

SECTION 1

The Data



The Data

In 2019, a team of researchers collaborated on a study that modeled the global burden of childhood cancer in disability adjusted life-years (DALYs).² DALYs are a way to measure the overall burden of disease—not just the deaths and survival rates. They are a way to measure the potential years lost when a person dies in childhood and also to measure the potential years of life impacted by disease. The study’s findings were profound—in the sample year (2017), 11.5 million healthy years were lost to childhood cancer. It is a number too big to fathom—over one hundred centuries of potential gone in just one year.

Yet, by the annual diagnosis numbers, childhood cancer is rare. In any given year, approximately 2 million Americans are diagnosed with cancer³ and less than 15,000 of those diagnosed are children.⁴ Globally, approximately 400,000 children develop cancer each year, but that number is most likely a low estimate—there isn’t a global way of counting childhood cancer diagnoses and many low- to middle-income countries lack a centralized registry.

The disparity between the healthy years of life lost and the total cases of childhood cancer are why tracking and analyzing childhood cancer data is so critical. The numbers tell a story of persistent challenges, continued progress, and the urgent need for more research. This section presents the most current data on incidence, survival, and outcomes for children with cancer, primarily in the United States. It also contains some explanations of how this data is collected—and where more data is needed.

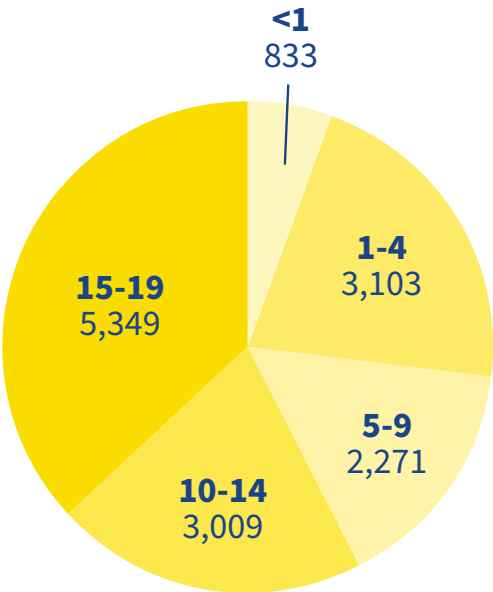
The Burden of Childhood Cancer in the United States

Childhood cancer is a group of diseases in which abnormal cells grow out of control in children and adolescents ages 0-19. It is not just one disease, but dozens of different types. While many tumors are malignant, some tumors in children may be non-malignant but still require oncology treatment. The data in this section shows a holistic overview of childhood cancer. Further ahead, read more about the data around individual disease types (leukemia, neuroblastoma, brain tumors, etc.), as well as the key milestones in research and treatments in Section 2 of this report.

Key Facts:⁵

- Approximately 15,000 children are diagnosed with cancer each year in the United States.
- About 1 in 274 children will be diagnosed with childhood cancer by age 20.
- Childhood cancer is the leading cause of death by disease in the United States.
- While incidence rates of childhood cancer are increasing, less children are dying of cancer.
- There are over 500,000 survivors of childhood cancer in the United States.⁶

Cases of Childhood Cancer in the United States by age, 2023⁷



The average age at diagnosis for childhood cancer is 8 years old. For adult cancers, that age is 67.⁸



Demographics of Childhood Cancer

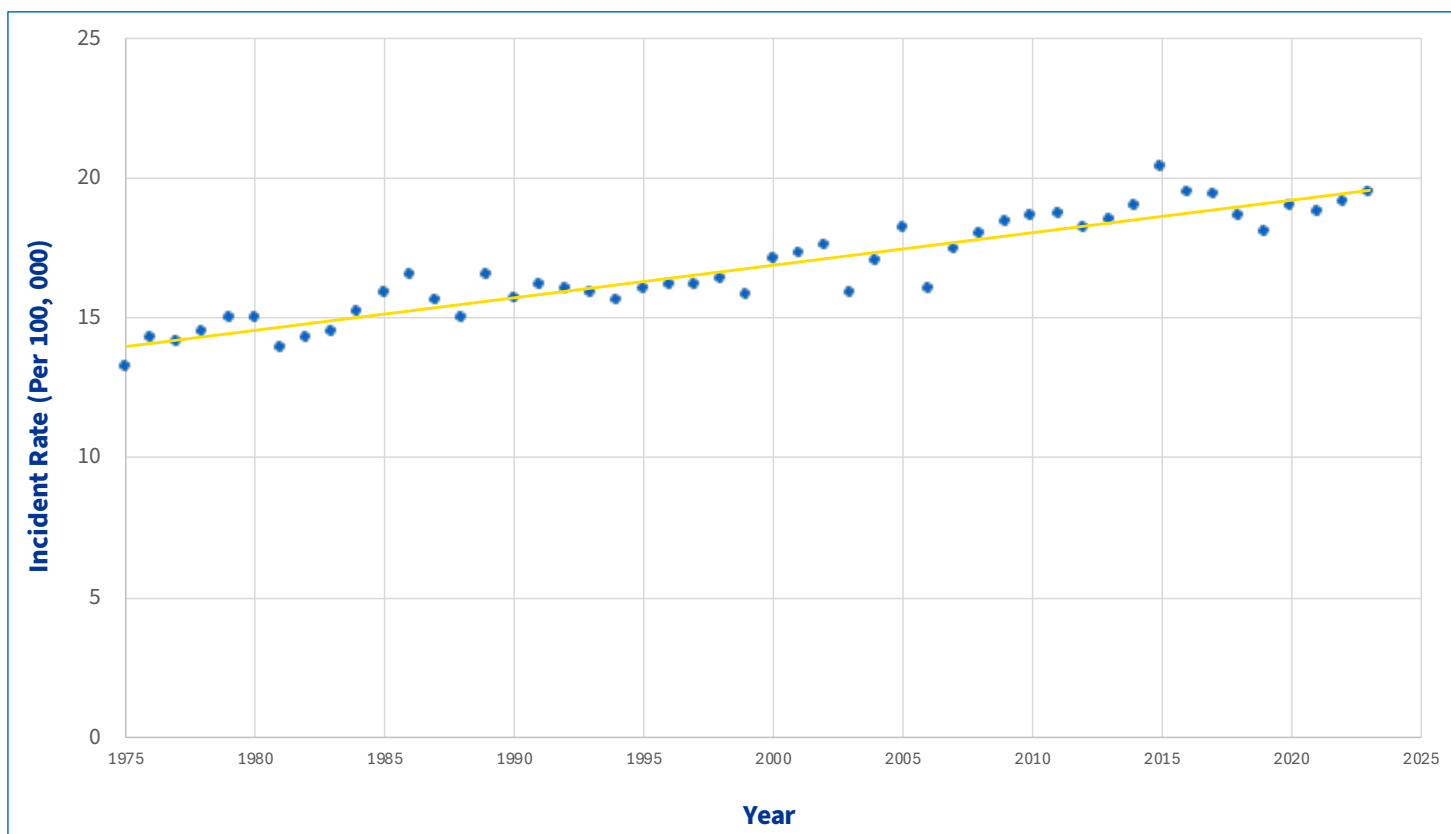
Childhood cancer registrars who maintain and review reported cases of childhood cancer track more than just the diagnosis. They track age, ethnicity, geographic location, and first primary treatment. This data gives valuable insights to oncology researchers as they try to understand the complexities of cancer, and also to researchers who are tracking treatment disparities, cancer clusters (areas with an increased number of cases), and other demographic indicators. For a more in-depth discussion on the demographics of childhood cancer, see Section 3.

