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2026 ILLINOIS CHILDHOOD CANCER REPORT AND RESOURCE GUIDE

This guide is designed to support families, caregivers, community health workers, community-based organizations, and health care professionals.

September 2026

TABLE OF CONTENTS

List of Figures and Tables	3
Acknowledgements	4
Introduction	5
Common Childhood Cancers	6
Genetics/Hereditary Cancers.....	10
Long-term Implications of Childhood Cancer	13
Reducing Modifiable Cancer Risk Factors among Childhood Cancer Survivors	16
Social Drivers of Health and Childhood Cancer Outcomes.....	21
Important Statistics of Childhood Cancer	24
Call To Action - What You Can Do	28
Clinical Trials	30
Resources.....	31

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LIST OF FIGURES AND TABLES

Figures

- Figure 1. Distribution of Childhood Cancer Types Among Children Under 1 Year of Age, 2001-2022, Illinois
- Figure 2. Distribution of Pediatric Cancer Types Among Children Ages 1-4 Years, 2001-2022, Illinois
- Figure 3. Distribution of Pediatric Cancer Types Among Children Ages 5-9 Years, 2001-2022, Illinois
- Figure 4. Distribution of Pediatric Cancer Types Among Children Ages 10-14 Years, 2001-2022, Illinois
- Figure 5. Distribution of Pediatric Cancer Types Among Children Ages 15-19 Years, 2001-2022, Illinois
- Figure 6. HPV-Associated Cancers by Cancer Type, U.S., 2019-2023
- Figure 7. Recommended Schedule for HPV Vaccination
- Figure 8. Up-to-Date HPV Vaccination Percentages, By Sex, Ages 13-17, Illinois (IL) and the United States (US) (2024)
- Figure 9. Up-to-Date HPV Vaccination Percentages, By Urbanicity, Ages, Illinois (2024)
- Figure 10. Percent of Children Who Received the 3-Dose Hepatitis B Series by Age 35 Months.
- Figure 11. Factors Impacting Access to Health Care
- Figure 12. Source of Insurance Coverage for Illinois Children, 2024
- Figure 13. Percent of Children (Age < 18 Years) Below Poverty, by Race / Ethnicity, 2023, Illinois
- Figure 14. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rate, 2001-2022, Illinois
- Figure 15: Pediatric (Less Than 20 Years of Age) Cancer Incidence Rates, by Age, 2001-2022, Illinois
- Figure 16. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rates, by Race/Ethnicity, 2001-2022, Illinois
- Figure 17. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rates, by Sex, 2001-2022, Illinois
- Figure 18. Pediatric (Less than 20 Years of Age) Cancer Deaths by Primary Site per 100,000 Children, 2020-2024, U.S.
- Figure 19. Pediatric (Less than 20 Years of Age) Cancer Deaths by Ages per 100,000 Children, 2020-2024, U.S.
- Figure 20. Five-Year Survival Rates, Comparison by Childhood Cancer Types (Ages 0 to 20), 2015–2021, U.S.

Tables

- Table 1. Description of Common Types of Cancer in Children

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INTRODUCTION

Cancer in children is rare, especially when compared to cancer occurrence among adults. However, cancer is still the leading cause of death from disease among children from birth to age 14 in the U.S.¹ In Illinois, cancer is the third leading cause of death in children ages 1 to 17.²

Advances in diagnostics, treatment, supportive care, and collaborative research have resulted in pediatric cancer death rates decreasing by nearly 70% over the past 40 years.³ In total, about 15,000 children between the ages of 0 to 19 are diagnosed with cancer each year in the United States and an estimated 1,590 will die.^{4,5} Among U.S. children between the ages 0 to 14 years, it is estimated that 9,680 will be diagnosed with cancer and 1,040 will die of the disease. And among U.S. adolescents between the ages of 15 to 19 years, it is estimated that 5,290 will be diagnosed with cancer and 550 will die of the disease.

The Illinois Department of Public Health's Illinois Cancer Partnership produced this report to support and provide resources for families, caregivers, community health workers, community-based organizations, and health care professionals. Advances in research and treatment for childhood cancer have improved survival rates over the past decades, but the journey for children involves not only complex medical care but also profound emotional, social, and financial challenges. Understanding the impacts of childhood cancer is essential for developing better prevention strategies, enhancing patient support, and ultimately improving outcomes for the youngest and most vulnerable members of our communities.

