



LEUKEMIA &
LYMPHOMA
SOCIETY®

FACTS 2019-2020

**UPDATED
DATA ON
BLOOD CANCERS**

Table of Contents

Executive Summary	2
About Blood Cancers	2
Leukemia	4
Hodgkin and Non-Hodgkin Lymphoma	10
Myeloma	14
Myelodysplastic Syndromes	16
Myeloproliferative Neoplasms	17
Incidence Rates: Leukemia, Lymphoma, Myeloma, Myelodysplastic Syndromes and Myeloproliferative Neoplasms	19
Estimated New Cases and Estimated Deaths, by State	20
Five-Year Incidence and Mortality Cases, by State	21
Five-Year Leukemia Incidence and Mortality Cases, by State	22
Notes and Definitions	23
About The Leukemia & Lymphoma Society	24
Citations and Acknowledgements	27

PAGE	FIGURES
2	Figure 1. Estimated New Cases (%) of Leukemia, Lymphoma and Myeloma, 2020
3	Figure 2. Five-Year Relative Survival Rates by Year of Diagnosis
5	Figure 3. Estimated Proportion of New Cases (%) in 2020 for Types of Leukemia, Adults and Children
6	Figure 4. Age-Specific Incidence Rates for Leukemia, 2012-2016
6	Figure 5. Age-Specific Incidence Rates for Acute Lymphoblastic Leukemia (ALL), 2012-2016
7	Figure 6. Age-Specific Incidence Rates for Acute Myeloid Leukemia (AML), 2012-2016
7	Figure 7. Age-Specific Incidence Rates for Chronic Lymphocytic Leukemia (CLL), 2012-2016
7	Figure 8. Age-Specific Incidence Rates for Chronic Myeloid Leukemia (CML), 2012-2016
9	Figure 9. Five-Year Relative Survival Rates for Acute Lymphoblastic Leukemia in Children Under 15, Diagnosed 1964-2015
11	Figure 10. Age-Specific Incidence Rates for Lymphoma, 2012-2016
11	Figure 11. Age-Specific Incidence Rates for Hodgkin Lymphoma (HL), 2012-2016
12	Figure 12. Age-Specific Incidence Rates for Non-Hodgkin Lymphoma (NHL), 2012-2016
14	Figure 13. Age-Specific Incidence Rates for Myeloma, 2012-2016

PAGE	TABLES
2	Table 1. Approximate US Prevalence of the Four Major Types of Blood Cancers as of January 1, 2016
4	Table 2. The Four Major Types of Leukemia
4	Table 3. Approximate US Prevalence of the Four Major Types of Leukemia as of January 1, 2016
5	Table 4. Estimated New Cases of Leukemia, by Gender, 2020
8	Table 5. Trends in Five-Year Relative Survival Rates for Leukemia, by Subtype, Race and Year of Diagnosis
9	Table 6. Estimated Deaths from Leukemia, by Gender, 2020
10	Table 7. Estimated New Cases of Lymphoma, by Gender, 2020
13	Table 8. Trends in Five-Year Relative Survival Rates for Lymphoma, by Subtype, Race and Year of Diagnosis
13	Table 9. Estimated Deaths from Lymphoma, by Gender, 2020
14	Table 10. Estimated New Cases of Myeloma, by Gender, 2020
15	Table 11. Trends in Five-Year Relative Survival Rates for Myeloma, by Race and Year of Diagnosis
15	Table 12. Estimated Deaths from Myeloma, by Gender, 2020
16	Table 13. Myelodysplastic Syndromes Age-Adjusted Incidence Rates, per 100,000 Population, 2012-2016
17	Table 14. Myeloproliferative Neoplasms Age-Adjusted Incidence Rates, per 100,000 Population, 2012-2016
19	Table 15. Age-Adjusted Incidence Rates, by Gender, All Races, per 100,000 Population, 2012-2016
19	Table 16. Age-Adjusted Incidence Rates, by Gender, for Blacks, per 100,000 Population, 2012-2016
19	Table 17. Age-Adjusted Incidence Rates, by Gender, for Whites, per 100,000 Population, 2012-2016
20	Table 18. Estimated New Cases of Blood Cancers, by State, 2020
20	Table 19. Estimated Deaths from Blood Cancers, by State, 2020
21	Table 20. Five-Year Blood Cancer Incidence Cases, by State, 2012-2016
21	Table 21. Five-Year Blood Cancer Mortality Cases, by State, 2012-2016
22	Table 22. Five-Year Leukemia Incidence Cases, by State, 2012-2016
22	Table 23. Five-Year Leukemia Mortality Cases, by State, 2012-2016

Executive Summary

Facts 2019-2020 is an update of data available for leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative neoplasms (blood cancers). Blood cancers are diseases that can affect the bone marrow, the blood cells, the lymph nodes and other parts of the lymphatic system.

Facts 2019-2020 provides updates from the American Cancer Society's *Cancer Facts & Figures 2020* (published online in 2020, <https://www.cancer.org/research/cancer-facts-statistics.html>) for estimated numbers of new blood cancer cases and estimated numbers of deaths due to blood cancers. The incidence rates, prevalence and mortality data in

Facts 2019-2020 reflect the statistics from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, *Cancer Statistics Review (CSR) 1975-2016* (published online in April 2019, www.seer.cancer.gov). National incidence counts are generated from the United States Cancer Statistics (USCS) Public Use Database for 2001-2016 (www.cdc.gov/cancer/uscs/public-use/). Incidence rates by state are provided by the North American Association of Central Cancer Registries, *Cancer in North America: 2012-2016* (published online in May 2019, www.naaccr.org).

Throughout this publication, "cases" and "counts" are used interchangeably.

About Blood Cancers

Leukemia, lymphoma, myeloma, myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs) are types of blood cancer that can affect the bone marrow, the blood cells, the lymph nodes and other parts of the lymphatic system. These diseases may result from acquired mutations to the DNA of a single lymph- or blood-forming stem cell. With blood cancers, 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 blood cells, white blood cells and platelets. The disease process can lead to severe anemia, bleeding, an impaired ability to fight infection and/or death.

Highlights from *Facts 2019-2020*

Prevalence

Prevalence is the estimated number of people alive on a certain date in a population who previously had a diagnosis of the disease.

An estimated 1,297,027 people in the United States (US) are living with or in remission from leukemia, lymphoma or myeloma (see Table 1).

Approximate US Prevalence of the Four Major Types of Blood Cancers as of January 1, 2016

Type	Prevalence
Myeloma	128,969
Hodgkin Lymphoma	146,789
Non-Hodgkin Lymphoma	644,761
Leukemia	376,508

Table 1. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016, National Cancer Institute; 2019.

With the release of the 1975-2016 Cancer Statistics Review, the calculation of limited-duration prevalence estimates were modified to use data from the SEER 13 areas (not including the Alaska Natives Registry) using cases diagnosed from 1992 through 2015. Prior publications used data from the SEER 9 registries using cases diagnosed from 1975+. SEER 13 provides a larger population base and one which is more representative of the entire US, which allows better projections of US counts. Due to this methodology change, the estimates may differ significantly from those published in previous years.

New Cases

Approximately every 3 minutes, one person in the US is diagnosed with a blood cancer*.

- An estimated combined total of 178,520 people in the US are expected to be diagnosed with leukemia, lymphoma or myeloma in 2020 (see Figure 1).
- New cases of leukemia, lymphoma and myeloma are expected to account for 9.9 percent of the estimated 1,806,590 new cancer cases that will be diagnosed in the US in 2020.

Estimated New Cases (%) of Leukemia, Lymphoma and Myeloma, 2020

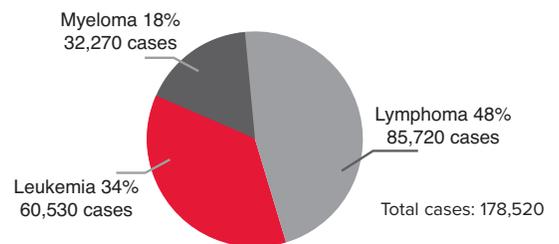


Figure 1. Source: *Cancer Facts & Figures, 2020*. American Cancer Society; 2020.

**Data specified for "blood cancer" include leukemia, lymphoma and myeloma, and do not include data for myelodysplastic syndromes (MDS) or myeloproliferative neoplasms (MPNs).*

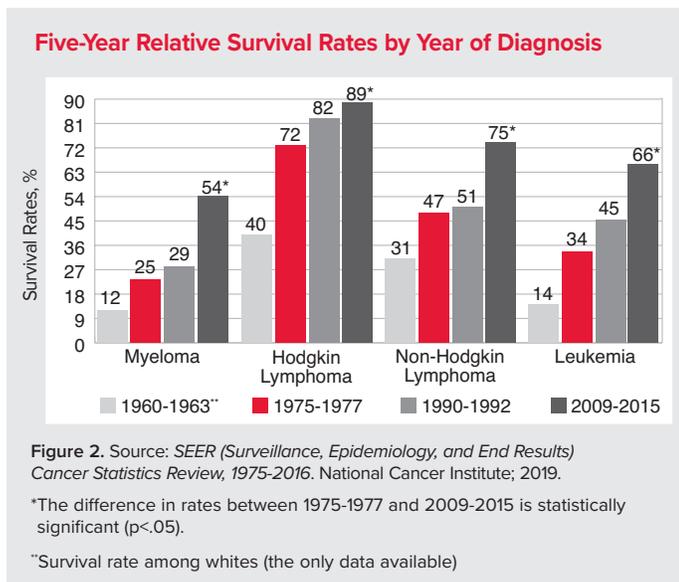
Incidence

Incidence rates are the number of new cases in a given year, not counting the preexisting cases. Incidence rates are usually presented as a specific number per 100,000 population. For large age groups, age-adjusted rates provide more reliable rates for comparison because they reduce the bias of age in the makeup of the populations that are being compared.

Overall age-adjusted incidence rates per 100,000 population reported in 2019 for leukemia, lymphoma and myeloma are close to data reported in 2018: leukemia 14.1 in 2019 vs 13.8 in 2018; non-Hodgkin lymphoma (NHL) 19.6 in 2019 vs 19.4 in 2018; Hodgkin lymphoma (HL) 2.7 in 2019 vs 2.5 in 2018; myeloma 6.9 in 2019 vs 6.7 in 2018.

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 impact of all current therapies and, as a result, may underestimate current survival. Figure 2 shows 5-year relative survival rates.



Deaths

Approximately every 9 minutes, someone in the US dies from a blood cancer*. This statistic represents approximately 156 people each day or more than 6 people every hour.

- Leukemia, lymphoma and myeloma are expected to cause the deaths of an estimated 56,840 people in the US in 2020.
- These diseases are expected to account for 9.4 percent of the deaths from cancer in 2020, based on the estimated total of 606,520 cancer deaths.
- Overall, the likelihood of dying from blood cancer* decreased from 2000 to 2016 (the most recent data

available). During this time, the mortality rate of leukemia decreased by 18.5 percent, lymphoma by 34.6 percent and myeloma by 15.9 percent.

Leukemia

- An estimated 376,508 people are living with or in remission from leukemia in the US.
- In 2020, 60,530 people are expected to be diagnosed with leukemia.
- In 2020, 23,100 people are expected to die from leukemia.
- Approximately 36.3 percent more males than females are living with leukemia. More males than females are diagnosed with leukemia and die of leukemia.

Hodgkin and Non-Hodgkin Lymphoma

- An estimated 791,550 people are living with or in remission from lymphoma in the US.
- An estimated 146,789 people are living with or in remission from HL.
- An estimated 644,761 people are living with or in remission from NHL.
- In 2020, 85,720 new cases of lymphoma are expected to be diagnosed in the US (8,480 cases of HL, 77,240 cases of NHL).
- In 2020, 20,910 people are expected to die from lymphoma (970 from HL, 19,940 from NHL).
- NHL is the seventh most common cancer in the US, and the age-adjusted incidence rate rose by 75.0 percent from 1975 (11.06 per 100,000 population) to 2016 (19.36 per 100,000 population).

Myeloma

- An estimated 128,969 people are living with or in remission from myeloma in the US.
- In 2020, 32,270 people are expected to be diagnosed with myeloma.
- In 2020, approximately 12,830 people are expected to die from myeloma.
- The age-adjusted incidence rate of myeloma increased by 42.2 percent from 1975 (4.91 per 100,000) to 2016 (6.98 per 100,000).
- The age-adjusted incidence rate of myeloma in black males and females (13.7 per 100,000) was 117 percent greater than that of white males and females (6.3 per 100,000) from 2012 to 2016.

*Data specified for "blood cancer" include leukemia, lymphoma and myeloma, and do not include data for myelodysplastic syndromes (MDS) or myeloproliferative neoplasms (MPNs).

Myelodysplastic Syndromes

- An average of 14,933 new cases of myelodysplastic syndromes (MDS) were diagnosed in the US each year from 2012 to 2016.
- The estimated overall age-adjusted incidence rate of MDS is 4.5 cases per 100,000 population. White males have the highest rate (6.5 per 100,000 population).