Age-Adjusted Incidence Rates⁹

Age-adjusted incidence rates help us understand the risk of cancer in a population by taking age differences into account. For example, a location with more children might appear to have higher rates of childhood cancer because there are more kids, not necessarily because the disease is more common there.

By adjusting for age, experts can make more accurate comparisons between different places or time periods and see whether the actual risk of cancer is truly going up or staying the same.

Age-Adjusted Incidence Rates 1975-2023, United States



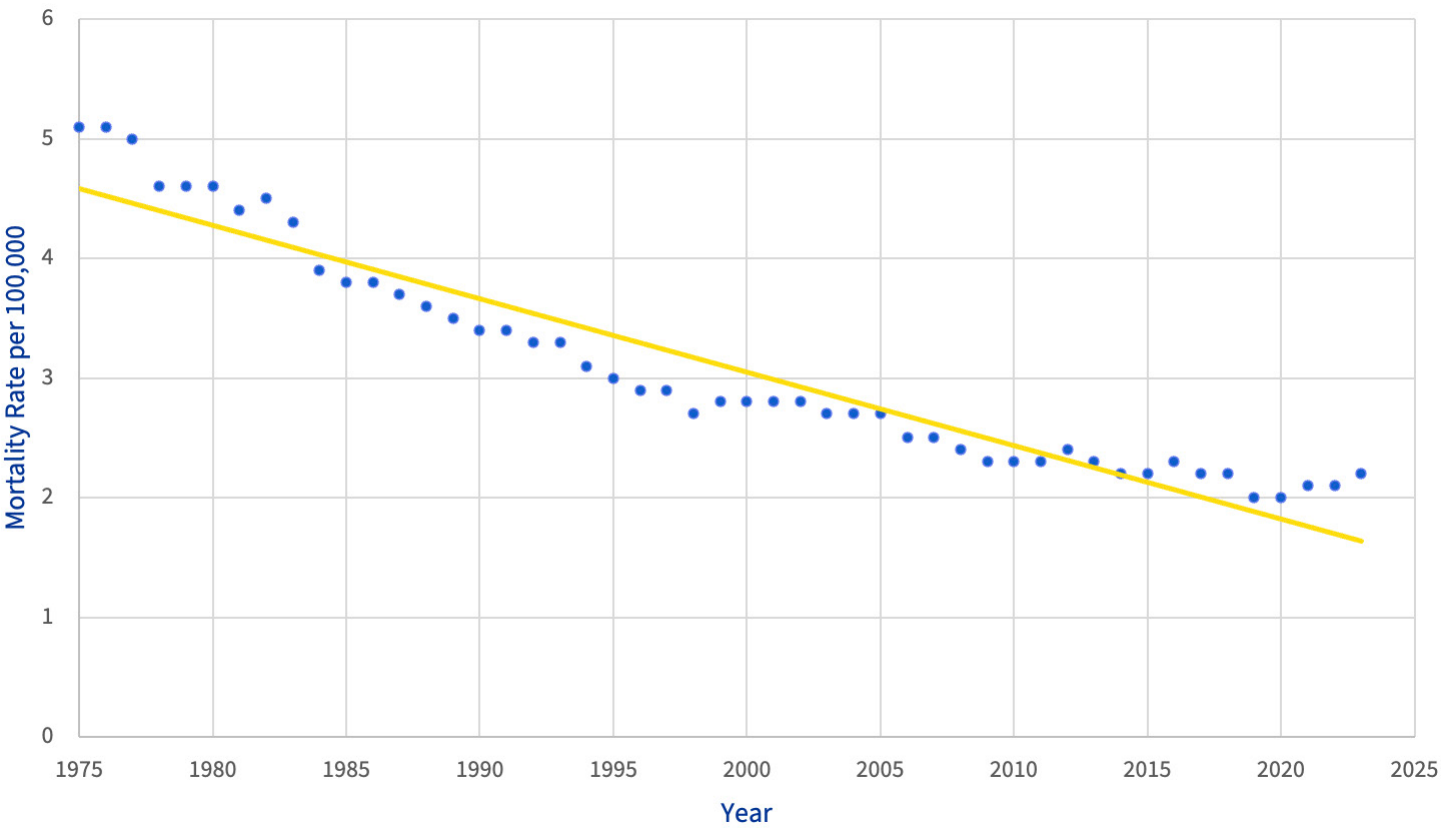
Incident rates have been increasing since 1975. Jump ahead to Incidence and Causation (page 10) for more information.