This report is divided into multiple sections describing topics related to childhood cancer. The introduction begins with an overview of childhood cancer occurrence, followed by a description of common childhood cancers, genetic/hereditary cancers, and signs and symptoms. The next sections delve into long-term implications and reducing the risk of future cancers.

This report will also look at different strategies for organizations to address childhood cancers. The next section discusses the importance and availability of clinical trials. The report concludes with resources available by county, regionally, statewide, and nationally.

For this report, childhood cancers are defined as cancer diagnosed among children from 0 years of age through 19 years of age. No standard definition exists to differentiate childhood cancers from adolescent and young adult cancers.

The information in this report is for awareness and educational purposes only. It is not intended to be used for diagnosing or treating a health problem. If a health problem is suspected, a qualified health care professional should be consulted. Inclusion in this report in no way implies endorsement of a particular organization or linked material.

¹ American Cancer Society. (2026). *Childhood Cancer Key Statistics*. Retrieved from <https://www.cancer.org/cancer/childhood-cancer/childhood-cancer-key-statistics.html>

² Illinois Department of Public Health. (2026). *Leading Causes of Death by Age Group, Illinois Residents, 2023*. Retrieved from <https://dph.illinois.gov/content/dam/soi/en/web/idph/publications/idph/data-and-statistics/vital-statistics/death-statistics/leading-causes-by-age-2023.pdf>

³ American Association for Cancer Research. (2025). *AACR Pediatric Cancer Progress Report*. Retrieved from <https://aacrjournals.org/clincancerres/article/32/3/465/772023/AACR-Pediatric-Cancer-Progress-Report-2025AACR>

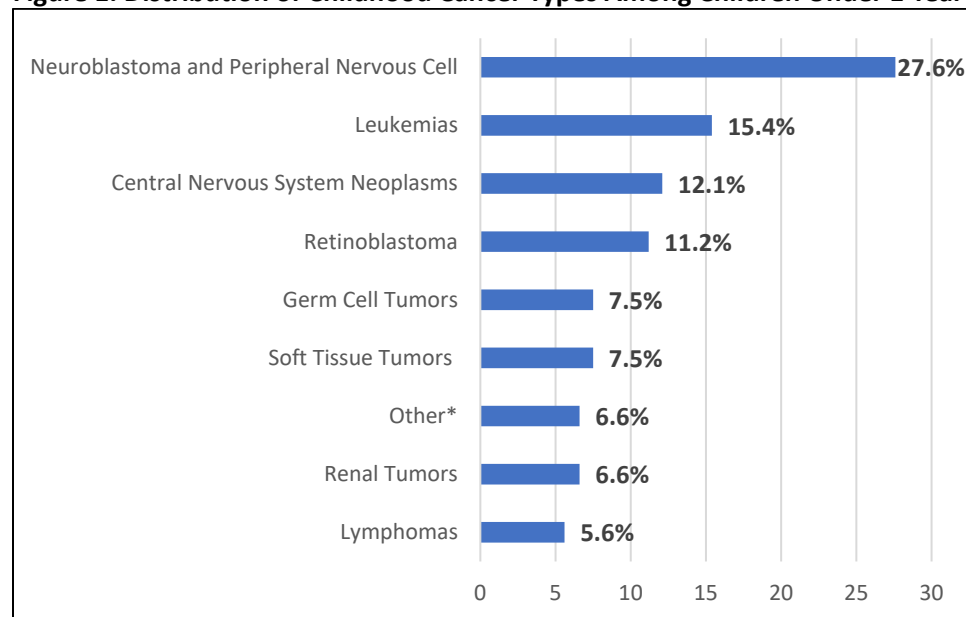
⁴ American Cancer Society. (2024). *Cancer in Children*. Retrieved from: [More information at American Cancer Society](#)

⁵ American Cancer Society. (2024). *Cancer in Adolescents*. Retrieved from: [More information at American Cancer Society](#)

COMMON CHILDHOOD CANCERS

The most common types of cancers diagnosed among children vary over the course of childhood. The figures that follow present the distribution of cancer types by different age groups from 2001-2022 in Illinois. These age-specific patterns are important for understanding differences in diagnosis, treatment approaches, survivorship needs, and supportive care across childhood and adolescence.⁶ For children under 1 year of age (Figure 1), the most common types of cancers diagnosed include neuroblastoma and peripheral nervous cell cancers (27.6%), leukemias (15.4%), and central nervous system neoplasms (12.1%).