Myeloproliferative Neoplasms

- An average of 11,430 new cases of myeloproliferative neoplasms (MPNs) were diagnosed in the US each year from 2012 to 2016.
- The estimated overall age-adjusted incidence rate of MPNs is 3.1 cases per 100,000 population. White males have the highest rate (3.4 per 100,000 population).

Childhood Blood Cancers

- Leukemia is the most common cancer diagnosed in children, adolescents and young adults younger than 20 years and accounts for 24.7 percent of all cancer cases in this age-group.
- From 2012 to 2016, the most recent 5 years for which data are available, leukemia and lymphoma accounted for 38.7 percent of all cancer types in children, adolescents and young adults younger than 20 years.

- The most common types of cancer in children, adolescents and young adults younger than 20 years are leukemia (24.7 percent), cancers of the brain and other nervous tissue (17.2 percent), NHL (7.5 percent), HL (6.5 percent), and soft tissue (5.9 percent).
- The age-adjusted incidence rate of leukemia and lymphoma in children, adolescents and young adults younger than 20 years was 7.2 per 100,000 (leukemia, 4.6 and lymphoma, 2.6).
- Leukemia is the second leading cause of cancer deaths (after cancers of the brain and other nervous tissue) among children, adolescents and young adults younger than 20 years. This accounts for 26.1 percent of all cancer-related deaths among this age-group.
- From 2012-2016, 4.8 percent of all leukemia and lymphoma cases were diagnosed in children, adolescents and young adults younger than 20 years.
- From 2012-2016, 3.5 percent of all blood cancers (leukemia, lymphoma, myeloma, MDS and MPNs*) were diagnosed in children, adolescents and young adults younger than 20 years.

**Myeloma, MDS and MPNs are not commonly diagnosed in children, adolescents and young adults younger than 20 years.*

Leukemia

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

The Four Major Types of Leukemia

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

Table 2. 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.

Prevalence

An estimated 376,508 people in the United States (US) are living with or in remission from leukemia (see Table 3). Thirty-six percent more males than females are living with leukemia.

Acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (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 blood cells and white blood cells. Anemia, a deficiency of red blood cells, develops in virtually everybody who has acute leukemia. The lack of normal white blood cells impairs the body’s ability to fight infections. A shortage of platelets results in bruising and easy bleeding.

Approximate US Prevalence of the Four Major Types of Leukemia as of January 1, 2016

Type	Prevalence
Acute Lymphoblastic Leukemia	70,308
Chronic Lymphocytic Leukemia	172,858
Acute Myeloid Leukemia	52,043
Chronic Myeloid Leukemia	51,342

Table 3. Source: *Surveillance, Epidemiology, and End Results (SEER) Program* (www.seer.cancer.gov). Prevalence database: “US Estimated 40-Year L-D Prevalence Counts on 1/1/2016.” National Cancer Institute, DCCPS, Surveillance Research Program, Data Modeling Branch, released April 2019, based on the November 2018 SEER data submission.

With the release of the 1975-2016 Cancer Statistics Review, the calculation of limited-duration prevalence estimates were modified to use data from the SEER 13 areas (not including the Alaska Natives Registry) using cases diagnosed from 1992 through 2015. Prior publications used data from the SEER 9 registries using cases diagnosed from 1975+. SEER 13 provides a larger population base and one which is more representative of the entire US, which allows better projections of US counts. Due to this methodology change, the estimates may differ significantly from those published in previous years.

The progression of chronic lymphocytic leukemia (CLL) and chronic myeloid leukemia (CML) is usually slower than that of acute types of leukemia. The slower disease progression of chronic leukemia allows greater numbers of more mature, functional cells to be made.

New Cases

An estimated 60,530 new cases of leukemia are expected to be diagnosed in the US in 2020 (see Figure 3 and Table 4). Chronic leukemia is expected to account for 13.0 percent more cases than those of acute leukemia.

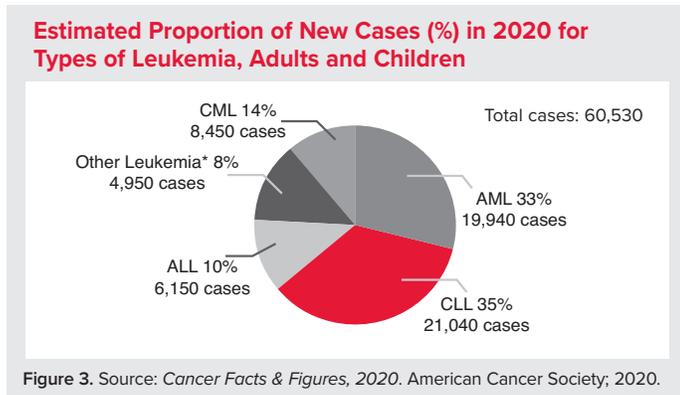


Figure 3. Source: *Cancer Facts & Figures, 2020*. American Cancer Society; 2020.

- Most cases of leukemia occur in older adults; the median age at diagnosis is 67 years.
- From 2012 to 2016, approximately 12 times as many adults over age 19 years (an average of 44,273 each year) were diagnosed with leukemia as children, adolescents and young adults younger than 20 years (an average of 3,718 each year).
- The most common types of leukemia in adults older than 19 years are CLL (39.7% of all new leukemia cases from 2012 to 2016) and AML (31.4% of all new leukemia cases from 2012 to 2016). CML accounted for 14.2 percent of new leukemia cases and ALL accounted for 5.5 percent of new leukemia cases in this age-group from 2012 to 2016.
- Most cases of CML occur in adults. From 2012 to 2016, approximately 98.0 percent of all cases of CML occurred in adults age 20 years and older.

Estimated New Cases of Leukemia, by Gender, 2020			
Type	Total	Male	Female
Acute Lymphoblastic Leukemia	6,150	3,470	2,680
Chronic Lymphocytic Leukemia	21,040	12,930	8,110
Acute Myeloid Leukemia	19,940	11,090	8,850
Chronic Myeloid Leukemia	8,450	4,970	3,480
Other Leukemia*	4,950	3,010	1,940
Total Estimated New Cases	60,530	35,470	25,060

Table 4. Source: *Cancer Facts & Figures 2020*. American Cancer Society; 2020.

*There are other rare subtypes of leukemia, beyond the four main subtypes, which comprise "Other Leukemia."

Incidence

Since 1975, the incidence of leukemia has increased slightly. In 1975 the incidence rate was 12.8 per 100,000 population and in 2016, it was 13.8 per 100,000 population. See Figure 4 (on page 6) for age-specific rates.

Gender. In 2020, approximately 59 percent of the new cases of leukemia are expected to occur in males. Incidence rates for all types of leukemia are higher among males than among females:

- ALL – 1.9 per 100,000 for males, 1.5 per 100,000 for females
- AML – 5.2 per 100,000 for males, 3.5 per 100,000 for females
- CLL – 6.8 per 100,000 for males, 3.5 per 100,000 for females
- CML – 2.4 per 100,000 for males, 1.4 per 100,000 for females.

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

- Age-adjusted incidence of leukemia is highest among non-Hispanic whites (15.3 per 100,000 population); it is lowest among Asian and Pacific Islander populations (7.8 per 100,000 population) and American Indian and Alaska Native populations (8.6 per 100,000 population).
- Leukemia is the tenth most common cancer in whites, eleventh most common cancer in blacks, and twelfth most common cancer in Hispanics.
- In children, adolescents and young adults younger than 20 years, leukemia incidence rates are highest among Hispanics (6.1 per 100,000 population) and lowest among blacks (3.1 per 100,000 population). The incidence rate in whites is 5.2 per 100,000 population.

Children, Adolescents and Young Adults. From 2012 to 2016, leukemia represented 24.7 percent of all types of cancer occurring among children, adolescents and young adults younger than 20 years.

- In 2020, about 3,094 children and adolescents younger than 15 years are expected to be diagnosed with leukemia throughout the US.
- About 30.5 percent of cancer cases in children and adolescents younger than 15 years are leukemia.
- An average of 3,718 children and adolescents younger than 20 years were diagnosed with leukemia each year (including 2,761 diagnosed with ALL) in the US from 2012 to 2016.
- ALL is the most common cancer in children, adolescents and young adults younger than 20 years, accounting for 18.8 percent of all cancer cases in this age-group.

- ALL is the most common type of leukemia in children, adolescents and young adults younger than 20 years, accounting for 76 percent of all types of new leukemia cases in this age-group from 2012 to 2016.
- From 1975 to 2016, incidence rates increased for childhood, adolescent and young adult ALL (1.9 in 1975 vs 3.7 in 2016) and AML (0.6 in 1975 vs 0.8 in 2016).
- The highest incidence rates for ALL are seen in children and adolescents younger than 15 years (see Figure 5.) Within this group, the highest rate is in children ages 1 to 4 years (7.6 per 100,000).
- The incidence of ALL in children ages 1 to 4 years (7.6 per 100,000) is approximately 11 times greater than the rate for young adults ages 30 to 34 years (0.7 per 100,000).
- In children, adolescents and young adults younger than 20 years, AML incidence is highest in children under 1 year (1.6 per 100,000) and lowest in children ages 5 to 9 years (0.4 per 100,000).
- From 2012 to 2016, among children ages 5 to 9 years, ALL incidence was nine times greater than that of AML (3.6 per 100,000 for ALL and 0.4 per 100,000 for AML).
- In young adults ages 25 to 29 years, AML incidence was 50 percent greater than that of ALL (1.2 per 100,000 for AML and 0.8 per 100,000 for ALL).

Adults. AML, CLL and CML are most prevalent in the sixth through ninth decades of life. Incidence rates begin to increase notably among people with

- AML – at age 60 years and older (see Figure 6 on page 7)
- CLL – at age 50 years and older (see Figure 7 on page 7)
- CML – at age 60 years and older. (see Figure 8 on page 7).