Mortality Rates

The graph below shows the decline in mortality rates since 1975, thanks to better treatments. In 2024, the most recent year for which mortality data is available, 1,801 children died from cancer.¹⁰

In the United States, mortality rates are tracked by the National Vital Statistics System, which captures information about every death from all cause from every county in the United States. Mortality data is shared with SEER and reviewed on a different cycle than the incidence data, which is reviewed and collated by cancer registrars. As a result, the timeline for reporting varies due to different agencies managing the data.

Mortality Rates 1975-2024, United States¹¹



Cancer mortality rates, which had been steadily declining for decades, showed a slight increase around 2020–2021 for both children and adults. While no single cause has been definitively established, researchers largely attribute this shift to the direct and indirect effects of the COVID-19 pandemic. These included disruptions to healthcare services, delays in cancer screening and diagnosis, interruptions in treatment, and increased vulnerability among patients with cancer. Together, these factors may have contributed to worse outcomes during this period.¹²

Childhood Cancer: A Group of Diseases

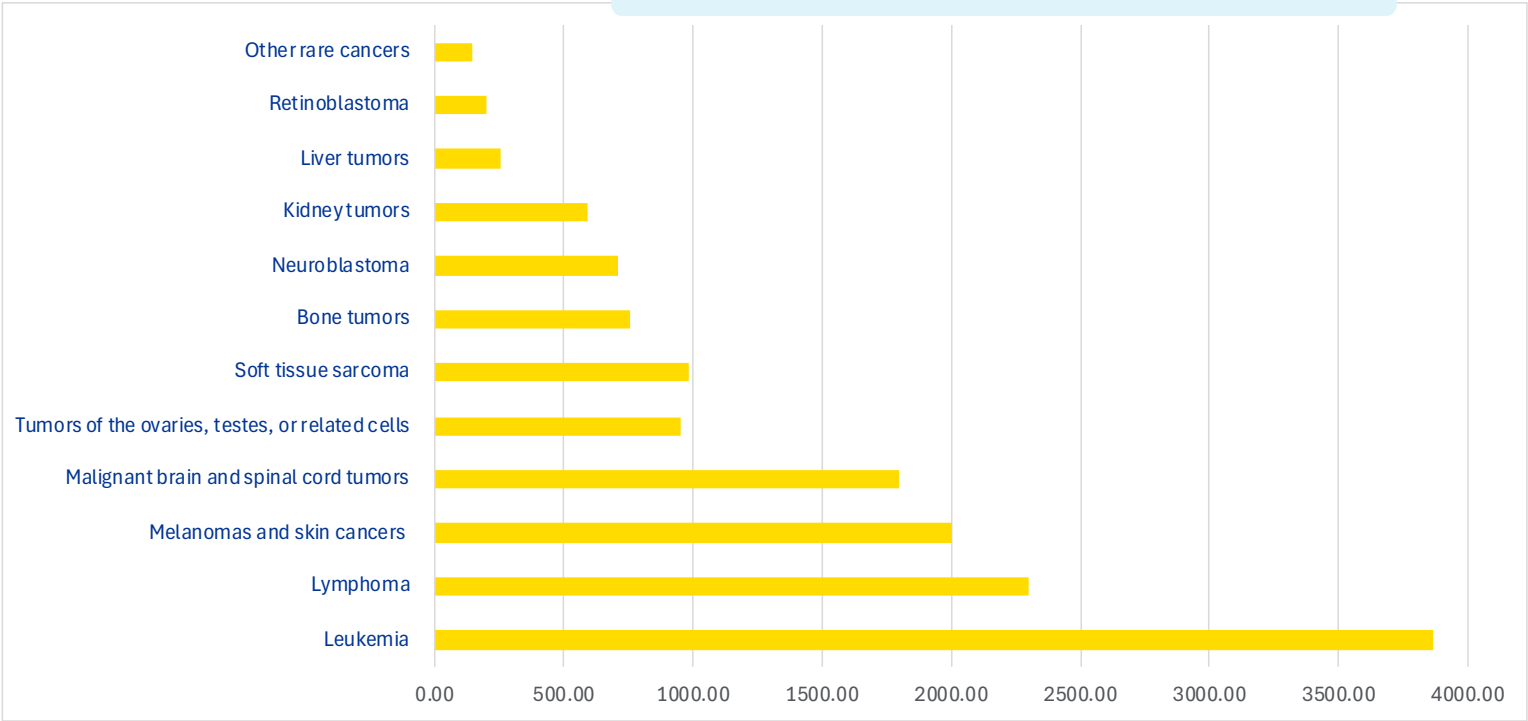
“Childhood cancer” is an umbrella term for many different types of malignancies—diseases in which abnormal cells grow uncontrollably and can spread throughout the body of a child or teen between the ages of 0 and 19. Like normal cells that carry out specific tasks, such as making blood or building bone, cancer cells are also specialized. They have unique biological and genetic features that drive how they grow and behave.