Figure 1. Distribution of Childhood Cancer Types Among Children Under 1 Year of Age, 2001-2022, Illinois

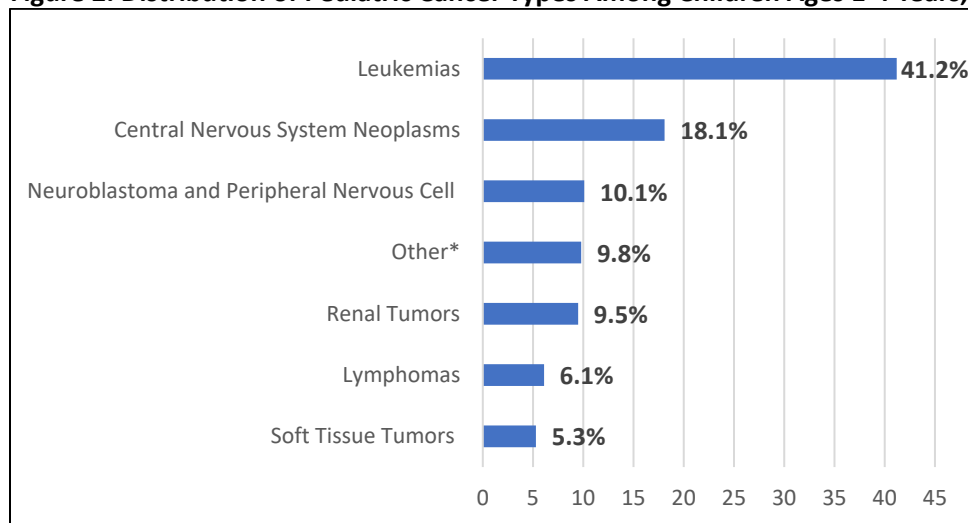


*Other includes hepatic tumors (4.0%), bone tumors (0.3%), epithelial neoplasms and melanomas (0.9%), and other/unspecified neoplasms (1.4%).

For children ages of 1-4 years (Figure 2), leukemias (41.2%) are most frequently diagnosed, followed by central nervous system neoplasms (18.1%), and neuroblastoma and peripheral nervous cell cancers (10.1%).

⁶ Case Data: Illinois Department of Public Health, Illinois State Cancer Registry, Public Data Set V32, 1986–2022, data as of November 2024.

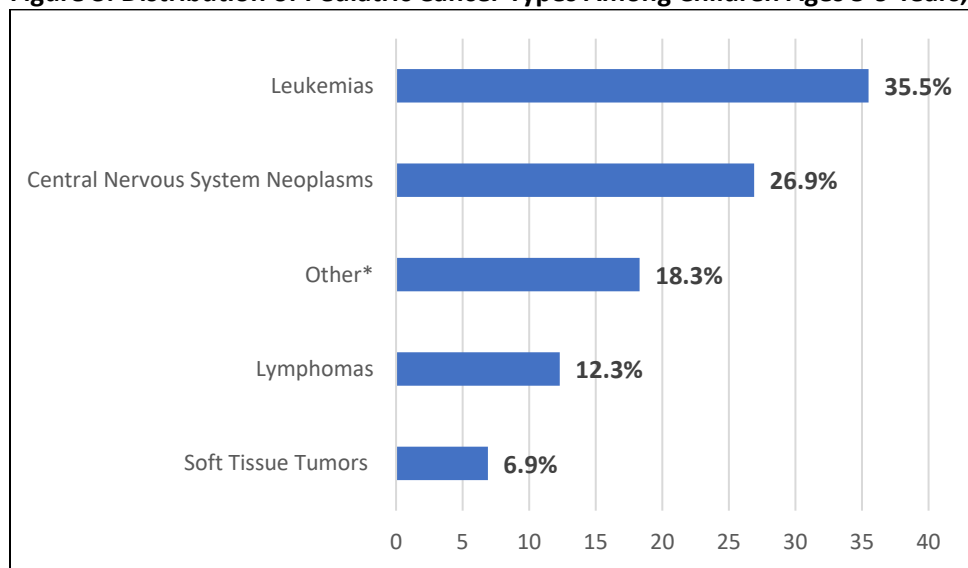
Figure 2. Distribution of Pediatric Cancer Types Among Children Ages 1-4 Years, 2001-2022, Illinois



* Other includes retinoblastoma (4.0%), hepatic tumors (2.0%), bone tumors (0.5%), germ cell tumors (2.0%), epithelial neoplasms and melanomas (0.7%), and other/unspecified neoplasms (0.6%).