Age-Specific Incidence Rates for Leukemia, 2012-2016

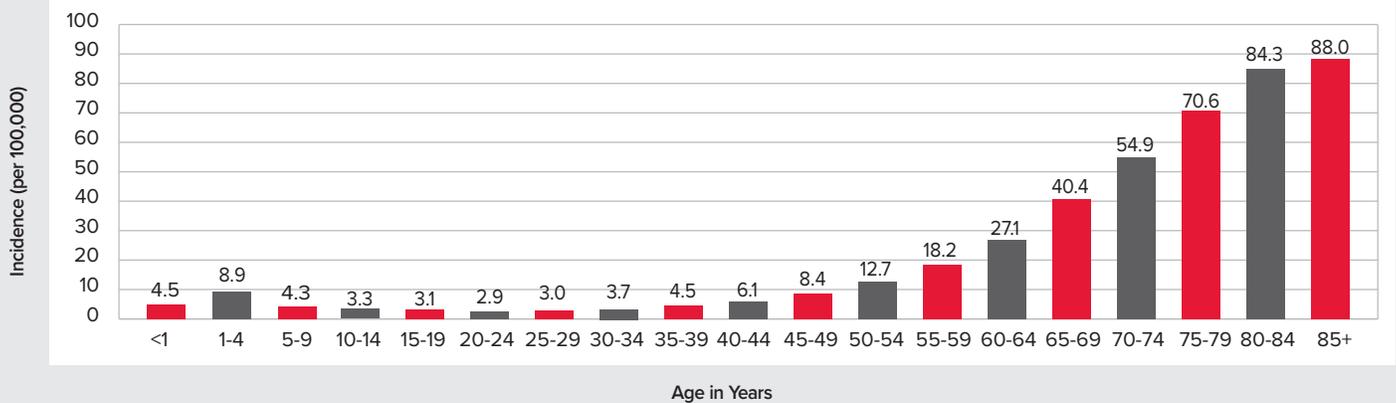


Figure 4. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

Age-Specific Incidence Rates for Acute Lymphoblastic Leukemia (ALL), 2012-2016

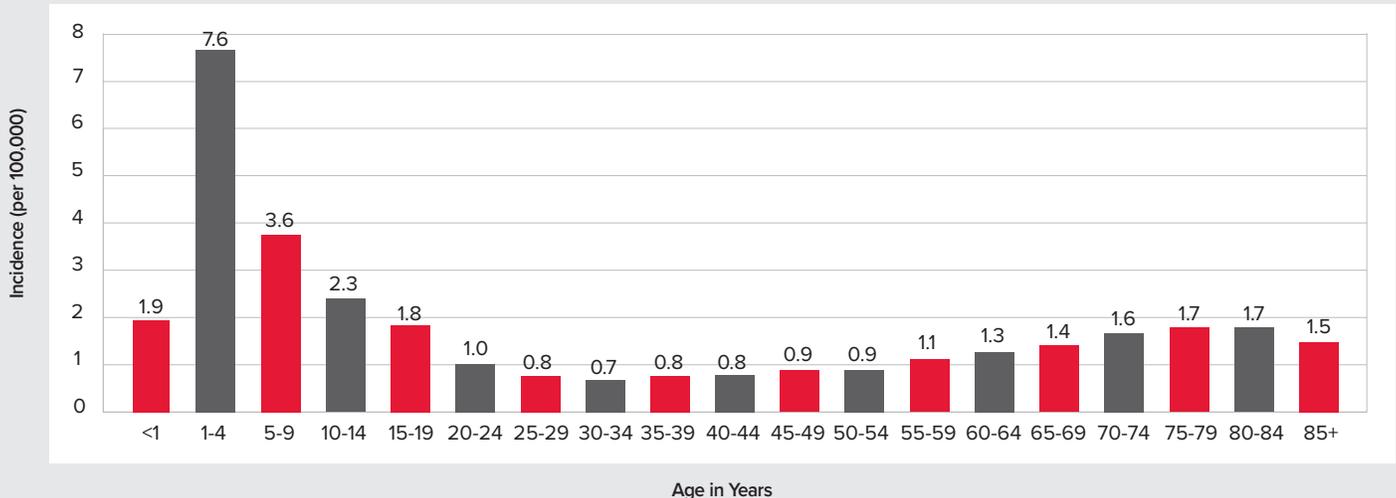


Figure 5. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

Age-Specific Incidence Rates for Acute Myeloid Leukemia (AML), 2012-2016

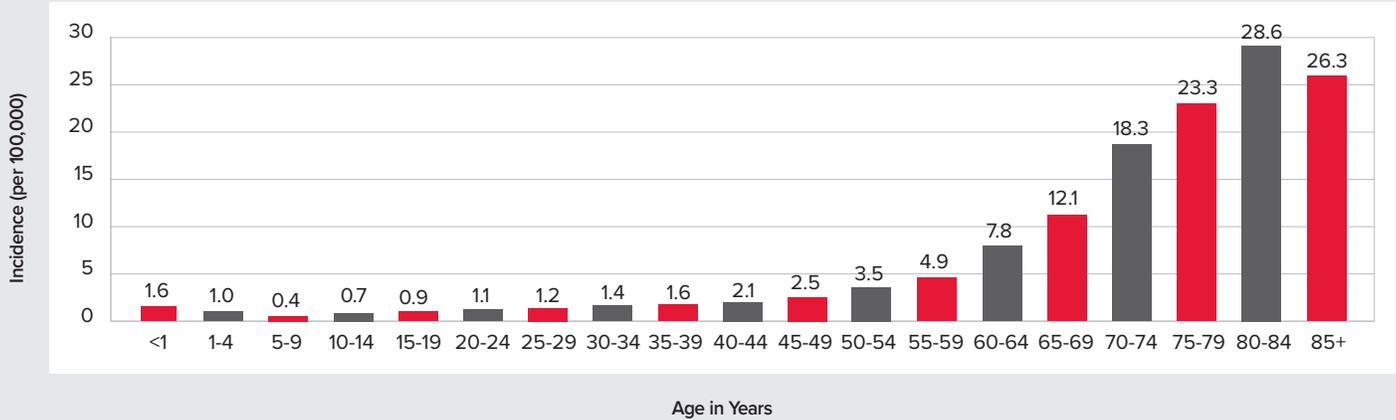


Figure 6. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

Age-Specific Incidence Rates for Chronic Lymphocytic Leukemia (CLL), 2012-2016

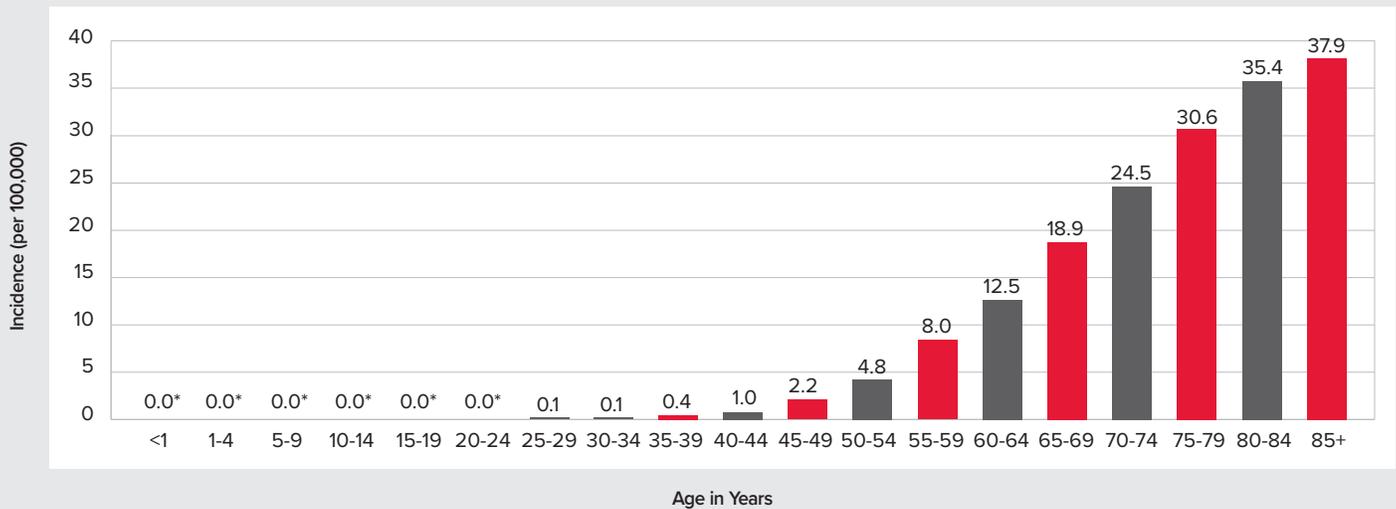


Figure 7. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

*<16 cases for each age and time interval, SEER 21 areas

Age-Specific Incidence Rates for Chronic Myeloid Leukemia (CML), 2012-2016

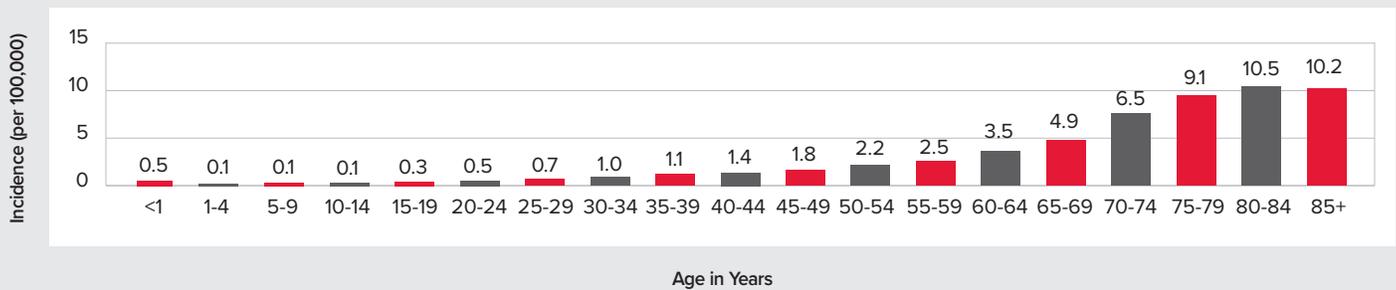


Figure 8. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

Signs and Symptoms

Signs and symptoms of acute leukemia may include easy bruising or bleeding (because of platelet deficiency), paleness or easy fatigue (because of anemia), and/or recurrent minor infections or poor healing of minor cuts (because of a low white blood cell count). These signs and symptoms 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 bone marrow. People who have chronic leukemia may not have major symptoms; they may be diagnosed as a result of a periodic physical examination and testing.

Possible Causes

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 acute myeloid leukemia (AML). Automobile exhaust and industrial emissions account for about 20 percent of the total national benzene exposure. About half of the benzene exposure in the US population 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 leukemia treatment is to bring about a complete remission. Patients with acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL) need to start treatment soon after diagnosis. Treatment may include chemotherapy, targeted therapies, monoclonal antibody therapy, immunotherapy and stem cell transplantation. Patients diagnosed with chronic myeloid leukemia (CML) are usually treated with tyrosine kinase inhibitors, oral drugs that may need to be taken indefinitely to keep CML under control. Some patients diagnosed with chronic lymphocytic leukemia (CLL) do not need treatment for a long period of time after diagnosis; this period is sometimes called “watch-and-wait.” Patients who need treatment may receive chemotherapy, targeted therapy, monoclonal antibody therapy or treatments in combination. All patients should consider new approaches under study (clinical trials).

Survival

Relative survival rates vary according to a person’s age at diagnosis, gender, race and type of leukemia. The 5-year relative survival rate for leukemia has more than quadrupled, from 14 percent in whites from 1960 to 1963 (the only data available) to 65.8 percent for all races from 2009 to 2015 (see Table 5; percentages in Table 5 are rounded to the nearest integer).

From 2009 to 2015, the 5-year relative survival rates overall were

- ALL – 71.7 percent overall, 91.9 percent for children and adolescents younger than 15 years, and 94.1 percent for children younger than 5 years
- AML – 29.4 percent overall and 68.7 percent for children and adolescents younger than 15 years
- CLL – 88.2 percent
- CML – 69.7 percent*.

**The survival rate of CML in clinical trials is higher than the survival rate reported here, based on SEER data. It is speculated that close clinical monitoring and better medication adherence in clinical trials are associated with a lower risk of disease progression and higher rates of survival.*

Gender. From 2009 to 2015, 5-year relative survival for leukemia was 67.3 percent for males and 63.7 percent for females.

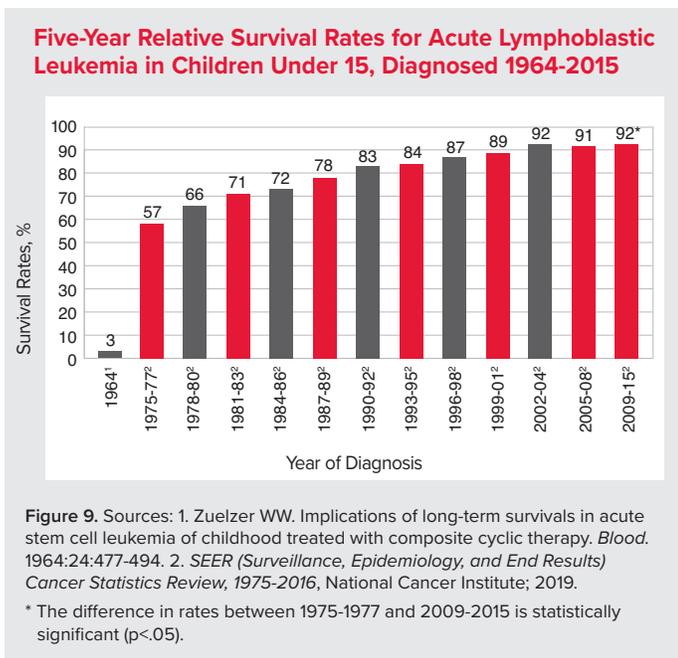
Race and Ethnicity. Table 5 shows the 5-year survival rates, rounded to the nearest integer, for all races and for blacks and whites, spanning four decades.

Trends in Five-Year Relative Survival Rates for Leukemia, by Subtype, Race and Year of Diagnosis				
Leukemia	1975-1977	1984-1986	1996-1998	2009-2015
All Races	34%	41%	48%	66%*
Whites	35%	42%	50%	67%*
Blacks	33%	33%	39%	60%*
ALL	1975-1977	1984-1986	1996-1998	2009-2015
All Races	41%	52%	66%	72%*
Whites	41%	53%	66%	73%*
Blacks	34%	36%	56%	63%*
AML	1975-1977	1984-1986	1996-1998	2009-2015
All Races	6%	11%	17%	29%*
Whites	6%	10%	16%	29%*
Blacks	10%	10%	22%	29%*
CLL	1975-1977	1984-1986	1996-1998	2009-2015
All Races	67%	72%	76%	88%*
Whites	68%	73%	77%	89%*
Blacks	57%	67%	58%	79%*
CML	1975-1977	1984-1986	1996-1998	2009-2015
All Races	22%	22%	37%	70%*
Whites	21%	23%	38%	69%*
Blacks	28%	21%	31%	74%*

Table 5. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

*The difference between 1975-1977 and 2009-2015 is statistically significant (p<.05).

Children, Adolescents and Young Adults. Figure 9 shows that childhood ALL 5-year survival rates have improved significantly over the past five decades. Most children, adolescents and young adults younger than 20 years who have ALL are expected to become 5-year survivors of the disease. However, significant treatment-related long-term morbidity and mortality for childhood cancer have been well established by several studies. Long-term treatment-related effects among ALL and other childhood cancer survivors may include cognitive impairment, subsequent cancer, cardiac disease, pulmonary disease or other diseases.



Deaths

Approximately 23,100 deaths (13,420 males and 9,680 females) in the US are expected to be attributed to leukemia in 2020. Estimated deaths for the four major types of leukemia in 2020 are

- ALL – 1,520 deaths
- AML – 11,180 deaths
- CLL – 4,060 deaths
- CML – 1,130 deaths
- Other leukemia* – 5,210 deaths.

In general, mortality rates for leukemia decreased from 1975 (8.1 per 100,000) to 2016 (6.3 per 100,000).

*There are other rare subtypes of leukemia, beyond the four main subtypes, which comprise "Other Leukemia."

Gender. From 2012 to 2016, leukemia was the sixth most common cause of cancer deaths in both men and women in the US. In 2020, the estimated number of deaths expected to be attributed to leukemia in the US is 38.6 percent higher for males than for females. Expected deaths from leukemia in 2020, according to gender, are shown in Table 6.