Childhood cancers can arise anywhere in the body:

- **Leukemia** and **Lymphoma** start in the blood and immune system.
- **Sarcoma** develops in bones and soft connective tissues.
- **Brain and spinal cord tumors** can be malignant or benign, but their location in the central nervous system makes them equally serious.
- **Retinoblastoma** attacks the eye, usually in very young children, threatening both sight and life.
- **Neuroblastoma** arises from immature nerve cells, often in the adrenal glands but sometimes in the neck, chest, or spine.
- **Hepatoblastoma** is a childhood liver cancer, and **Wilms tumor** is a kidney cancer.

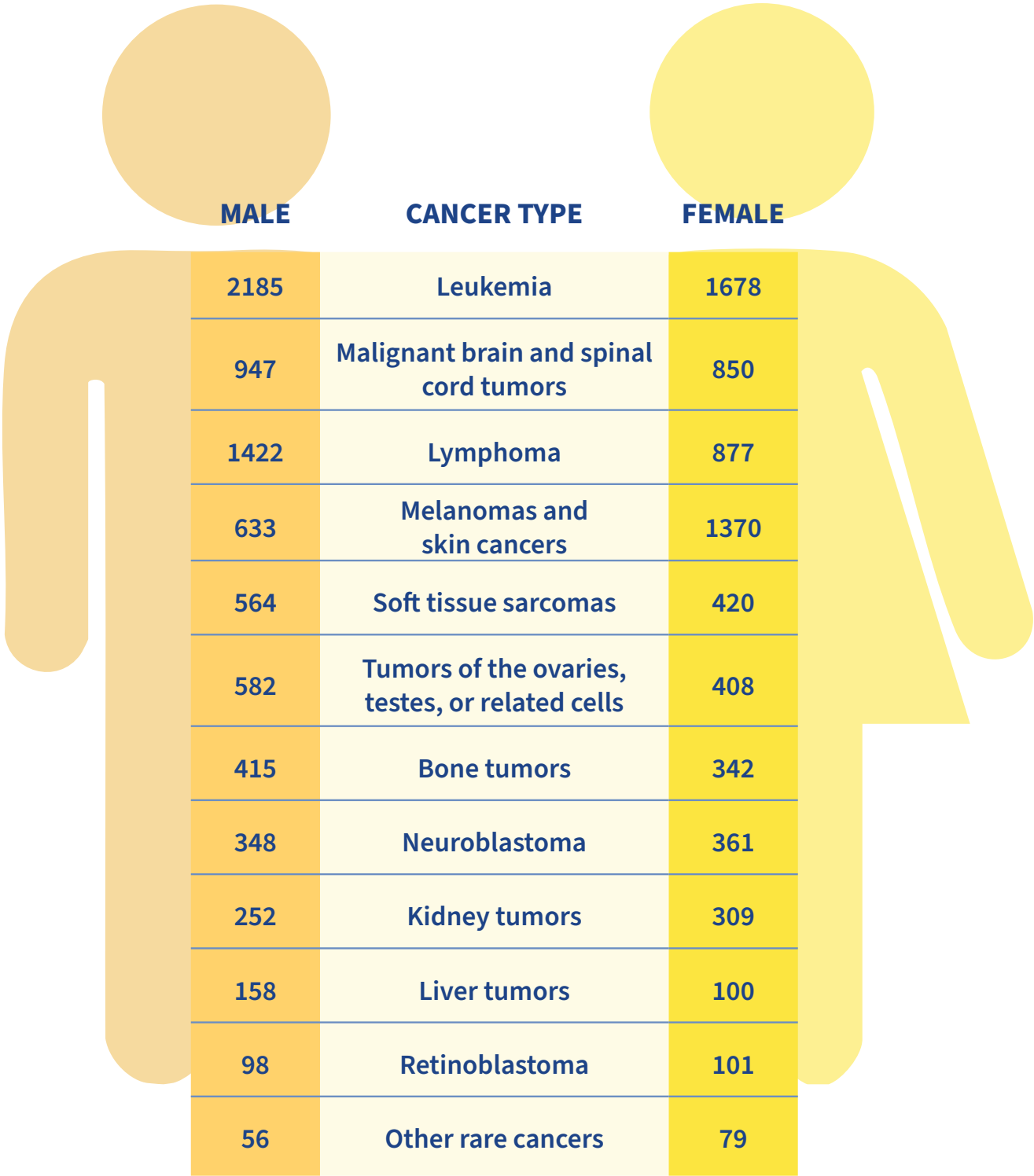
Within each of these types there are many distinct subtypes; for example, there are multiple forms of leukemia, brain tumors, and sarcomas—each with their own cellular and genetic characteristics. Some, like Wilms tumor and acute lymphoblastic leukemia (ALL), now have excellent cure rates. Others, such as diffuse intrinsic pontine glioma (DIPG), a brain tumor, and osteosarcoma, a bone cancer, remain stubbornly difficult to cure.

Cases of Childhood Cancer in the United States by type, 2023¹³



*The counts presented here only include malignant brain tumors, consistent with CDC reporting. When nonmalignant tumors are included the total number of pediatric brain tumor diagnoses is higher.