Among children between the ages of 5-9 years (Figure 3), the most diagnosed cancers include leukemias (35.5%), central nervous system neoplasms (26.9%), and lymphomas (12.3%).

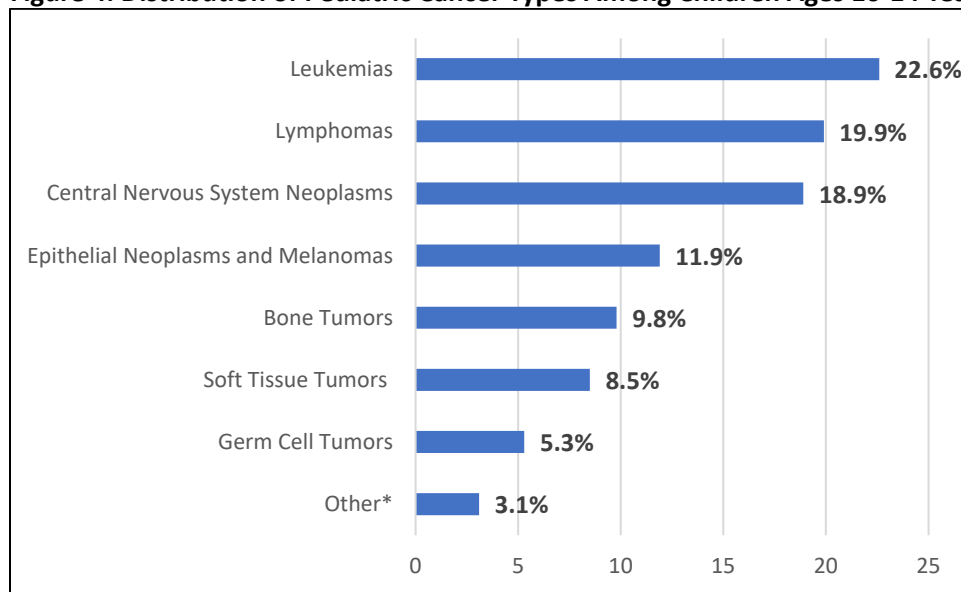
Figure 3. Distribution of Pediatric Cancer Types Among Children Ages 5-9 Years, 2001-2022, Illinois



*Other includes neuroblastoma and peripheral nervous cell (2.9%), retinoblastoma (0.3%), renal tumors (4.6%), hepatic tumors (0.7%), bone tumors (4.0%), germ cell tumors (2.1%), epithelial neoplasms and melanomas (2.8%), and other/unspecified neoplasms (1.1%). Numbers were rounded to one decimal. The total is based upon the unrounded numbers.

For children ages 10-14 years (Figure 4), leukemias (22.6%), lymphomas (19.9%), central nervous system neoplasms (18.9%), and epithelial neoplasms and melanomas (11.9%) are the most common.

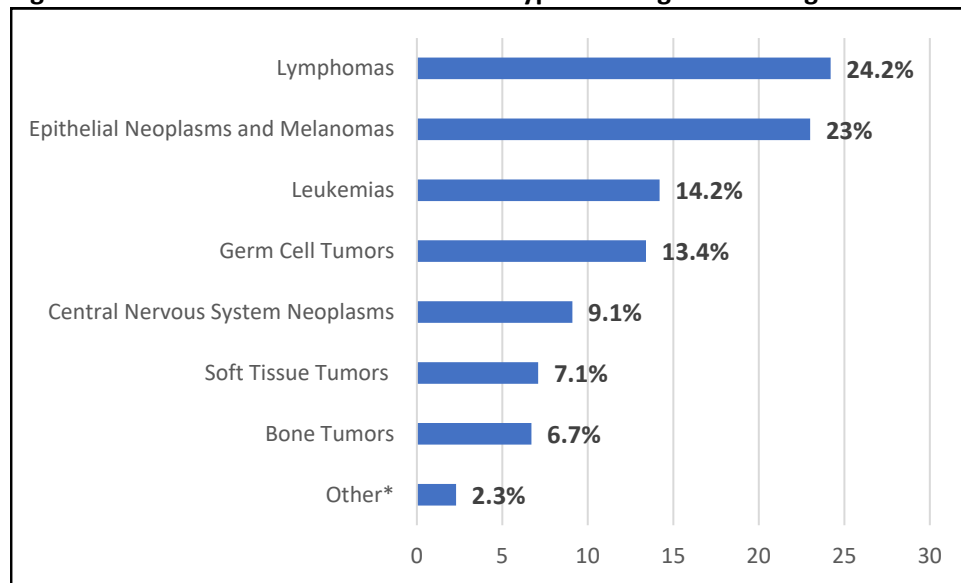
Figure 4. Distribution of Pediatric Cancer Types Among Children Ages 10-14 Years, 2001-2022, Illinois