Estimated Deaths from Leukemia, by Gender, 2020			
Type	Total	Male	Female
Acute Lymphoblastic Leukemia	1,520	860	660
Chronic Lymphocytic Leukemia	4,060	2,330	1,730
Acute Myeloid Leukemia	11,180	6,470	4,710
Chronic Myeloid Leukemia	1,130	670	460
Other Leukemia*	5,210	3,090	2,120
Total	23,100	13,420	9,680

Table 6. Source: *Cancer Facts & Figures 2020*. American Cancer Society; 2020.

Race and Ethnicity. For leukemia, the highest age-adjusted rates of death from 2012 to 2016 were in non-Hispanic whites at 6.9 per 100,000 population, followed by blacks at 5.5 per 100,000 population and Hispanic whites at 5.0 per 100,000 population.

- Leukemia is the fifth most common cause of cancer deaths in white males and the sixth most common in white females.
- Leukemia is the eighth most common cause of cancer deaths in black males and the ninth most common in black females.
- From 2012 to 2016, blacks between the ages of 30 and 64 years had a higher death rate from leukemia than whites.

Children, Adolescents and Young Adults. The leukemia age-adjusted death rate for children, adolescents and young adults younger than 20 years in the US has declined by 78.6 percent from 2.8 per 100,000 population in 1969 to 0.6 per 100,000 population in 2016. Despite this decline, leukemia is the second leading cause of cancer death among children, adolescents and young adults younger than 20 years, accounting for 26.1 percent of all cancer deaths in this age-group.

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 blood 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.

Hodgkin Lymphoma. Hodgkin lymphoma (HL) represents 9.9 percent of all types of lymphoma expected to be diagnosed in 2020. This disease has characteristics that distinguish it from other diseases classified as lymphoma, including the presence of Reed-Sternberg cells, which are large, abnormal B lymphocytes found in a tissue sample.

Non-Hodgkin Lymphoma. Non-Hodgkin lymphoma (NHL) represents 90.1 percent of all types of lymphoma expected to be diagnosed in 2020. This disease comprises a diverse group of diseases (subtypes) 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.

Prevalence

An estimated total of 791,550 people in the United States (US) are living with or in remission from lymphoma.

- There are 146,789 people living with or in remission from Hodgkin lymphoma.
- There are 644,761 people living with or in remission from non-Hodgkin lymphoma.

With the release of the 1975-2016 Cancer Statistics Review, the calculation of limited-duration prevalence estimates were modified to use data from the SEER 13 areas (not including the Alaska Natives Registry) using cases diagnosed from 1992 through 2015. Prior publications used data from the SEER 9 registries using cases diagnosed from 1975+. SEER 13 provides a larger population base and one which is more representative of the entire US, which allows better projections of US counts. Due to this methodology change, the estimates may differ significantly from those published in previous years.

New Cases

About 85,720 people in the US are expected to be diagnosed with lymphoma in 2020 (8,480 cases of HL and 77,240 cases of NHL). The incidence of HL is consistently and considerably lower than that of NHL. Table 7 shows estimated new cases of lymphoma in 2020, by gender.

Estimated New Cases of Lymphoma by Gender, 2020			
Type	Total	Male	Female
Hodgkin Lymphoma	8,480	4,690	3,790
Non-Hodgkin Lymphoma	77,240	42,380	34,860
Total	85,720	47,070	38,650

Table 7. Source: *Cancer Facts & Figures 2020*. American Cancer Society; 2020.

Incidence

From 2012 to 2016, the age-adjusted incidence rate for lymphoma was 22.3 per 100,000. See Figure 10 (on page 11) for age-specific rates.

- The age-adjusted incidence rate for HL was 2.7 per 100,000.
- The age-adjusted incidence rate for NHL was 19.6 per 100,000.

The age-adjusted incidence rate of HL declined by 16.2 percent from 1975 (3.09 per 100,000) to 2016 (2.59 per 100,000), an annual percentage decrease of 0.4 percent. The age-adjusted incidence rate of NHL rose by 75.0 percent from 1975 (11.06 per 100,000) to 2016 (19.36 per 100,000), an average annual percentage increase of 1.8 percent.

Gender. Age-adjusted incidence rates for HL and NHL are higher among males than among females.

- HL – 3.0 per 100,000 for males; 2.3 per 100,000 for females
- NHL – 23.9 per 100,000 for males; 16.2 per 100,000 for females

In 2020, it is expected that 23.7 percent more males than females will be diagnosed with HL and about 21.6 percent more males than females will be diagnosed with NHL.

NHL is the sixth most common cancer in males and the seventh most common cancer in females in the US.

Race and Ethnicity. The highest age-adjusted incidence rate of lymphoma is in non-Hispanic whites (24.0 per 100,000), followed by Hispanic whites (20.8 per 100,000) and blacks (17.4 per 100,000).

- The highest age-adjusted incidence rate of HL is in non-Hispanic whites (3.0 per 100,000), followed by blacks (2.7 per 100,000) and Hispanic whites (2.5 per 100,000).
- The highest age-adjusted incidence rate of NHL is in non-Hispanic whites (21.0 per 100,000), followed by Hispanic whites (18.3 per 100,000) and blacks (14.7 per 100,000).

Blacks, from their early-20s to their early-40s, have higher incidence rates of NHL than whites. However, beginning at age 50 years, whites generally have considerably higher incidence rates of NHL than blacks.

NHL is the fifth most common cancer in Hispanics.

Children, Adolescents and Young Adults. Lymphoma (HL, 6.5 percent; NHL, 7.5 percent) is the third most common cancer in children, adolescents and young adults younger than 20 years.

- In 2020, lymphoma will account for 8 percent (HL, 3 percent; NHL, 5 percent) of all cancers expected to be diagnosed in children and adolescents younger than 15 years. The number of cases expected to be diagnosed in children and adolescents younger than 15 years is 332 for HL and 553 for NHL.
- In children younger than 15 years, the age-adjusted incidence rate for NHL (1.2 per 100,000) is higher than for HL (0.6 per 100,000).
- In adolescents and young adults between the ages of 15 and 29, the age-adjusted incidence rate for HL (3.9 per 100,000) is higher than for NHL (2.7 per 100,000).
- In young adults ages 30 to 34, NHL incidence (4.9 per 100,000) is higher than HL incidence (3.6 per 100,000).

The following data are based on age-adjusted incidence rates for children, adolescents and young adults younger than 20 years:

- Lymphoma is most commonly diagnosed in non-Hispanic whites (3.0 per 100,000 population), followed by blacks (2.4 per 100,000 population).

- Lymphoma is least commonly diagnosed among American Indians and Alaska Natives (1.3 per 100,000 population).

Adults. HL incidence rates are higher in adolescents and young adults ages 15 to 34 years than in adults ages 35 to 64 years. Incidence is highest at ages 20 to 24 and at ages 75 to 79 years (see Figure 11).

In contrast, the incidence rates of NHL increase with age (see Figure 12 on page 12).

- From ages 20 to 24 years, the incidence rate of NHL is 2.7 cases per 100,000 population.
- From ages 60 to 64 years, the incidence rate increases 17 times to 44.5 cases per 100,000 population.
- From ages 80 to 84 years, the incidence rate increases 44 times to 119.3 cases per 100,000 population.

Age-Specific Incidence Rates for Lymphoma, 2012-2016

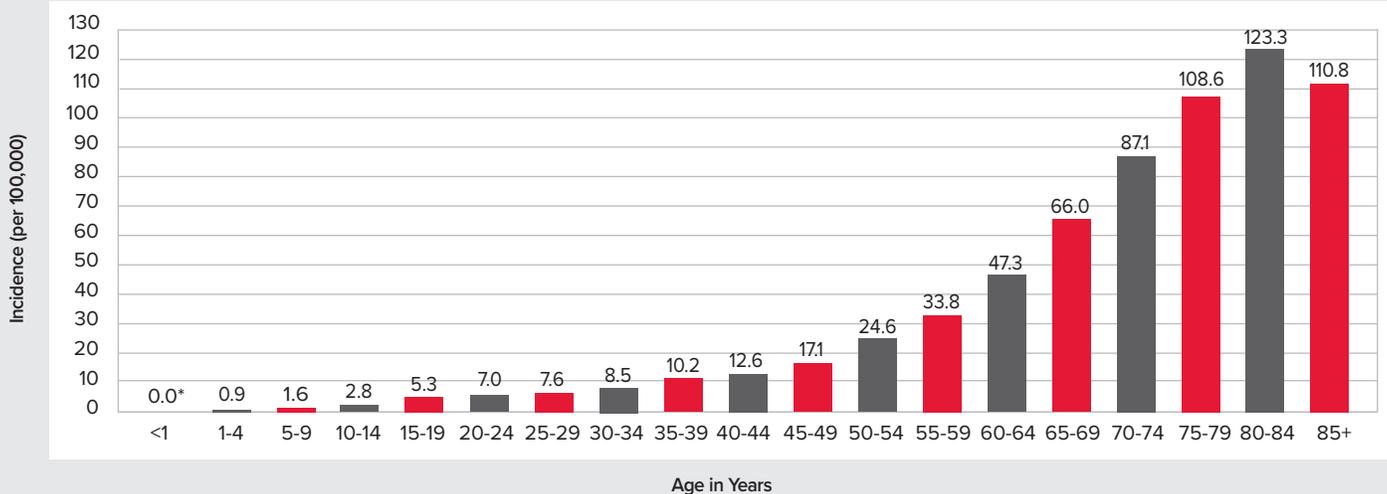


Figure 10. Source: *Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence - SEER 21 Regs Limited-Field Research Data + Hurricane Katrina Impacted Louisiana Cases, Nov 2018 Sub (2000-2016) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2017 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, released April 2019, based on the November 2018 submission.*
 *<16 cases for each age and time interval, SEER 21 areas

Age-Specific Incidence Rates for Hodgkin Lymphoma (HL), 2012-2016

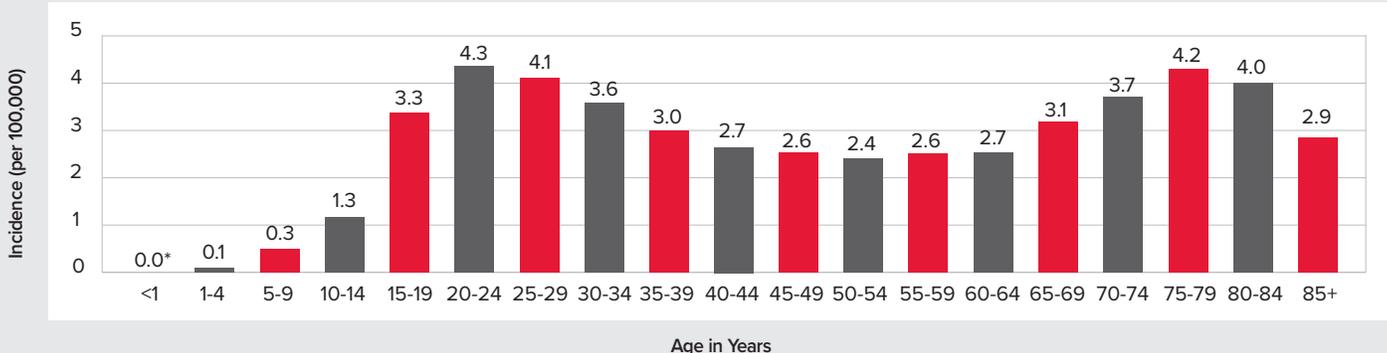


Figure 11. Source: *SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016.* National Cancer Institute; 2019.
 *<16 cases for each age and time interval, SEER 21 areas

Age-Specific Incidence Rates for Non-Hodgkin Lymphoma (NHL), 2012-2016

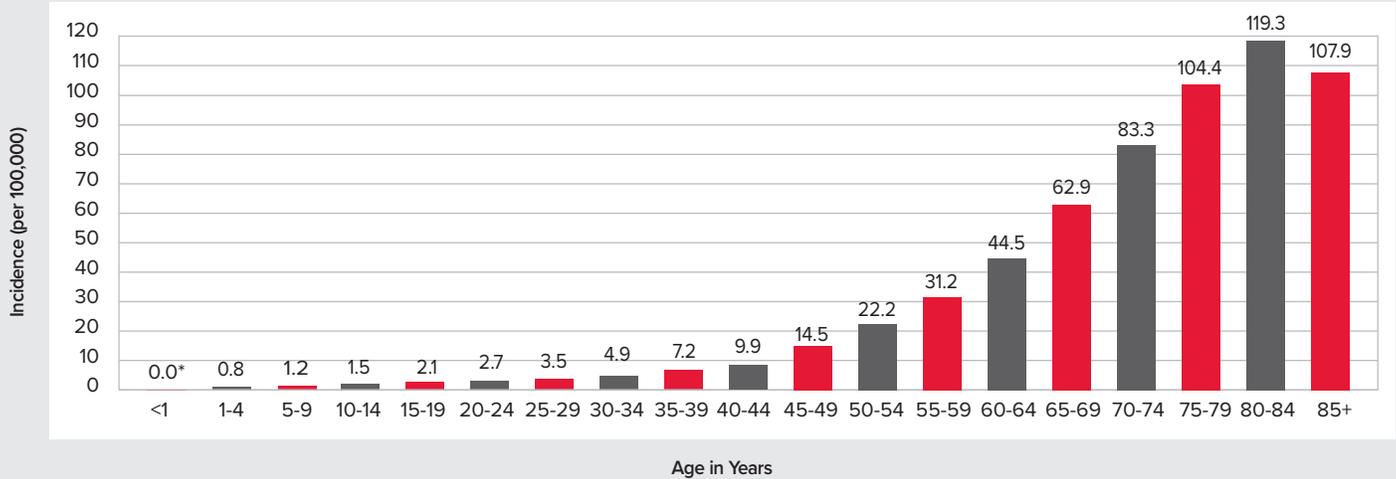


Figure 12. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

*<16 cases for each age and time interval, SEER 21 areas

Signs and Symptoms

A common early sign of HL or NHL is a painless enlargement of one or more lymph nodes. Enlarged lymph nodes may also 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.

