peer volunteer who has experienced a similar diagnosis. A trained patient-volunteer currently in remission phones the new patient to share information and support. This program is available through Society chapters.
- Cancer Clinical Trials Education Series. The Cancer Clinical Trials Education Series was designed by the National Cancer Institute to improve access to current and accurate information about cancer clinical trials for patients, families and healthcare professionals.
- Meet the Expert on Non-Hodgkin Lymphoma. This program presents basic information on terminology, risk factors, diagnosis, staging and classification of non-Hodgkin lymphoma (NHL). New insights, treatments and future directions for NHL are also discussed. This program is also accessible as a Webcast at [www.LLS.org](http://www.LLS.org) and is being sponsored by a generous, unrestricted educational grant from Genentech BioOncology and Biogen Idec Inc.
- Exploring Myeloma. This program presents an overview of myeloma, treatments, emerging therapies and managing side effects and how to find emotional support when living with the illness. This Society program is being supported by Celgene Corporation.
- CML Issues and Insights: A Nursing Education Program on Chronic Myelogenous Leukemia. This nursing education program provides an overview of chronic myelogenous leukemia, treatments, emerging therapies and side effects. The program addresses the unique challenges of nursing management of these patients. This program is

being sponsored by an unrestricted education grant from Novartis Oncology.

- Patient Financial Aid Program. For more than 31 years, the Society has helped patients demonstrating a need for financial assistance to cover a portion of their treatment costs. Through the Patient Financial Aid Program, reimbursement of up to \$500 per year helps cover the costs of transportation, drugs and various treatments not covered by insurance. Patient financial aid funds are subject to availability.
- The Trish Greene Back to School Program for the Child with Cancer. This program is designed to increase communication among healthcare professionals, parents, patients and school personnel to assure youngsters a smooth transition from active treatment back to school. Printed literature, videos and other materials to aid the process are available through all local chapters.
- Educational Materials. An extensive collection of educational materials are offered free-of-charge to patients and health professionals. Each year, the Society distributes nearly 1 million booklets, brochures and videos through the Information Resource Center and local Society chapters. Much of the content of these materials is available to view and download on the Society's Web site, [www.LLS.org](http://www.LLS.org).
- Teleconferences and Webcasts. The Society sponsors teleconferences and Webcasts on topics of interest to patients and caregivers. Information on these free events can be accessed via the Web at [www.LLS.org](http://www.LLS.org).

### *Advocacy*

Since 1994, The Leukemia & Lymphoma Society's advocacy program has been a strong voice in Washington, DC, representing to policy makers at all levels of government the healthcare quality concerns and medical research interests of patients and their families. Society 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 23,000 and has

become a potent voice in public policy deliberations.

The Society has identified key issues that currently shape its advocacy agenda, including:

- Insurance coverage of patient-care costs in clinical trials
- Ready access by all Americans 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

In 2001, the Society successfully lobbied Congress to institute a blood cancer research initiative as part of the U.S. Department of Defense's medical research program. To date, that program has funded \$18 million in additional blood cancer research.

In 2002, the Society 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 \$3 million in 2004, providing additional support for blood cancer patients and their families nationwide.

On the state level, the Society has successfully ensured coverage of routine care in cancer clinical trials in three states and secured additional funding for patient support programs in three others.

The Society encourages volunteers to join its Advocacy Network by enrolling on its Web site, [www.LLS.org](http://www.LLS.org). Advocates receive Action Alerts and routine news updates on important legislative issues, giving them the opportunity to contribute to the Society's objectives.

#### Acknowledgements

Milton Eisner and Benjamin Hankey of SEER, NCI, provided statistical assistance. Alicia Samuels, of the American Cancer Society (ACS), provided ACS's state-by-state statistics on Hodgkin lymphoma and myeloma. Phyllis Wingo of the Centers for Disease Control (CDC) advised on appropriate CDC statistics to use. The Society extends special thanks to Myrna Watanabe, Ph.D., for compilation of data for this publication.

---

*This publication is designed to provide information in regard to the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society Inc. with the understanding that the Society is not engaged in rendering medical or other professional services.*

Home Office

1311 Mamaroneck Avenue, Suite 310

White Plains, New York 10605

Tel: 888.HELP.LLS

Information Resource Center (IRC): 800.955.4572

[www.LLS.org](http://www.LLS.org)

*Our mission: Cure leukemia, lymphoma,  
Hodgkin's disease and myeloma, and improve  
the quality of life of patients and their families.*

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



**The Leukemia &  
Lymphoma Society**<sup>®</sup>  
*Fighting Blood Cancers*