*Other includes neuroblastoma and peripheral nervous Cell (1.0%), retinoblastoma (0.1%), renal tumors (0.9%), hepatic tumors (0.6%), and other/unspecified neoplasms (0.6%). Numbers were rounded to one decimal. The total is based upon the unrounded numbers.

Finally, for children 15-19 years, (Figure 5), the most commonly diagnosed cancers include lymphomas (24.2%), epithelial neoplasms and melanomas (23.0%), leukemias (14.2%), and germ cell tumors (13.4%).

Figure 5. Distribution of Pediatric Cancer Types Among Children Ages 15-19 Years, 2001-2022, Illinois



*Other includes neuroblastoma and peripheral nervous cell (0.5%), renal tumors (0.7%), hepatic tumors (0.5%), and other/unspecified neoplasms (0.6%).

The common types of cancer in children are described below (Table 1). Additional information is available from the National Cancer Institute’s [Childhood Cancers page](#) and [PDQ® Cancer Information Summaries](#).⁷

Table 1. Description of Common Types of Cancer in Children

Type	Description
Bone	Bone cancer is a growth of abnormal cells that starts in a bone. Even though bone cancer can start in any bone, it primarily affects the femur or thighbone. Osteosarcoma Treatment at National Cancer Institute
Brain and Spinal Cord Tumors	Brain and spinal cord tumors are masses of abnormal cells in the brain or spinal cord that have grown out of control. Spinal and brain tumors are called central nervous system (CNS) tumors. Brain Tumors at National Cancer Institute
Epithelial Neoplasms	Childhood epithelial neoplasms are malignant tumors from epithelial cells, which are the tissue lining organs, body cavities, and surfaces. In children, they are relatively rare compared to other pediatric cancers, but they can occur in various sites, including the ovary, conjunctiva, and other epithelial-lined organs. A Summary of the Inaugural WHO Classification of Pediatric Tumors: Transitioning from the Optical into the Molecular Era - PMC
Germ Cell Tumors	Germ cell tumors often form in the reproductive organs; however, they can form in other parts of the body as well. This form of cancer normally develops in the ovary or testicle. Germ Cell Tumor Cleveland Clinic
Leukemia	Leukemia is a form of blood cancer that often impacts the white blood cells; however, the cancer can also start in other blood cells. Leukemia at National Cancer Institute
Lymphoma (Hodgkin and Non-Hodgkin)	Lymphomas start in the lymph system, the part of the immune system that fights infection. Because the lymph system is found throughout the body, lymphoma can begin almost anywhere. The two main types are Hodgkin lymphoma and non-Hodgkin lymphoma. Lymphoma at National Cancer Institute
Melanomas	Melanoma is a type of cancer that forms in the melanocytes (cells that color the skin). This form of cancer occurs anywhere on the skin. Melanoma at National Cancer Institute
Neuroblastoma	Neuroblastoma is a cancer often found in the small glands on top of the kidneys (adrenal glands). It can develop in the belly, chest, neck, pelvis, and bones. Neuroblastoma at National Cancer Institute
Retinoblastoma	Retinoblastoma is a rare form of cancer that develops in the retina, the light-sensitive tissue at the back of the eye. Retinoblastoma at National Cancer Institute
Rhabdomyosarcoma	Rhabdomyosarcoma is a rare type of cancer that develops in soft tissues, specifically muscles that connect to bones and help with movement. The most common types are embryonal (most common, often in head, neck, and genitals) and alveolar (often in arms, legs, and torso). Rhabdomyosarcoma at National Cancer Institute
Wilms Tumor	Wilms tumor is a rare type of kidney cancer that usually forms on one kidney. Wilms tumor at National Cancer Institute

Note: Links to the specific cancer information summary are provided for each cancer type listed. The links go to patient information, and the site provides another link for the health professional version.