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. People infected with human immunodeficiency virus (HIV) have increased probability of developing 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 NHL. 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 develop NHL. These risk factors explain only a small proportion of cases.

Treatment

The goal of treatment for HL is to cure the disease. Chemotherapy, either alone or combined with an antibody-drug conjugate or modality therapy (chemotherapy and radiation), are commonly administered treatment approaches for HL. Involved site radiation therapy (ISRT) is the most common type of radiotherapy used to treat HL. The radiation targets primarily the lymph node regions involved by disease. Chemotherapy is used to kill neighboring lymphoma cells.

In general, the goal of treatment for NHL is to destroy as many lymphoma cells as possible and to induce a complete remission. Treatment protocols vary according to the type of disease. Chemotherapy and radiation therapy are the two principal forms of treatment. Although radiation therapy is often neither the sole nor the principal curative therapy, it is an important additional treatment in some cases. Immunotherapy is indicated to treat individuals with specific types of NHL. Stem cell transplantation and a watch-and-wait strategy are also used to treat some NHL subtypes.

Survival

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

- The 5-year relative survival rate for people with HL has more than doubled, from 40 percent in whites from 1960 to 1963 (the only data available) to 88.5 percent for all races from 2009 to 2015.
- The 5-year relative survival rate is 94.4 percent for all people with HL who were younger than 45 years at diagnosis.

The 5-year relative survival rate for people with NHL has risen from 31 percent in whites from 1960 to 1963 (the only data available) to 74.7 percent for all races from 2009 to 2015.

- The 5-year relative survival rate is 84.0 percent for all people with NHL who were younger than 45 years at diagnosis.

Gender. From 2009 to 2015, 5-year relative survival rates were

- HL – 87.5 per 100,000 for males and 89.9 per 100,000 for females
- NHL – 73.9 per 100,000 for males and 75.7 per 100,000 for females.

Race and Ethnicity. Table 8 shows the 5-year relative survival rates, rounded to the nearest integer, for all races and for blacks and whites, spanning four decades.

Trends in Five-Year Relative Survival Rates for Lymphoma, by Subtype, Race and Year of Diagnosis				
Lymphoma	1975-1977	1984-1986	1996-1998	2009-2015
All Races	53%	57%	63%	77%*
Whites	53%	57%	63%	77%*
Blacks	56%	53%	60%	72%*
Hodgkin Lymphoma	1975-1977	1984-1986	1996-1998	2009-2015
All Races	72%	78%	85%	89%*
Whites	72%	79%	86%	89%*
Blacks	70%	75%	81%	85%*
Non-Hodgkin Lymphoma	1975-1977	1984-1986	1996-1998	2009-2015
All Races	47%	52%	59%	75%*
Whites	47%	52%	60%	76%*
Blacks	49%	47%	55%	70%*

Table 8. Source: SEER (Surveillance, Epidemiology, and End Results) 9 Registries, 1975-2016. National Cancer Institute; 2019

*The difference between 1975-1977 and 2009-2015 is statistically significant ($p < .05$).

Children, Adolescents and Young Adults. Five-year relative survival is 97.6 percent for HL in children, adolescents and young adults younger than 20 years.

In children, adolescents and young adults younger than 20 years, 5-year relative survival for NHL is 90.3 percent. This represents a significant improvement in the rate of survival. As recently as the mid-1970s, most children and adolescents with NHL did not survive 5 years after they were diagnosed (44.6 percent in 1975 to 1977).

Deaths

In 2020, an estimated 20,910 members of the US population are expected to die from lymphoma (970 HL and 19,940 NHL), as shown in Table 9.

Estimated Deaths from Lymphoma, by Gender, 2020			
Type	Total	Male	Female
Hodgkin Lymphoma	970	570	400
Non-Hodgkin Lymphoma	19,940	11,460	8,480
Total	20,910	12,030	8,880

Table 9. Source: *Cancer Facts & Figures 2020*. American Cancer Society; 2020.

Gender. NHL is the eighth most common cause of cancer death in males and females in the US. Death rates for HL are much lower than those for NHL for both males and females.

- Males – 0.4 per 100,000 for HL; 7.3 per 100,000 for NHL
- Females – 0.2 per 100,000 for HL; 4.4 per 100,000 for NHL.

Race and Ethnicity. For NHL, the highest age-adjusted rates of death from 2012 to 2016 were in non-Hispanic whites at 5.9 per 100,000 population, followed by Hispanic whites at 5.1 per 100,000 population and blacks at 4.1 per 100,000 population.

Children, Adolescents and Young Adults. For children, adolescents and young adults under 20 years, age-adjusted death rates for HL and NHL per 100,000 population declined from 1975 to 2016.

- For HL, the rate was 0.1 in 1975 vs 0.0* in 2016.
- For NHL, the rate was 0.4 in 1975 vs 0.1 in 2016.

*Statistic is not reported due to fewer than 16 deaths.

Myeloma

Myeloma is a cancer of the plasma cells (a type of white blood cell). Plasma cells are found primarily in the bone marrow. About 90 percent of people with myeloma have disease involving multiple sites at the time of diagnosis (multiple myeloma). 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 in 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.

Prevalence

An estimated 128,969 people in the United States (US) are living with or in remission from myeloma.

With the release of the 1975–2016 Cancer Statistics Review, the calculation of limited-duration prevalence estimates were modified to use data from the SEER 13 areas (not including the Alaska Natives Registry) using cases diagnosed from 1992 through 2015. Prior publications used data from the SEER 9 registries using cases diagnosed from 1975+. SEER 13 provides a larger population base and one which is more representative of the entire US, which allows better projections of US counts. Due to this methodology change, the estimates may differ significantly from those published in previous years.

New Cases

An estimated 32,270 new cases of myeloma (17,530 males and 14,740 females) are expected to be diagnosed in the US in 2020 (see Table 10).

Estimated New Cases of Myeloma, by Gender, 2020

Cancer Type	Total	Male	Female
Myeloma	32,270	17,530	14,740

Table 10. Source: Cancer Facts & Figures 2020. American Cancer Society; 2020.

The median age at diagnosis is 69 years; myeloma is seldom diagnosed in people younger than 40 years.

Incidence

For the years 2012 to 2016, the age-adjusted incidence rate for myeloma was 6.9 per 100,000.

Gender. The age-adjusted incidence rate for the years 2012 to 2016 was 55.4 percent higher in males (8.7 per 100,000 population) than it was in females (5.6 per 100,000 population).

Race and Ethnicity. From 2012 to 2016, myeloma was the ninth most commonly diagnosed cancer among black males and females.

- The median age at diagnosis is 66 years for blacks and 70 years for whites.
- Blacks have more than twice the age-adjusted incidence rate (13.7 per 100,000 population) of myeloma than whites (6.3 per 100,000 population).
- Black males have a higher age-adjusted myeloma incidence rate (16.3 per 100,000) than males or females of any other race or ethnicity.
- The highest incidence rate is found in black males who are ages 80 to 84 (109.8 per 100,000 population).

Age. Figure 13 shows the age-specific incidence rates for myeloma for the years 2012 to 2016.

Age-Specific Incidence Rates for Myeloma, 2012-2016

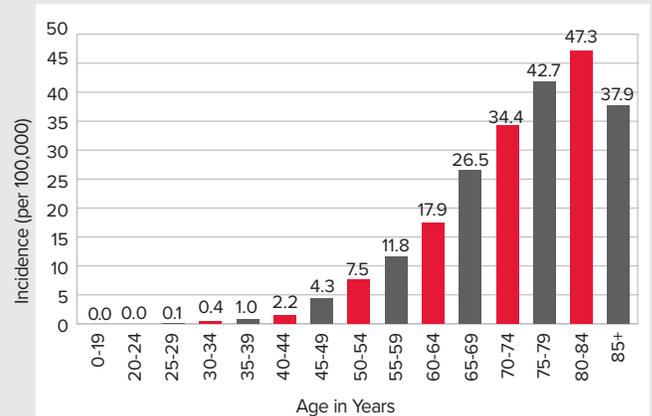


Figure 13. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975–2016, National Cancer Institute; 2019.

Signs and Symptoms

The first symptom of myeloma is often bone pain from the effects that myeloma cells are having 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 tire more easily and feel weak, or they may have no symptoms.

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 a major role. There are presently clinical trials going on to look at possible causes and precursors of myeloma. Contact an LLS Information Specialist at (800) 955.4572 for more information.

Treatment

The goals of treatment for people with myeloma are to reduce symptoms, to slow disease progression and to provide prolonged remission. 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.

Survival

Current statistical databases show that overall 5-year relative survival in people with myeloma has improved significantly since the 1960s. Table 11 shows the 5-year relative survival rates, rounded to the nearest integer, for all races and for blacks and whites, spanning four decades.

- Five-year relative survival increased from 12 percent from 1960 to 1963 (for whites, the only data available) to 53.7 percent from 2009 to 2015 (for all races and ethnicities).
- The 3-year survival rate as of January 1, 2016, was 66.3 percent (for all races and ethnicities).
- The 5-year survival rate is 76.2 percent for people with myeloma who were younger than 45 years at diagnosis.

Gender. From 2009 to 2015, 5-year relative survival was 54.4 percent for males and 52.9 percent for females.

Race and Ethnicity. Five-year survival from 2009 to 2015 is highest for black females (55.4 percent) compared to 54.8 percent for black males, 54.1 percent for white males and 52.0 percent for white females.

Trends in Five-Year Relative Survival Rates for Myeloma, by Race and Year of Diagnosis				
	1975-1977	1984-1986	1996-1998	2009-2015
All Races	25%	27%	33%	54%*
Whites	24%	26%	32%	53%*
Blacks	29%	32%	32%	55%*

Table 11. Source: *SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016*, National Cancer Institute; 2019.
*The difference between 1975-1977 and 2009-2015 is statistically significant ($p < .05$).

Deaths

Approximately 12,830 deaths from myeloma are expected in 2020 (see Table 12).

Estimated Deaths from Myeloma, by Gender, 2020			
Cancer Type	Total	Male	Female
Myeloma	12,830	7,190	5,640

Table 12. Source: *Cancer Facts & Figures 2020*. American Cancer Society; 2020.

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 2012 to 2016.

Myeloma was the seventh leading cause of cancer death for black males and the thirteenth most common cause of cancer death for white males from 2012 to 2016.

Race and Ethnicity. As reported in *Cancer Facts & Figures for African Americans 2019-2021*, the American Cancer Society estimated that approximately 3 percent of all cancer-related deaths among blacks are expected to be caused by myeloma.

- The age-adjusted mortality rate for myeloma from 2012 to 2016 for black males was nearly double the rate for white males (7.4 per 100,000 population vs 4.0 per 100,000 population).
- For black females, the age-adjusted mortality rate from myeloma was more than twice the rate for white females (5.4 per 100,000 population vs 2.4 per 100,000 population).
- The US median age at death from myeloma is 75 years. It is 76 years for whites, 71 years for blacks and 72 years for Hispanics.

Myelodysplastic Syndromes

Myelodysplastic syndromes (MDS) comprise a group of diseases of the blood and marrow, with varying degrees of severity and life expectancy. A myelodysplastic syndrome 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 cell numbers 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 a person with MDS, blasts often constitute more than 5 percent of the cells, and in a person with acute myeloid leukemia (AML), blasts constitute more than 20 percent of the cells 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.

The most common MDS subtypes are

- Refractory anemia with excess blasts, 16.3 percent
- Refractory cytopenia with multilineage dysplasia, 7.9 percent.

People diagnosed with MDS, not otherwise specified (MDS NOS), constitute 61.0 percent of all MDS cases.

Prevalence

The SEER program only recently began maintaining statistics for MDS. Prevalence statistics were not reported by SEER for MDS in 2020 at the time of this publication.

New Cases

For the 5-year period from 2012 to 2016, there were 74,667 new cases of MDS throughout the United States (US), averaging 14,933 cases per year.

Incidence

The overall age-adjusted incidence rate of MDS is 4.5 cases per 100,000 population (see Table 13).

Gender. In the US, for the 5-year period from 2012 to 2016, 43,292 MDS cases were diagnosed in males (averaging 8,658 per year) and 31,375 MDS cases were diagnosed in females (averaging 6,275 per year). The overall age-adjusted incidence rates of MDS by gender are 6.2 per 100,000 in males and 3.3 per 100,000 in females.