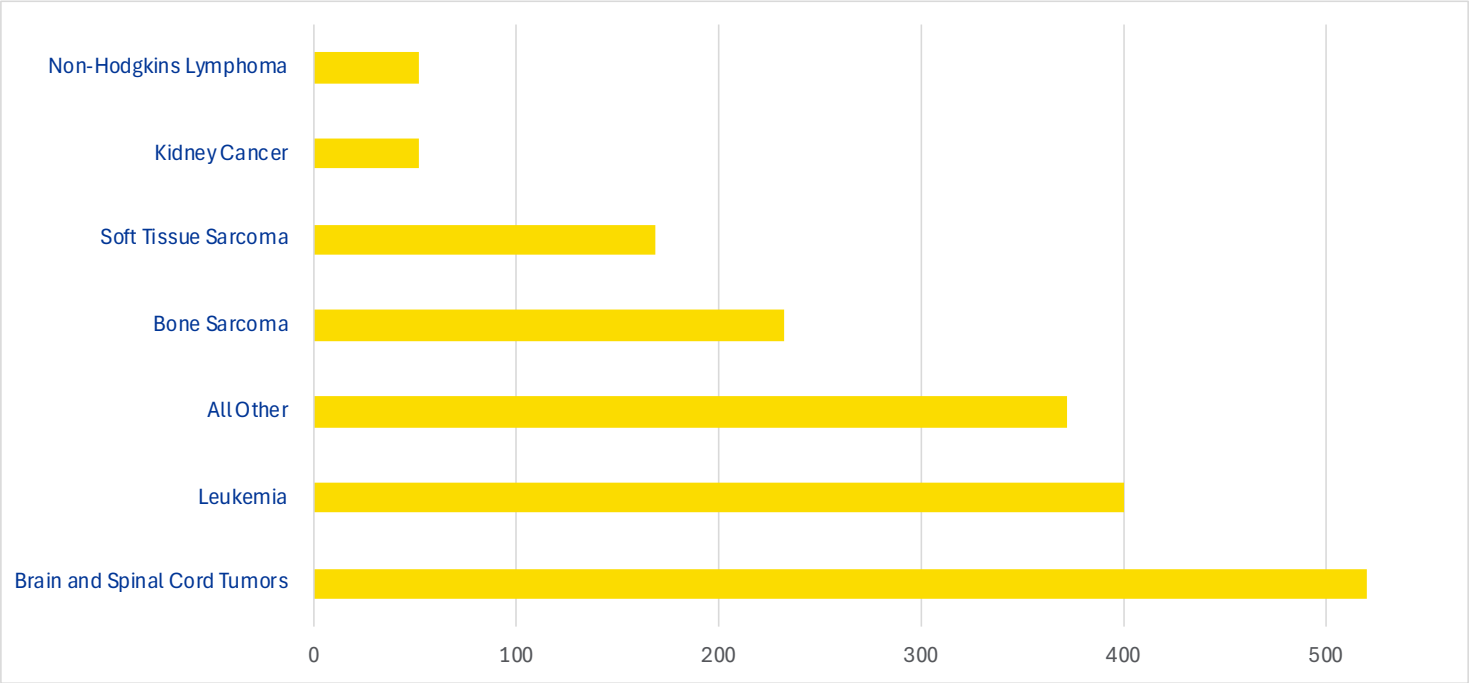
Cases of Childhood Cancer in the United States
by type and sex, 2023¹⁴



In 2023, males were diagnosed with childhood cancer approximately 11% more than females. There is no clear, definitive known reason; however, researchers think it’s a mix of biology and genetics. Boys and girls differ in hormones, immune system function, and even how certain genes are expressed (including genes on the X chromosome), which can influence cancer risk. Understanding these differences in diagnosis and sex can help researchers understand the drivers of cancer.

U.S. Childhood Cancer Deaths: A Snapshot of 2024¹⁵

Childhood cancers are not uniformly deadly. Brain and spinal cord tumors account for the most deaths—a spot once occupied by leukemia.



U.S. 5-Year Relative Survival Rates by Type:¹⁶

The chart below shows the 5-year relative survival rates of childhood cancer by type. Relative survival is different than overall survival because it compares the survival of children with cancer to children without. Survival is tracked from date of diagnosis through cancer registrars in each state. Relapse and survival is not tracked in the same way but is sometimes tracked in clinical trials and other studies. Relative survival rates are not a prediction for individual children but instead serve as an overall population measure.

By tracking how many children in both groups are still alive after 5 years, researchers can have a realistic sense of prognosis for a disease that is not skewed by unrelated causes of death. For more on survivorship, see page 11.

Cancer Type	5-Year Relative Survival (%)
All Types Combined	87.0%
Leukemia	87.3%
Lymphoma	95.2%
Brain and Spinal Cord Tumors	76.9%
Neuroblastoma	84.9%
Retinoblastoma	97.3%
Kidney Tumors	91.2%
Liver Tumors	76.8%
Bone Sarcomas	71.7%
Soft Tissue Sarcomas	75.0%

Within each of these major types of childhood cancer, there are dozens of subtypes that vary in severity and survivability.

Key Facts



The most common type of childhood cancer is leukemia.



The deadliest childhood cancers are brain tumors, which killed 520 kids in 2024.¹⁷



Bone cancers like osteosarcoma and Ewing sarcoma tend to metastasize to the lungs, and when this happens, 5-year survival rates drop from around 70% to 30%.



Section 2 explores the treatment and research milestones by specific cancer type.

Incidence and Causation

The steady increase in the incidence of childhood cancer since 1975 gives rise to the question: What causes childhood cancer? But before delving into this question, it is important to clarify what incidence rates explain. In the United States, the childhood cancer incidence rate has increased over the past several decades, from approximately 13–14 per 100,000 children in the late 1970s to about 19 per 100,000 children in recent years (including 2022), representing a roughly one-third increase over time based on SEER registry data.¹⁸

However, this does not mean that the actual cases of childhood cancer increased by 40%. Incidence rates are population based, which gives scientists more information about what is happening in a population of people (in this case children in the United States) versus raw numbers.