⁷ National Cancer Institute at the National Institutes of Health. (2025). *Childhood Cancers* was originally published by the National Cancer Institute. Retrieved from [National Cancer Institute at the National Institutes of Health](#).

GENETICS/HEREDITARY CANCERS

Some children carry DNA changes (mutations) from a parent that increase their risk of certain types of cancer. These changes are present in every cell of the child's body, and they can often be tested for in the DNA of blood cells or other body cells.⁸ Some of these DNA changes are linked only with an increased risk of cancer, while others can cause syndromes that include other health or developmental problems. It is estimated that 7-15% of childhood cancer cases have an identifiable genetic condition.

However, most childhood cancers are not caused by DNA changes. They are the result of DNA changes that happen early in the child's life, sometimes even before birth. Every time a cell divides into two new cells, it must copy its DNA. This process isn't perfect, and errors sometimes occur, especially when the cells are growing quickly. This kind of gene mutation can happen at any time in life and is called an acquired mutation.

Of the two most common adult-onset cancer predisposition genes, Lynch syndrome (LS) can rarely cause childhood cancers, and monoallelic BRCA1/2 variants have not been shown to confer a measurable pediatric cancer risk.^{9, 10} A monoallelic BRCA1/2 variant means the person has a harmful change in only one copy of the BRCA1 or BRCA2 gene, while the other copy remains normal.¹¹

More information is available at [Childhood Cancer Genomics \(PDQ®\) - NCI](#).

Key childhood syndromes associated with childhood cancer include but are not limited to the following:¹²

- **Beckwith–Wiedemann Syndrome (and other overgrowth syndromes):** Beckwith-Wiedemann syndrome (BWS) is a genetic disorder that affects different parts of a child's body. Most babies are large at birth and have other symptoms across a wide spectrum. BWS also increases a child's risk for developing certain childhood cancers such as embryonal cancers. BWS can't be cured, but there are many treatments available. See [Beckwith-Wiedemann Syndrome \(BWS\) | American Cancer Society](#).
- **Constitutional Mismatch Repair Deficiency:** Constitutional mismatch repair deficiency (CMMRD) syndrome is a rare disorder that greatly increases the risk of developing different types of cancer throughout a person's lifetime. Affected individuals often develop their first cancer in childhood. The cancers that most commonly occur in people with CMMRD are cancers of the colon and rectum, blood, and brain. See [CMMRD | St. Jude](#).
- **DICER1 syndrome:** DICER1 syndrome is an inherited disorder that increases the risk of a variety of cancerous and noncancerous (benign) tumors, most commonly certain types of tumors that occur in the lungs, kidneys, ovaries, and thyroid. See [DICER1 Syndrome | St. Jude](#).
- **Down Syndrome:** Down syndrome is a genetic condition caused when an unusual cell division results in an extra full or partial copy of chromosome 21. Down syndrome can lead to leukemia. See [Causes, Risk Factors, and Prevention of Childhood Leukemia | American Cancer Society](#).
- **Familial Adenomatous Polyposis:** Familial adenomatous polyposis (FAP) is an inherited disorder that is characterized by a greatly increased risk of cancer of the large intestine (colon) and rectum (collectively known as colorectal cancer). People with FAP have multiple precancerous (benign) growths

⁸ American Cancer Society. (2026). Family Cancer Syndromes. Retrieved from [Family Cancer Syndromes | American Cancer Society](#)

⁹ [Identification, management, and evaluation of children with cancer-predisposition syndromes](#). American Society of Clinical Oncology Educational Book: American Society of Clinical Oncology. Annual Meeting, 2012.

¹⁰ [A comprehensive review of pediatric tumors and associated cancer predisposition syndromes](#). Journal of Genetic Counseling, 2017

¹¹ National Cancer Institute. (2024). BRCA Gene Changes: Cancer Risk and Genetic Testing. Retrieved from [BRCA Gene Changes: Cancer Risk and Genetic Testing Fact Sheet - NCI](#)

¹² [The University of Texas MD Anderson Cancer Center Hereditary Cancer Syndromes](#)

(polyps) in the colon, and one or more of these polyps will likely develop into colorectal cancer. There are two forms of FAP: the classic type and the attenuated type. See [Familial Adenomatous Polyposis \(FAP\) | American Cancer Society](#).