Race and Ethnicity. White males have the highest age-adjusted incidence rates (6.5 per 100,000 population), while the lowest occur among American Indian and Alaska Native females (1.9 per 100,000 population).

Myelodysplastic Syndromes Age-Adjusted Incidence Rates, per 100,000 Population, 2012-2016

By Race	Rate
All Races	4.5
White	4.7
Black	3.6
Asian/Pacific Islander	3.0
American Indian/Alaska Native*	2.7
Hispanic**	3.2
By Age	Rate
Ages <40	0.1
Ages 40-49	0.7
Ages 50-59	2.1
Ages 60-69	8.2
Ages 70-79	26.9
Ages 80+	55.4

Table 13. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016. National Cancer Institute; 2019.

*Incidence data for American Indians/Alaska Natives are based on the PRCDA (Purchased/Referred Care Delivery Areas) 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.

Age. The age-adjusted incidence rate for MDS is highest for males ages 80 years and older (83.8 per 100,000) and lowest for both males and females younger than 40 years (0.1 per 100,000).

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

Most people with MDS have “primary MDS,” for which there is usually 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 benzene exposure in the US population 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. Secondary MDS is caused by previous cancer treatments, such as chemotherapy or radiation.

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 (either used alone or in combination) include a watch-and-wait strategy; transfusion; administration of blood cell growth factors; drug therapy with newer agents; or chemotherapy used to treat AML.

Survival

Because the SEER program only recently began maintaining statistics for MDS, survival statistics were not reported in 2020 at the time of this publication.

Deaths

Because the SEER program only recently began maintaining statistics for MDS, mortality statistics were not reported in 2020 at the time of this publication.

Myeloproliferative Neoplasms

Myeloproliferative neoplasms (MPNs) make up a group of blood cancers characterized by the overproduction of one or more types of blood cells—red blood cells, white blood cells and/or platelets. MPNs usually develop slowly over time, and different MPNs affect different blood cells.

There are several types of MPNs. The following three classic types are traditionally grouped together because of their overlapping features:

- Essential thrombocythemia (ET), which accounted for 45.5 percent of MPNs from 2012 to 2016
- Polycythemia vera (PV), which accounted for 41.5 percent of MPNs from 2012 to 2016
- Myelofibrosis (MF), which accounted for 11.7 percent of MPNs from 2012 to 2016.

Prevalence

The SEER program only recently began maintaining statistics for MPNs. Prevalence statistics were not reported by SEER for MPNs in 2020 at the time of this publication.

New Cases

For the 5-year period from 2012 to 2016, there were 57,151 new cases of MPNs throughout the United States (US), averaging 11,430 cases per year.

Incidence

The overall age-adjusted incidence rate of MPNs is 3.1 cases per 100,000 population (see Table 14).

Gender. In the US, for the 5-year period from 2012 to 2016, 27,882 MPN cases were diagnosed in males (averaging 5,576 per year) and 29,269 MPN cases were diagnosed in females (averaging 5,854 per year). The overall age-adjusted incidence rates of MPNs by gender are 3.3 per 100,000 in males and 3.0 per 100,000 in females.

Race and Ethnicity. White males have the highest age-adjusted incidence rates of MPNs (3.4 per 100,000 population), while the lowest occur among American Indian and Alaska Native females (1.6 per 100,000 population).

Age. The age-adjusted incidence rate for MPNs is highest for males ages 80 years and older (19.2 per 100,000) and lowest for both males and females younger than 40 years (0.5 per 100,000).

Myeloproliferative Neoplasms Age-Adjusted Incidence Rates, per 100,000 Population, 2012-2016

By Race	Rate
All Races	3.1
White	3.2
Black	2.8
Asian/Pacific Islander	1.9
American Indian/Alaska Native*	1.7
Hispanic**	2.0
By Age	Rate
Ages <40	0.5
Ages 40-49	2.3
Ages 50-59	4.1
Ages 60-69	8.3
Ages 70-79	14.3
Ages 80+	18.6

Table 14. Source: *SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016*. National Cancer Institute; 2019.

*Incidence data for American Indians/Alaska Natives are based on the PRCD (Purchased/Referred Care Delivery Areas) 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

Many people with MPNs experience few or no signs or symptoms for extended periods of time with proper monitoring and treatment. Each type of MPN may show different signs and symptoms.

Essential thrombocythemia (ET) is often detected during a routine blood test before an individual has any signs or symptoms. One of the first indications of ET may be the development of a blood clot (thrombus). In a small subset of patients, ET may cause bleeding in individuals with an extremely high platelet count.

Polycythemia vera (PV) develops slowly, and it may not cause signs or symptoms for many years. The condition is often diagnosed during a routine blood test, before severe symptoms occur.

Myelofibrosis (MF) usually develops slowly. Often, MF does not cause early signs or symptoms and it may be found during a routine blood test. However, as disruption of normal blood cell production increases, people may experience symptoms such as fatigue, weakness, shortness of breath or pale skin.

Possible Causes

MPNs are considered “clonal disorders.” Clonal disorders begin with one or more changes to the DNA of a single stem cell in the bone marrow.

In most cases, the cause of the change to the stem cell is unknown. Mutations may be caused by environmental factors or by an error during cell division. While family clusters of ET, PV and MF have been reported, these are generally not inherited diseases. They arise from gene mutations that occur during a person’s lifetime.

Researchers believe that proteins known as “Janus kinases” (JAKs) are involved. JAKs send signals that affect the production of blood cells in the bone marrow. These proteins help control the numbers of red blood cells, white blood cells and platelets. When JAKs send too many signals, they cause the bone marrow to make too many blood cells. This chain of events is referred to as “overactive JAK signaling.” JAK signaling may become overactive in many ways. One way is a mutation of the *JAK2* gene.

Approximately 95 percent of PV patients have a mutation of the *JAK2* gene. Mutations in genes of hematopoietic stem cells are thought to be responsible for the overactive JAK signaling that causes MF. The mutations may be in the genes that make JAKs, or the mutations may be in genes that affect how JAKs work. Most patients with MF have either a mutation of the *JAK2*, *MPL* or *CALR* gene.

Most cases of ET are associated with one or more acquired genetic mutations to a hematopoietic stem cell that results in the overproduction of megakaryocytes, the precursor cells of platelets in the bone marrow. Most patients with ET have a mutation of the *JAK2*, *MPL* or *CALR* gene.

Treatment

Treatment for MPNs can vary based on specific diagnosis. Patients have symptoms and circumstances that require different treatments. There is no single treatment that is effective for all patients. Treatment for patients may include low-dose aspirin, therapeutic phlebotomy, drug therapy or allogeneic stem cell transplantation. The doctor will monitor the patient closely through regular examinations, watching for any signs of disease progression. All patients, however, need to be closely monitored.

Survival

Because the SEER program only recently began maintaining statistics for MPNs, survival statistics were not reported in 2020 at the time of this publication.

Deaths

Because the SEER program only recently began maintaining statistics for MPNs, mortality statistics were not reported in 2020 at the time of this publication.

Incidence Rates

Leukemia, Lymphoma, Myeloma, Myelodysplastic Syndromes and Myeloproliferative Neoplasms

Tables 15, 16 and 17 show incidence rates for leukemia, non-Hodgkin lymphoma, Hodgkin lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative neoplasms using data figures from 2012 to 2016 (the most recent data available). Rates are per 100,000 population and are age-adjusted to the 2000 US standard population.

Age-Adjusted Incidence Rates, by Gender, All Races, per 100,000 Population, 2012-2016

Type	Total	Male	Female
Leukemia	14.1	18.1	10.9
Non-Hodgkin Lymphoma	19.6	23.9	16.2
Hodgkin Lymphoma	2.7	3.0	2.3
Myeloma	6.9	8.7	5.6
Myelodysplastic Syndromes	4.5	6.2	3.3
Myeloproliferative Neoplasms	3.1	3.3	3.0

Table 15. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016, National Cancer Institute; 2019.

Age-Adjusted Incidence Rates, by Gender, for Blacks, per 100,000 Population, 2012-2016

Type	Total	Male	Female
Leukemia	10.9	13.9	8.9
Non-Hodgkin Lymphoma	14.7	17.7	12.4
Hodgkin Lymphoma	2.7	3.1	2.3
Myeloma	13.7	16.3	11.9
Myelodysplastic Syndromes	3.6	4.7	2.9
Myeloproliferative Neoplasms	2.8	3.0	2.7

Table 16. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016, National Cancer Institute; 2019.

Age-Adjusted Incidence Rates, by Gender, for Whites, per 100,000 Population, 2012-2016

Type	Total	Male	Female
Leukemia	14.9	19.1	11.5
Non-Hodgkin Lymphoma	20.6	25.0	17.0
Hodgkin Lymphoma	2.8	3.1	2.5
Myeloma	6.3	8.1	4.9
Myelodysplastic Syndromes	4.7	6.5	3.4
Myeloproliferative Neoplasms	3.2	3.4	3.1

Table 17. Source: SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review, 1975-2016, National Cancer Institute; 2019.

Estimated New Cases and Estimated Deaths, by State

Estimated New Cases of Blood Cancers, by State, 2020

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	810	1,000	500	110
Alaska	90	120	*	*
Arizona	990	1,500	570	150
Arkansas	630	650	300	80
California	6,060	8,200	2,890	890
Colorado	910	1,150	470	150
Connecticut	400	930	310	110
Delaware	230	260	130	*
Dist. of Columbia	110	130	80	*
Florida	3,370	7,170	3,090	630
Georgia	1,550	2,280	1,100	270
Hawaii	230	290	110	*
Idaho	340	390	150	*
Illinois	2,400	2,920	1,240	340
Indiana	1,290	1,590	640	170
Iowa	840	800	320	80
Kansas	620	650	280	70
Kentucky	920	1,040	430	110
Louisiana	930	1,110	520	120
Maine	160	390	120	*
Maryland	820	1,330	690	160
Massachusetts	580	1,670	450	200
Michigan	2,060	2,450	1,060	260
Minnesota	1,600	1,350	590	160
Mississippi	500	570	330	60
Missouri	1,370	1,410	600	160
Montana	250	250	100	*
Nebraska	480	450	180	50
Nevada	520	650	230	60
New Hampshire	180	370	100	*
New Jersey	2,100	2,340	1,000	270
New Mexico	340	410	170	50
New York	4,600	5,120	2,290	610
North Carolina	1,640	2,480	1,280	260
North Dakota	190	170	70	*
Ohio	2,280	2,820	1,160	310
Oklahoma	860	860	360	90
Oregon	740	1,000	320	110
Pennsylvania	3,050	3,480	1,350	390
Rhode Island	100	270	90	*
South Carolina	1,220	1,300	720	140
South Dakota	230	200	90	*
Tennessee	1,280	1,580	680	150
Texas	5,260	5,650	2,480	690
Utah	500	550	200	70
Vermont	90	170	60	*
Virginia	1,370	1,940	880	220
Washington	1,430	1,740	620	180
West Virginia	480	500	200	50
Wisconsin	1,420	1,460	580	160
Wyoming	110	120	50	*
United States	60,530	77,240	32,270	8,480

Table 18. *Estimate is fewer than 50 cases
Estimates are rounded to the nearest 10. State estimates may not sum to US total due to rounding and exclusion of state.

Source: American Cancer Society.

(Note: The projected numbers of new cancer cases and deaths in 2020 should not be compared with previous years to track cancer trends because they are model-based and vary from year to year for reasons other than changes in cancer occurrence. Age-standardized incidence and death rates should be used to measure cancer trends.)

Estimated Deaths from Blood Cancers, by State, 2020

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	370	290	210	*
Alaska	*	*	*	*
Arizona	520	410	260	*
Arkansas	240	190	120	*
California	2,400	2,140	1,290	120
Colorado	330	260	190	*
Connecticut	260	230	130	*
Delaware	90	80	60	*
Dist. of Columbia	*	*	*	*
Florida	1,800	1,500	940	70
Georgia	600	530	420	*
Hawaii	90	90	50	*
Idaho	110	120	70	*
Illinois	900	750	470	*
Indiana	510	450	270	*
Iowa	250	240	150	*
Kansas	240	180	120	*
Kentucky	370	330	170	*
Louisiana	320	280	190	*
Maine	120	110	70	*
Maryland	410	340	290	*
Massachusetts	480	390	260	*
Michigan	770	720	480	*
Minnesota	430	390	210	*
Mississippi	220	160	150	*
Missouri	480	390	250	*
Montana	70	70	*	*
Nebraska	150	120	80	*
Nevada	200	170	100	*
New Hampshire	110	90	50	*
New Jersey	620	560	340	*
New Mexico	120	120	70	*
New York	1,370	1,230	760	60
North Carolina	710	610	470	*
North Dakota	60	50	*	*
Ohio	930	850	530	*
Oklahoma	330	270	160	*
Oregon	310	270	170	*
Pennsylvania	1,070	950	580	*
Rhode Island	80	70	*	*
South Carolina	390	320	270	*
South Dakota	70	60	*	*
Tennessee	530	460	300	*
Texas	1,620	1,350	890	80
Utah	170	130	90	*
Vermont	50	50	*	*
Virginia	540	490	330	*
Washington	490	450	260	*
West Virginia	180	150	90	*
Wisconsin	470	400	240	*
Wyoming	50	*	*	*
United States	23,100	19,940	12,830	970

Table 19. *Estimate is fewer than 50 deaths
Estimates are rounded to the nearest 10. State estimates may not sum to US total due to rounding and exclusion of state.