Understanding why the incidence rate is rising is important as scientists study cancer; however, the cause of a vast majority of childhood cancers remains unknown. Here is what is known:

1. **Childhood cancer is distinctly different from adult cancer.** It has unique molecular and biological characteristics. How does this relate to causation? Well, this simply means the things that can cause adult cancer don't necessarily cause childhood cancer.
2. **Tracking and classifying cancer rates continues to improve** and really did not begin in earnest until 1973¹⁹ with the launch of Surveillance, Epidemiology, and End Results (SEER) Program. Before SEER, childhood cancer data were fragmented and largely based on hospital records and mortality statistics, making long-term incidence comparisons less precise.
3. **Classification systems have grown and shifted to identify more tumors as malignancies.** Specifically, previously "benign" brain tumors started to be classified as malignant in the mid-1980s. The World Health Organization also continues to classify and define more subtypes of childhood cancer. This does not mean there is more cancer; it simply means more diseases are considered cancer.²⁰
4. **The causes of childhood cancer remain largely unknown.** Most cases arise from random genetic mutations that occur during development or in early childhood.
5. **Current studies indicate that 10-18% of all cancers are caused by cancer predisposition,** including some types of retinoblastoma (see Section 2, page 33). These can be spontaneous syndromes or inherited, like Li-Fraumeni (see Section 2, page 35), which increases a child's lifetime risk of cancer by 90% (females) and 70% (males).²¹
6. **Environmental exposures are suspected contributors to childhood cancer increases,** but there are not widespread conclusive studies. Exposure to radiation could play a role in the development of secondary cancers, as could environmental toxins like pesticides. Several studies on cancer clusters—geographic areas with high childhood cancer incidence rates—point to some correlation between exposure and cancer risk.²²

Why incidence rates matter

A group can have more cases just because it has more people. Rates show the chance of getting a disease.

Example:

- **Group A: 10 kids out of 100 are diagnosed with cancer (10%)**
- **Group B: 5 out of 10 are diagnosed with cancer (50%)**

Even though Group A has more cases, Group B has a much higher risk.

Counts show how many. Rates show how likely.

Survivorship

In 1989, researchers interviewed 1,928 adult survivors of childhood cancer. The cohort had been diagnosed between 1945 and 1974. Nearly 20% of the survivors didn't know what type of cancer they had, and even more surprising: 14% of the people interviewed said they never had cancer in the first place. The study's authors concluded that "physicians should be aware that a substantial proportion of long-term survivors of childhood cancer may not reveal their past history of cancer and its treatment, and possible clues to the cause of the presenting condition may thus be missed."²³

Survivorship seemed to be a mystery, even to the survivors themselves.

But the long-term impacts of childhood cancer treatment had long been an interest to scientists. One of the earliest indications that treatments could kill cancer while also harming growing bodies was in 1952, when M. H. Wittenborg, a radiologist, discovered that radiation to the spine would result in scoliosis.²⁴ In the 1960s, the international Late Effects Study Group was established, which then inspired more efforts.²⁵

In 1975, the landmark and much-cited perspective piece "Pediatric Cancer in Perspective: Cure Is Not Enough" was published in the journal *Cancer*.²⁶ Authored by Dr. Giulio J. D'Angio, this piece fueled the continued belief that survivorship needed to be studied, treatments needed to come without costs, and childhood cancer survivors needed to be able to access long-term care.

Side Effects of Childhood Cancer

At diagnosis, children typically are experiencing symptoms from their cancer. Treatment can reduce those symptoms but can also cause a bevy of short-term, immediate side effects. When those side effects don't go away, they become long-term. But children treated for childhood cancer can also experience late-term side effects—new health conditions that emerge years after diagnosis and treatment.

Both long- and late-term side effects impact quality of life for childhood cancer survivors. There are the physical impacts, which are detailed below and organized by treatment type. There are also long-term impacts on cognitive, psychological, social, and even financial health. Cancer survivors ages 18-64 were more likely to report high out-of-pocket health related expenses, and one-fourth reported having long-term financial hardship.²⁷



500,000
childhood cancer
survivors in the United
States²⁸

85%
overall childhood
cancer survival rate
in the U.S.

At least 60%
of childhood cancer
survivors develop one
or more chronic health
conditions²⁹

20%+ of survivors
experience severe
or life-threatening
complications in
adulthood

Long- and Late-Term Side Effects from Treatment³⁰

Listed below are possible long- and late-term side effects from common childhood cancer treatments. As new treatments, like immunotherapies or targeted drugs, become more widely used, researchers will continue to track and monitor the health of survivors. Read more about these treatments in Section 4. The severity and existence of these side effects is dependent upon the dose and frequency of treatment, the area of the body impacted by treatment or surgery, the age at diagnosis and treatment, and many other factors.

- **Chemotherapy**

Cardiomyopathy (heart muscle damage), lung damage, thyroid problems, growth hormone deficiency, delayed puberty, infertility, early menopause, memory and concentration issues (“chemo brain”), learning problems, nerve damage (neuropathy), hearing loss, vision issues (cataracts, glaucoma), osteoporosis (weak bones), dental abnormalities (short roots, missing teeth), growth issues, kidney and liver dysfunction, increased risk of developing new cancers later in life, depression, anxiety, and PTSD.