- **Li-Fraumeni Syndrome:** Li-Fraumeni Syndrome increases a person's risk of developing one or more cancers at some point in their life. Potential cancers include osteosarcoma, soft-tissue sarcomas, leukemia, brain tumors, adrenal cortex, breast cancer, gastrointestinal cancers, and melanoma. This condition can be passed down from parents to their children (inherited). See [Li-Fraumeni Syndrome \(LFS\) | American Cancer Society](#).
- **Multiple Endocrine Neoplasia (MEN):** A person with MEN1 may have tumors in the endocrine glands. The endocrine glands make hormones that control the activities of cells and organs. People with MEN1 may also have tumors in other parts of their bodies, which are not in the endocrine system. See [Multiple Endocrine Neoplasia | National Cancer Institute](#).
- **Neurofibromatosis type 1:** Neurofibromatosis type 1 (NF1) is a rare genetic disorder that can be passed down from parents to their children (inherited). People with NF1 have a higher risk of developing certain kinds of tumors, such as breast cancer, gastrointestinal tumors, and sarcomas. These tumors are usually non-cancerous (benign) but may sometimes be cancerous (malignant). NF1 can affect many areas of the body. The severity of the condition and the body areas affected can vary. See [Neurofibromatosis Type 1 \(NF1\) | American Cancer Society](#).
- **Von Hippel-Lindau (VHL):** VHL syndrome is a rare genetic disorder that makes a person more likely to develop certain types of tumors—such as hemangioblastomas, clear cell renal cell carcinoma, pheochromocytoma, paragangliomas, and pancreatic neuroendocrine tumors. These tumors can be either non-cancerous (benign) or cancerous (malignant). See [Von Hippel-Lindau \(VHL\) Syndrome | American Cancer Society](#).

Common childhood cancers with genetic links:

- **Leukemias:** Certain inherited syndromes (e.g., Down syndrome) significantly increase risk.
- **Brain tumor:** Often linked to inherited mutations affecting DNA repair and cell-cycle control.
- **Wilms tumor:** Associated with several genetic syndromes and chromosomal abnormalities.
- **Sarcomas:** Associated with several genetic syndromes including Li-Fraumeni, neurofibromatosis type 1, and hereditary retinoblastoma syndrome.

More information about family cancer syndromes is available at [Family Cancer Syndromes | American Cancer Society](#)

What is genetic testing?

Genetic testing is the analysis of DNA, RNA, chromosomes, or proteins to find changes that can be used to diagnose diseases, guide treatment, and predict future health risks. Genetic testing can provide insights into risks related to conditions like cancer, heart health, neurological disorders, or cystic fibrosis. However, not all medical conditions can be diagnosed through genetic testing.

How does genetic testing work?

A health care professional will collect a blood or saliva sample, which is sent to a laboratory. The sample will be analyzed for specific genetic variations that might impact your health.

The three main types of genetic tests are:

- **Diagnostic tests** confirm or rule out specific genetic conditions.
- **Predictive tests** estimate your risk of developing health issues in the future.

- **Carrier screening** checks to see if parents have genes for hereditary conditions that could impact their children.

What is genetic counseling?

Genetic counseling is a professional service provided by trained counselors who help individuals and families understand the implications of genetic information. Genetic counseling provides education on how genetics can impact your health. Typically, genetic counseling starts with reviewing family and medical history to assess hereditary health risks. If cancer runs in the family, genetic counselors can help manage your risk. Individuals should discuss genetic testing with a health care provider.

During a genetic counseling session, a genetic counselor can offer:

- Customized advice and guidance tailored to the patient
- Simplified results
- Emotional reassurance
- Family planning advice

Genetic counseling may be recommended when:

- A child is diagnosed with cancer at an unusually young age.
- There are multiple cancers in the child or family.
- Rare tumor types are present.
- There is a known cancer predisposition syndrome in the family.

For more information about referrals to a genetic specialist, consult a health care professional.

LONG-TERM IMPLICATIONS OF CHILDHOOD CANCER

Surviving childhood cancer can affect health and daily life for many years. These effects are called long-term effects or late effects. They may not appear right away. Not everyone has these effects. Many survivors feel well, but regular check-ups help catch problems early.