Source: American Cancer Society.

(Note: The projected numbers of new cancer cases and deaths in 2020 should not be compared with previous years to track cancer trends because they are model-based and vary from year to year for reasons other than changes in cancer occurrence. Age-standardized incidence and death rates should be used to measure cancer trends.)

Five-Year Incidence and Mortality Cases, by State

Five-Year Blood Cancer Incidence Cases, by State, 2012-2016

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	3,392	4,595	2,045	557
Alaska	358	568	153	61
Arizona	4,251	6,025	2,039	758
Arkansas	2,405	3,144	1,220	418
California	24,914	37,162	11,989	4,355
Colorado	3,684	4,755	1,720	646
Connecticut	3,078	4,627	1,611	609
Delaware	790	1,195	452	137
Dist. of Columbia	270	504	275	99
Florida	22,865	30,178	10,460	3,155
Georgia	7,282	9,349	4,412	1,276
Hawaii	890	1,422	479	115
Idaho	1,416	1,711	573	199
Illinois	9,441	13,877	4,763	1,791
Indiana	5,006	6,962	2,535	886
Iowa	3,090	3,967	1,319	489
Kansas	2,471	3,276	1,110	345
Kentucky	3,994	5,208	1,805	578
Louisiana	3,520	4,908	2,091	627
Maine	1,305	1,838	572	222
Maryland	4,120	5,772	2,475	806
Massachusetts	4,353	7,198	2,362	962
Michigan	7,971	11,668	4,106	1,379
Minnesota	5,111	6,659	2,133	801
Mississippi	1,985	2,790	1,281	362
Missouri	4,911	6,726	2,390	870
Montana	988	1,219	448	140
Nebraska	1,492	2,077	666	275
Nevada	1,812	2,340	729	248
New Hampshire	1,139	1,750	519	201
New Jersey	7,875	11,156	3,846	1,453
New Mexico	1,543	1,878	678	264
New York	18,622	24,541	9,516	3,295
North Carolina	7,887	9,891	4,395	1,278
North Dakota	644	769	267	111
Ohio	8,276	13,213	4,294	1,619
Oklahoma	3,072	3,920	1,437	484
Oregon	2,955	4,458	1,275	471
Pennsylvania	11,747	17,210	5,663	2,142
Rhode Island	922	1,369	383	169
South Carolina	3,758	4,789	2,444	641
South Dakota	772	943	326	116
Tennessee	5,018	6,671	2,533	868
Texas	17,814	22,465	9,125	3,159
Utah	1,797	2,291	757	347
Vermont	480	837	237	93
Virginia	4,927	7,786	2,933	980
Washington	5,698	7,773	2,483	916
West Virginia	1,682	2,310	750	224
Wisconsin	5,775	7,139	2,464	897
Wyoming	432	542	181	61
United States	250,000	345,421	124,719	42,955

Table 20. Reported in NAACCR's Cancer in North America: 2012-2016: Volume Two: Registry-specific Cancer Incidence in the United States and Canada.

Five-Year Blood Cancer Mortality Cases, by State, 2012-2016

State	Leukemia	Non-Hodgkin Lymphoma	Myeloma	Hodgkin Lymphoma
Alabama	1,913	1,539	1,050	92
Alaska	162	144	89	^
Arizona	2,443	2,013	1,151	112
Arkansas	1,241	979	587	57
California	12,156	10,601	6,058	676
Colorado	1,589	1,275	828	75
Connecticut	1,394	1,222	707	55
Delaware	378	361	222	19
Dist. of Columbia	159	137	113	11
Florida	8,750	7,582	4,286	363
Georgia	2,937	2,569	1,841	154
Hawaii	399	433	228	18
Idaho	566	552	304	25
Illinois	4,869	4,073	2,362	205
Indiana	2,611	2,361	1,284	114
Iowa	1,353	1,259	676	46
Kansas	1,221	980	615	44
Kentucky	1,837	1,613	852	65
Louisiana	1,653	1,493	934	92
Maine	588	564	290	22
Maryland	2,039	1,709	1,305	94
Massachusetts	2,500	2,128	1,293	93
Michigan	4,018	3,846	2,185	182
Minnesota	2,151	1,920	1,057	97
Mississippi	1,115	867	660	57
Missouri	2,545	1,969	1,270	112
Montana	390	359	209	16
Nebraska	776	617	366	24
Nevada	936	755	427	38
New Hampshire	520	460	242	30
New Jersey	3,227	2,865	1,682	139
New Mexico	663	593	346	48
New York	7,151	6,214	3,600	344
North Carolina	3,471	3,009	2,139	145
North Dakota	279	248	153	11
Ohio	4,826	4,348	2,547	213
Oklahoma	1,689	1,360	720	72
Oregon	1,489	1,469	841	74
Pennsylvania	5,665	5,123	2,801	242
Rhode Island	434	368	178	15
South Carolina	1,886	1,505	1,216	85
South Dakota	374	283	184	11
Tennessee	2,589	2,332	1,435	132
Texas	7,812	6,660	3,885	448
Utah	797	626	399	34
Vermont	255	241	138	12
Virginia	2,688	2,418	1,537	123
Washington	2,423	2,279	1,230	113
West Virginia	906	771	437	36
Wisconsin	2,493	2,037	1,177	117
Wyoming	230	181	95	^
United States	116,556	101,310	60,231	5,417

Table 21. Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1969-2016) <Katrina/Rita Population Adjustment>, National Cancer Institute, DCCPS, Surveillance Research Program, released December 2018. Underlying mortality data provided by NCHS (www.cdc.gov/nchs). Underlying mortality data provided by NCHS (www.cdc.gov/nchs). ^ Statistic not displayed due to fewer than 10 cases.

Five-Year Leukemia Incidence and Mortality Cases, by State

Five-Year Leukemia Incidence Cases, by State, 2012-2016

State	Leukemia	Acute Lymphoblastic Leukemia	Chronic Lymphocytic Leukemia	Acute Myeloid Leukemia	Chronic Myeloid Leukemia
Alabama	3,392	317	1,116	1,049	430
Alaska	358	43	92	113	55
Arizona	4,251	578	1,080	1,473	532
Arkansas	2,405	217	903	719	306
California	24,914	3,859	7,511	7,874	3,136
Colorado	3,684	372	1,253	1,106	451
Connecticut	3,078	246	1,213	899	395
Delaware	790	86	275	237	97
Dist. of Columbia	270	42	70	84	35
Florida	22,865	1,788	8,234	6,178	3,088
Georgia	7,282	653	2,628	2,141	1,049
Hawaii	890	108	188	345	153
Idaho	1,416	143	561	354	204
Illinois	9,441	1,041	2,950	3,220	1,188
Indiana	5,006	504	1,626	1,709	695
Iowa	3,090	245	1,218	962	371
Kansas	2,471	222	968	692	340
Kentucky	3,994	324	1,494	1,190	589
Louisiana	3,520	309	1,271	1,068	519
Maine	1,305	104	572	361	146
Maryland	4,120	404	1,363	1,356	519
Massachusetts	4,353	429	1,437	1,406	555
Michigan	7,971	723	2,791	2,575	1,104
Minnesota	5,111	409	2,062	1,439	668
Mississippi	1,985	210	654	639	289
Missouri	4,911	425	1,660	1,556	604
Montana	988	61	453	245	119
Nebraska	1,492	153	503	497	178
Nevada	1,812	208	583	548	211
New Hampshire	1,139	87	431	321	151
New Jersey	7,875	740	3,056	2,197	989
New Mexico	1,543	187	533	440	218
New York	18,622	1,563	7,624	5,174	2,353
North Carolina	7,887	739	2,961	2,281	1,105
North Dakota	644	46	282	169	89
Ohio	8,276	842	2,556	2,722	1,042
Oklahoma	3,072	308	1,096	903	410
Oregon	2,955	321	1,039	963	320
Pennsylvania	11,747	1,029	4,317	3,627	1,506
Rhode Island	922	64	351	250	128
South Carolina	3,758	344	1,282	1,173	552
South Dakota	772	60	283	229	121
Tennessee	5,018	472	1,784	1,509	690
Texas	17,814	2,446	5,827	4,596	2,474
Utah	1,797	239	625	504	230
Vermont	480	44	167	167	59
Virginia	4,927	509	1,451	1,666	649
Washington	5,698	595	2,241	1,637	717
West Virginia	1,682	108	624	526	235
Wisconsin	5,775	431	2,323	1,584	864
Wyoming	432	48	154	130	54
United States	250,000	25,445	87,736	74,803	32,982

Table 22. Reported in NAACCR's Cancer in North America: 2012-2016, Volume Two: Registry-specific Cancer Incidence in the United States and Canada. All Races, Males and Females.

Five-Year Leukemia Mortality Cases, by State, 2012-2016

State	Leukemia	Acute Lymphoblastic Leukemia	Chronic Lymphocytic Leukemia	Acute Myeloid Leukemia	Chronic Myeloid Leukemia
Alabama	1,913	89	298	705	74
Alaska	162	10	19	89	^
Arizona	2,443	202	469	1036	111
Arkansas	1,241	50	212	476	59
California	12,156	1,214	2,152	5,361	569
Colorado	1,589	103	333	715	66
Connecticut	1,394	73	277	600	76
Delaware	378	18	79	174	21
Dist. of Columbia	159	12	33	61	^
Florida	8,750	543	1,524	3,666	449
Georgia	2,937	195	469	1128	136
Hawaii	399	18	45	201	19
Idaho	566	41	115	241	26
Illinois	4,869	273	906	2,002	196
Indiana	2,611	124	512	1,212	120
Iowa	1,353	75	320	605	61
Kansas	1,221	60	284	494	54
Kentucky	1,837	110	382	767	73
Louisiana	1,653	82	259	594	83
Maine	588	22	136	265	26
Maryland	2,039	91	381	844	89
Massachusetts	2,500	139	517	1,077	90
Michigan	4,018	232	814	1,680	183
Minnesota	2,151	109	517	986	93
Mississippi	1,115	61	181	359	42
Missouri	2,545	139	526	1,114	105
Montana	390	24	92	154	19
Nebraska	776	43	189	346	34
Nevada	936	75	139	405	34
New Hampshire	520	22	117	220	25
New Jersey	3,227	170	596	1,276	113
New Mexico	663	44	119	299	20
New York	7,151	435	1,348	3,306	297
North Carolina	3,471	184	716	1,525	189
North Dakota	279	14	57	140	^
Ohio	4,826	257	941	2,069	233
Oklahoma	1,689	112	310	642	74
Oregon	1,489	87	316	668	66
Pennsylvania	5,665	286	1,152	2,333	226
Rhode Island	434	25	95	170	23
South Carolina	1,886	100	330	805	103
South Dakota	374	22	85	152	19
Tennessee	2,589	133	502	1,116	145
Texas	7,812	674	1,273	3,123	401
Utah	797	55	167	291	41
Vermont	255	11	52	134	13
Virginia	2,688	141	537	1,116	107
Washington	2,423	170	515	1,243	96
West Virginia	906	37	207	351	46
Wisconsin	2,493	128	490	1,107	117
Wyoming	230	12	42	96	^
United States	116,556	7,346	22,147	49,539	5,297

Table 23. Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1969-2016) <Katrina/Rita Population Adjustment>, National Cancer Institute, DCCPS, Surveillance Research Program, released December 2018. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

^ Statistic not displayed due to fewer than 10 cases.

Notes and Definitions

The data within *Facts 2019-2020* reflect the most recent statistics from The National Cancer Institute's *Surveillance, Epidemiology, and End Results (SEER) Program, Cancer Statistics Review (CSR) 1975-2016*. The CSR reports cancer incidence, mortality, survival, prevalence and lifetime risk statistics. Incidence, prevalence and survival data were released online by SEER, www.seer.cancer.gov, on April 15, 2019. The next SEER Cancer Statistics Review is expected to be published online in the spring of 2020.

Incidence and mortality rates measure exactly what occurred, and cover the entire period through the most recent year reported, 2016. However, in order to calculate survival rates, the most current year of data is not considered, because not enough time has passed for it to be included.

The SEER Program's CSR presents statistics by age, sex, race and ethnicity. 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.

Data on Hispanic ethnicity are not shown for statistics/years for which they are not available. The Hispanic ethnicity categorization is not mutually exclusive with race, so in instances where comparisons are made using ethnicity, the groupings Hispanic whites and non-Hispanic whites are used to enable meaningful comparisons.

Mortality data reflected in the 2019 referenced SEER report reflect data from the National Cancer for Health Statistics (NCHS) from 1969 to 2016, and were made available in 2019.