- **Radiation**

Learning disabilities, memory issues, seizure disorders, balance problems, growth hormone deficiency, thyroid issues (hypo/hyperthyroidism), puberty problems (early or delayed), adrenal issues, dental problems (dry mouth, tooth decay, shape/enamel issues), vision/hearing loss (cataracts, glaucoma), jaw stiffness, facial asymmetry, permanent hair loss, short stature, scoliosis (curvature), bone thinning, fractures, reduced muscle growth, joint problems, osteonecrosis (bone death), increased risk of heart conditions, chronic pain (fibrosis), infertility, metabolic issues (obesity, syndrome X), chronic pain, secondary cancers.

- **Stem Cell Transplant**

Growth hormone deficiency, thyroid issues, delayed puberty, infertility, osteoporosis (bone loss), attention deficits, memory problems, organizational challenges, slower processing speed, poor handwriting, increased risk of heart problems earlier in life, restrictive lung disease, liver scarring, iron overload, kidney toxicity from medications, high blood pressure, Chronic Graft-Versus-Host Disease (cGVHD can affect skin, eyes, mouth, lungs, gut, liver, muscles, and joints and appear months to years post-transplant), cataracts, dry eyes, dental problems, anxiety, depression, sleep disturbances, and social challenges.

- **Surgery**

Varies greatly per cancer type for brain tumors and surgical resection can cause permanent neurological side effects impacting speech, movement, balance, and vision; it can also head to hydrocephalus, a condition caused by excess cerebrospinal fluid. Because of the dangerous pressure hydrocephalus causes within the brain, a shunt placement is required to drain the excess fluid. Bone tumor resection can lead to limb loss or bone weakening. Surgery to remove tumors on organs can impact those organs’ functions.

- **Immunotherapy**

Since immunotherapies work by boosting the immune system, this can sometimes lead to it attacking the body’s own healthy tissues, causing autoimmune-like conditions (like type 1 diabetes) or chronic inflammation.

- **Newer treatments**

As new treatments are developed and FDA-approved, scientists are working to understand the potential long- and late-term side effects.

Long-Term Follow Up Guidelines

For childhood cancer survivors, long-term follow up at a specialized oncology survivors clinic is critical. The Children's Oncology Group (COG)³¹ established survivorship guidelines for childhood cancer survivors. Updated in 2023, the guidelines give clinicians a roadmap for long-term follow up care, including transitioning to adult care (See Section 3). While most COG institutions have a dedicated survivor clinic, less than 75% of eligible patients are accessing those services.³² A survivorship care plan should include:³³

1. **Exams and imaging to check for recurrence or secondary cancers**
2. **Supportive care for long- or late-term side effects**
3. **Mental health support**
4. **Referrals for legal and financial support**
5. **Referrals to specialists such as cardiologists, neuropsychologists, physical therapists, and others, as needed**
6. **Nutrition and health and wellness planning**
7. **Transition to adult care**

Beyond the COG Survivorship Guidelines, the *Childhood Cancer Survivors* guide offers practical and personal guidance.



Childhood Cancer Survivor Study

In 1994, a landmark multi-institutional collaborative study, operated by St. Jude Children's Research Hospital, was funded by the National Cancer Institute. The Childhood Cancer Survivor Study (CCSS)³⁴ first tracked survivors diagnosed between 1970-1986 (and later expanded to 1999). The initial cohort included 14,054 subjects who had survived a variety of cancers: leukemia, brain tumors, neuroblastoma, bone and soft-tissue sarcomas, and kidney tumors.³⁵ Study leads reviewed medical records and survivors completed a 24-page baseline questionnaire. Siblings of survivors were also included as a comparison control group. The CCSS was and remains the largest and most extensive cohort of childhood cancer survivors. The CCSS data have resulted in over 500 publications, includes 31 collaborating institutions, and has expanded to gather and track data from 38,000 childhood cancer survivors and their siblings. Beyond publications the CCSS also developed "risk calculators," which are tools clinicians can use to judge the risk of secondary malignancies, cardiomyopathy, and other late-term side effects.

Global Childhood Cancer: The Great Divide

In Kenya, there are only a few primary hospitals with specialized pediatric oncology units. Of the estimated 3,200 Kenyan children diagnosed with cancer each year, only 20-30% survive.

In the United States, 85% of children diagnosed with cancer are alive five years later.

Kenya and the United States are just two examples of the great divide that exists for kids with cancer.

Low- and middle-income countries have systemic and chronic infrastructure issues, long travel distances to clinics, lack of access to medications and specialized treatments, high out-of-pocket medical costs, and delays in diagnosis, which all contribute to the high mortality rates among childhood cancer types that have low mortality rates in the United States.³⁶

Childhood cancer represents a substantial and inequitable global health burden and remains one of the leading causes of death in children worldwide. No one knows the true burden of childhood cancer because there is not a comprehensive global childhood cancer registry. However, estimates suggest around 275,000-400,000 new cases of cancer develop annually in children and that there are more than 100,000 deaths each year.³⁷

And while this report primarily focuses on childhood cancer in the United States, the movement to cure childhood cancer is for all children, no matter where they live. Here are some key global childhood cancer facts:

- **Only 29% of low-income countries report that common, widely-used and researched medications are available to their populations compared to 96% of high-income countries.**³⁸
- **In some low-middle income countries the 5-year survival rates are 10%.**³⁹
- **Population-based incidence rates seem to be steadily increasing globally, as they have been in the United States (see Section 1). This is partly due to improved diagnosis.**⁴⁰
- **The lowest 3-year survival rates are in Africa, followed by South America, parts of Southeast Asia, and the Middle East.**⁴¹
- **The Global Initiative for Childhood Cancer, launched in 2018 by the World Health Organization and other global partners, aims to increase survival rates to at least 60% by 2030.**⁴²

Addressing these disparities is critical, as every child, regardless of where they are born, deserves access to timely diagnosis, effective treatment, and the hope of survival. Global efforts, like the WHO's initiative, highlight that progress is possible when resources, policies, and partnerships align to fight childhood cancer worldwide.

Cancer Registries

Cancer is a reportable disease worldwide, which means when it is diagnosed the law mandates that it must be reported to public health officials.

Tracking cancer had a slow start—in 1929 Yale-New Haven Hospital in Connecticut established the first hospital registry. It was 1956 when the American College of Surgeons required a cancer registry for approved cancer treatment programs. In 1973⁴³ the Surveillance, Epidemiology, and End Results (SEER) Program launched at the National Cancer Institute, and it started tracking a representative portion of the population. The National Cancer Registrars Association was established a year later as an effort to create consistency and professional training in the field. And then in 1992 the United States Congress passed the Cancer Registries Amendment Act, establishing a registry program within the Centers for Disease Control and Prevention. Congress encouraged states to establish their own registries, and by 2001, the registry, known as the National Program of Cancer Registries (NPCR), was collecting data from all 50 states (who had mandated cancer reporting from hospitals).⁴⁴

The state registries track a wide range of data—demographic, primary treatment type, specific diagnosis, geography, residence, age, patient status, and deaths. All of this critical information can help support public health and oncology researchers as they look for trends in long-term survival (a key indicator treatments are working), in incidence rates (by age, location, and cancer type), and other demographic factors. It can influence state public health programs and funding for childhood cancer and the allocation of community resources.⁴⁵

This is how tracking cases of childhood cancer works:⁴⁶

STEP 1

At diagnosis and before the end of the first cycle of treatment, the hospital registrar enters information about the patient, their diagnosis, and their treatment into their database. That information is then sent to the central cancer registry in the hospital's state.

STEP 2

The state registry verifies the information from the hospital and if the patient happens to be a resident of another state, the registrar will send that information to the state of residence.⁴⁷

STEP 3

Once a year, the central state registries send information on the cancers diagnosed in their state to the Centers for Disease Control and Prevention. There, it is collated and used to produce the U.S. Cancer Statistics (USCS), the official federal source.

STEP 4

In the USCS, central state registry data is combined with data surrounding cancer deaths from offices of Vital Statistics.

The process takes time as registrars work to verify, code, and ensure information is accurate. The data on childhood cancer incidence is 3-4 years behind the current year—so for 2026, the most recent data available is from 2023. Death and mortality data is just 2-3 years behind current time.

SEER also tracks and analyzes cancer rates but uses the data from approximately 18 core registries that represent 48% of the U.S. population. Both USCS and SEER are complementary, not competing, and allow for trend tracking, data comparisons, and modeling of future trends. For example, the American Cancer Society uses SEER and USCS data on an annual basis to model and forecast current rates for the year.⁴⁸

Glossary of Terms

Age-Adjusted

A way of comparing data between different populations by taking into account differences in age distribution. This makes it easier to see true trends, not just the effects of having more younger or older people in one group.

Cancer Registry

A database that collects and stores information about cancer cases, such as diagnosis, type, treatment, and outcomes. Cancer registries help researchers and public health experts track trends and improve care. In the United States, each state office of public health has a cancer registry which reports data to the national registry. Not every country has a robust or comprehensive system of cancer registries.

Case Count

The actual number of children diagnosed with cancer in a certain group or area during a specific period.

Childhood Cancer

Cancers that are diagnosed in children, adolescents, and young adults under the age of 19. These cancers often differ from those seen in adults—they tend to start in developing cells and tissues and are not usually linked to lifestyle or environmental factors.

Incidence Rate

The number of new cases of a disease, such as cancer, diagnosed in a specific group of people during a certain time period—usually expressed as the number of cases per 100,000 children each year.

Malignancy

A term for cancerous tumors or diseases that can grow uncontrollably and spread to other parts of the body.

Mortality Rate

The number of deaths from a disease in a specific group of people during a certain time—usually shown as the number of deaths per 100,000 children each year.

Overall Survival Rate

The percentage of people who are still alive after a certain amount of time (often 5 years) after being diagnosed with cancer, no matter the cause of death.

Population-Based

Data or studies that include all people in a defined population (such as all children in the United States).

Prevalence

The total number of people who are living with cancer or who have ever been diagnosed with it at a given time. Depending on context, this may refer to current prevalence (people currently living with cancer) or lifetime prevalence (all people ever diagnosed, regardless of current status).

Primary Site

The part of the body where the cancer first started to grow, before it spread elsewhere.

Progression-Free Survival

The length of time during and after treatment that the cancer does not get worse. It is often used in studies to see how well a new treatment stops the disease from progressing.

Refractory

Describes cancer that does not respond to treatment or stops responding after an initial response. A refractory cancer keeps growing or does not go away despite therapy.

Relative Survival Rate

A measure that compares how long people with cancer live, on average, after diagnosis compared to people of the same age and sex who do not have cancer. It helps show how well treatments are improving survival. This can also be represented on a specific disease basis.

SEER (Surveillance, Epidemiology, and End Results Program)

A long-running program of the U.S. National Cancer Institute that collects detailed information on cancer cases across many regions of the country. SEER data are used to track trends in cancer incidence, survival, and mortality.

Standard of Care

The best-known and most widely accepted treatment for a disease, based on evidence and expert consensus. It represents what doctors generally agree is the most effective and safest option.

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