When reporting statistics using the SEER data, different populations are used depending on the statistic type. The SEER 21 regions, used for recent incidence rates, cover about 36.7 percent of the US population. Survival data is not available for all of the SEER 21 areas, so the SEER 18 areas (about 27.8 percent of the US population) are used for recent survival statistics. Data is not available for either the SEER 21 or SEER 18 regions before 2000, so long-term incidence and survival trends must rely on a smaller subset of the data, most often SEER 9, which covers only about 9.4 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, or region-specific health risks.

With the release of the 1975-2016 Cancer Statistics Review, the calculation of limited-duration prevalence estimates were modified to use data from the SEER 13 areas (not including the Alaska Natives Registry) using cases diagnosed from 1992 through 2015. Prior publications used data from the SEER 9 registries using cases diagnosed from 1975+. SEER 13 provides

a larger population base and one which is more representative of the entire US, which allows better projections of US counts. Due to this methodology change, the estimates may differ significantly from those published in previous years.

Data on American Indians and Alaska Natives (AIs/ANs) should be interpreted with care because the data reflect statistics from purchased/referred care delivery areas only. A purchased/referred care delivery area (PRCDA) is a geographic area within which purchased/referred care is made available by the Indian Health Service (IHS) to members of an identified Indian community who reside in the area. A PRCDA was formerly a contract health service delivery area (CHSDA). Many AIs/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 data on myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs) were included in the SEER statistics as separate entities beginning in 2007.

State level incidence rates presented in *Facts 2019-2020* are provided by the North American Association of Central Cancer Registries (NAACCR). NAACCR presents the most current 5-year incidence rate for the US and Canada in the annual publication, *Cancer in North America*.

The American Cancer Society (ACS) projected the number of estimated cancer cases for 2020 using a model based on incidence data from 49 states and the District of Columbia for the years from 1995 to 2016. That incidence data met the NAACCR's high-quality data standard for incidence. This method considers geographic variations in sociodemographic and lifestyle factors, medical settings and cancer screening behaviors as predictors of incidence, and also accounts for expected delays in case reporting. The ACS projected the estimated number of US cancer deaths by fitting the number of cancer deaths from 1995 to 2016 to a statistical model that forecasts the number of deaths expected to occur in 2020. The estimated number of cancer deaths for each state is calculated similarly, using state-level data. For both US and state estimates, data on the number of deaths are obtained from the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC).

In instances where 2020 incidence count estimates are not available from the ACS, actual national incidence counts were obtained using the United States Cancer Statistics (USCS) public use database, which contains cancer incidence for the entire US for 2001 to 2016, sourced from the CDC's National Program for Cancer Registries (NPCR) and SEER. National incidence counts are presented as a yearly average of the 5 most recent years of US incidence available.

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 that are 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 either 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.” This publication is using the “24-year limited duration” prevalence figures, based on the “first invasive tumor for each cancer site diagnosed during the previous 24 years (1992-2015),” as per SEER Table 1.21. The specified date is January 1, 2016, for the prevalence estimates. The prevalence counts in *Facts 2019-2020* 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.)

Remission is when signs of a disease disappear. This usually follows treatment. The words “complete” and “partial” are sometimes used to further define the term “remission.” Complete remission means that all evidence of the disease is gone. Partial remission means that the disease is markedly improved by treatment, but residual evidence of the disease is present.

About The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society has helped millions impacted by cancer since our founding in 1949, funding research to advance breakthroughs and providing lifesaving support and advocacy for patients.

- LLS has invested nearly \$1.3 billion in research since our founding in 1949, leading to breakthroughs in cancer treatment.
- LLS is the leading source of free blood cancer information, education and support, and helps patients navigate their cancer treatment, access quality care and find clinical trials.
- LLS advocates for policy changes to break down the barriers that stand between patients and the care they need.

Research

Since our founding in 1949, LLS has invested nearly \$1.3 billion in research to advance therapies and save lives. We provide funding across the continuum, from basic research through clinical trials—from bench to bedside. LLS research grants have funded many of today’s most promising advances, including targeted therapies and immunotherapies. Our funding supports the training of the next generation of first-rate cancer researchers.

Our **Research Grant programs** support scientific studies at academic centers throughout the world.

- The *Career Development Program (CDP)* provides stipends to investigators of exceptional promise in the early stages of their careers. CDP is stratified into two separately reviewed programs: basic or clinical research.
- The *Translational Research Program (TRP)* supports outstanding investigations likely to translate basic biomedical discoveries into safe and effective treatments. Awards are for an initial three-year period. Renewals to support clinical trials are possible for an additional two years.

- The *Specialized Center of Research Program (SCOR)* encourages multidisciplinary academic investigations by teams of at least three research groups, regardless of their location.
- The *New Idea Award* seeks innovative approaches that can lead to significant improvements in clinical outcomes and changes to standards of care for blood cancer patients.
- The *Screen to Lead Program (SLP)* provides support for medicinal chemistry and/or drug target screening in blood cancers.
- The *Blood Cancer Discoveries Grants Program (BCDG)* supports groundbreaking early-stage research aimed at understanding and advancing the treatment and cure of blood cancers.
- The *Impactful Medicine Providing Access to Clinical Trials (IMPACT)* program supports clinical trial networks that expand access to patients in underserved communities.

LLS creates partnerships with universities and biotechnology and pharmaceutical companies to get treatments to patients faster than ever—especially to patients with unmet medical needs.

Our **Therapy Acceleration Program® (TAP)** speeds the path of potentially better therapies into preclinical development and clinical trials. Working with academic investigators, medical centers, and biotechnology and pharmaceutical companies, TAP is increasing the likelihood that breakthrough treatments will be available to patients sooner. Three TAP programs have led to FDA-approved therapies in 2017-2018.

LLS has foundation partnerships with

- The MPN Research Foundation, to fund innovative grants to better understand and treat the range of myeloproliferative neoplasms (MPN)
- The International Waldenström's Macroglobulinemia (WM) Foundation, to fund research to improve quality of life and to better understand and treat WM and other B-cell malignancies
- The Rising Tide Foundation for Clinical Cancer Research, to fund novel immunotherapy and prevention research linked to clinical trials for all blood cancers
- The Babich Family Foundation/RUNX1 Research Program, to fund translational research seeking to control familial platelet disorder (FPD) leading to acute myeloid leukemia (AML)
- Global T-Cell Lymphoma (TCL) Clinical Trials Network, an international network of community and university centers dedicated to accelerating scientific breakthroughs into effective care for patients with TCL
- The Sarah Cannon Research Institute, to fund an intensive research program in mantle cell lymphoma
- The Snowdome Foundation, to fund translational research on blood cancer in Australia

- The Mark Foundation and The Paul G. Allen Frontiers Group, to fund early-stage discovery research
- Major partnerships with University of Colorado, University of Miami, Weill Cornell Medical School, Emory University and the Fred Hutchinson Cancer Center, to support large, multi-investigator research grants.

Visit www.LLS.org or email researchprograms@LLS.org for information about LLS research grant programs.

Public Policy

LLS recognizes that finding cures is not enough. We must also work diligently to ensure patients have access to treatments that allow them to live healthy, productive lives. The LLS Office of Public Policy (OPP) is dedicated to removing public policy barriers that pose obstacles to treatment. The Office of Public Policy works directly with lawmakers and regulators in Washington, D.C. and state capitals across the country to advance policies that promote patients' access to affordable health insurance coverage and medical care. The Office of Public Policy also promotes policies that ensure new, innovative treatments can reach blood cancer patients safely and without delay.

The department is composed of leaders in government affairs, advocacy and communications. They are proud to work closely with an incredible network of volunteer patient advocates whose lives have been touched by blood cancer. Together, we work to elevate the voices of cancer patients and their families and make their interests heard by all levels of government.

The work of OPP helps to provide **access to better therapies**, faster.

To learn more about OPP's work and how to get involved, visit www.LLS.org/Policy-Advocacy or text SPEAK to 698-66 to join the LLS Mobile Action Network.

Education and Support Services

LLS is the leading source of free blood cancer information, education and support. To help ensure access to the latest treatments and survivorship care, and improve quality of life, staff and volunteers provide assistance and resources to patients, caregivers and healthcare professionals nationally and in communities through our chapters across the US and Canada.

- **Personalized disease and treatment information and support.** Our Information Specialists are master's level oncology professionals who provide free one-on-one assistance to patients, families and healthcare professionals. These Specialists offer personalized guidance for coping with a blood cancer diagnosis, current disease and treatment information, and referral to financial and support resources within LLS and beyond.

Information Specialists can be contacted at (800) 955-4572, Monday through Friday, from 9 am to 9 pm Eastern Time, or by email or live chat at www.LLS.org/InformationSpecialists.

- **Clinical Trial Support Center (CTSC).** When appropriate, patients and caregivers can work one-on-one with an LLS Clinical Trial Nurse Navigator who will conduct a comprehensive clinical trial search and personally assist them throughout the entire clinical trial process. Clinical Trial Nurse Navigators are registered nurses with expertise in blood cancers. To speak with a CTSC nurse navigator at no cost, call an Information Specialist or visit www.LLS.org/CTSC.

- **Nutrition consultations.** LLS offers free one-on-one nutrition consultations to patients and caregivers by phone or email with a registered dietitian who has expertise in oncology nutrition. Visit www.LLS.org/Nutrition.
- **Assistance with financial burdens.** The Leukemia & Lymphoma Society (LLS) offers financial assistance to help individuals with blood cancer.

Our *Co-Pay Assistance Program* has provided over \$528 million to date to help patients pay for co-payments and health insurance premiums. Eligibility for this program is based on fund availability for specific blood cancer diagnoses and financial need criteria. A current list of funds by blood cancer diagnosis is available at www.LLS.org/Copay or at (877) 557-2672.

Our *Susan Lang Pay-it-Forward Patient Travel Assistance Program* provides financial assistance to patients diagnosed with a blood cancer who struggle to pay for treatment-related transportation and/or lodging costs. Eligible patients will receive \$500. Patient assistance is based upon available funding. Visit www.LLS.org/Travel or call (877) 557-2672.

The *Urgent Need Program*, established in partnership with Moppie's Love, helps pediatric and young adult blood cancer patients, or adult blood cancer patients who are enrolled in clinical trials, with acute financial need. The program provides a \$500 grant to assist with non-medical expenses, including utilities, rent, mortgage, food, lodging, dental care, child care, elder care and other essential needs. Visit www.LLS.org/UrgentNeed or call (877) 557-2672.

- **Information booklets.** Free disease, treatment and support booklets in English, Spanish and several other languages are available through our Information Specialists and LLS chapters, and can be downloaded and ordered at www.LLS.org/Booklets.
- **Education programs.** LLS provides free education programs online and in local communities for patients, caregivers and healthcare professionals.

Programs and videos for patients and caregivers feature experts who share the latest disease, treatment and research updates, including information about survivorship.

These programs are available via telephone, Web and in person. Visit www.LLS.org/programs and www.LLS.org/EducationVideos.

LLS also offers free continuing education programs online and in person for nurses, social workers and physicians. Visit www.LLS.org/ProfessionalEd.

- **LLS Health Manager™ App.** This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Visit www.LLS.org/HealthManager to download for free.
- **Podcasts.** Our podcast series for patients and caregivers, *The Bloodline with LLS*, features patients, caregivers, advocates, doctors and other healthcare professionals who discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. For more information and to subscribe, visit www.LLS.org/TheBloodline.

Our podcast series for healthcare professionals (HCPs), *Treating Blood Cancers*, provides up-to-date and accurate information on diagnosis, treatment and survivorship to educate HCPs. For more information and to subscribe, visit www.LLS.org/CE.

- **Connection with other blood cancer survivors.** LLS has created many opportunities for peer-to-peer support. Weekly online chats are moderated by a licensed social worker; the chats give cancer patients and caregivers the opportunity to reach out, share information, and provide support to one another in a structured, online setting. For more information, visit www.LLS.org/Chat.
The *Patti Robinson Kaufmann First Connection Program* gives patients and caregivers the opportunity to talk about their experiences one-on-one with someone who has "been through it," and obtain valuable information about the community resources available to support them. Visit www.LLS.org/FirstConnection.

LLS Community is a one-stop virtual meeting place for talking with other patients and caregivers, receiving the latest blood cancer resources and information, and getting personalized support from trained LLS staff. To join, visit www.LLS.org/Community.

Support groups in local communities provide mutual support and offer the opportunity to discuss anxieties and concerns with others who share the same experiences. To find out if there is a support group near you, visit www.LLS.org/ChapterFind to contact your chapter.

- **Blood Cancer Conferences.** LLS Blood Cancer Conferences are free, in-person and web-based educational events where blood cancer patients, caregivers and their families can learn more about the latest disease-specific breakthroughs, current treatments and survivorship information from local and national experts. Visit www.LLS.org/BCC for a list of these upcoming regional events.

- **Myeloma Link.** *Myeloma Link* is a special program designed to connect African American communities to information, expert myeloma care, treatment and support, as African Americans are at twice the risk for myeloma as whites. This unique community-based program is currently being implemented in select cities around the US. Visit www.LLS.org/MyelomaLink to learn more.

Visit www.LLS.org/PatientSupport for access to up-to-date disease, treatment and support information.

Citations and Acknowledgements

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**BEATING
CANCER
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OUR BLOOD.**

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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.