Life after childhood cancer and its treatment can bring ongoing, late, or long-term effects that may impact physical health, emotional well-being, learning, work/education, financial health, relationships, and daily life. Some effects may continue from treatment, while others may develop years later. Not every survivor will experience these challenges. Continued follow-up care based on the cancer diagnosis, treatment, and follow-up guidelines are important for all. Survivors and their families should receive guidance and a survivorship care plan from their cancer care team to help them understand what to watch for and how to access appropriate support and care to move forward with the best possible quality of life.

To learn more about surviving a childhood cancer diagnosis, refer to the [Children's Oncology Group, Survivorship for Patients and Families](#).

Common late and long-term effects

- Heart problems (especially after certain chemotherapies or chest radiation)
- Hormonal and growth disorders (e.g., thyroid, puberty, fertility concerns)
- Learning, memory, or attention difficulties
- Hearing or vision changes
- Lung or kidney problems
- Chronic pain or fatigue
- Bone health

Risk of Secondary Cancers

Childhood cancer survivors have a higher risk of developing secondary cancers later in life, particularly if they receive radiation therapy or certain chemotherapies.

Examples include:

- Breast cancer after childhood chest radiation
- Thyroid cancer after neck or head radiation
- Therapy-related leukemias

Ongoing screening and early detection are essential. Survivors of childhood cancers should follow risk-based screening recommendations throughout adulthood.

Mental and Emotional Well-being

Survivors may experience at any point in life:

- Anxiety or depression
- Fear of recurrence
- Post-traumatic stress symptoms
- Survivor guilt

Support options for cancer patients can include counseling or therapy, peer support groups, and survivorship-focused mental health services.

Education, Work, and Financial Health

Long-term effects can influence:

- School performance and learning needs
- Employment opportunities
- Insurance access and medical costs

Survivors with cognitive or physical late effects may benefit from:

- Educational accommodations
- Vocational rehabilitation services
- Financial counseling or assistance programs

Reproductive and Sexual Health

Some cancer treatments affect fertility or sexual development and sexual health.

Survivors may need:

- Fertility evaluations or counseling at diagnosis, during treatment, and into survivorship.
- Family building support and resources.
- Hormonal or sexual healthcare, education, and resources.

Early conversations with health care providers can help survivors make informed decisions.

Healthy Living for Survivors

Healthy behaviors can reduce the risk of chronic disease and improve quality of life.

Key recommendations:

- Stay as physically active as possible through activities you enjoy, such as walking, dancing, exercising, taking the stairs, or practicing yoga. Spending less time sitting and more time moving can benefit overall health and quality of life. Try to eat a variety of healthy foods, including fruits, vegetables, whole grains, and proteins, to help support your health and well-being after cancer treatment and throughout life.
- Avoid tobacco, nicotine, and limit alcohol.
- Finding healthy ways to cope with stress and getting enough sleep can support physical, emotional, and mental health.

Survivorship Care Plans

A survivorship care plan is a comprehensive personalized document summarizing:

- Cancer diagnosis and treatments
- Potential late effects
- Guidelines on recommended screenings and follow-up care, including physical and emotional, for lifelong well-being

The survivorship care plan should include the following:

- Type and stage of cancer
- Date of cancer diagnosis and dates of any relapses
- Genetic testing
- Types and dates of imaging tests
- Contact information for the hospitals and doctors who provided treatment
- Names and total doses of all chemotherapy drugs used in treatment

- Parts of the body that were treated with radiation and the total doses of radiation that were given
- Types and dates of all surgeries
- Any other cancer treatments received
- Any serious complications that occurred during treatment and how those complications were treated
- Date that cancer treatment was completed

Survivors are encouraged to keep their survivorship care plan in paper or digital form and share it with all health care providers going forward in life.

REDUCING MODIFIABLE CANCER RISK FACTORS AMONG CHILDHOOD CANCER SURVIVORS

Reducing future cancer risk among childhood cancer survivors involves adopting a healthy lifestyle: avoiding tobacco, maintaining a healthy weight, limiting alcohol, staying active, and protecting skin from UV rays. Key prevention strategies also include getting vaccinated against HPV and hepatitis B and getting recommended cancer screenings.

While many childhood cancers cannot be prevented, focusing on healthy lifestyles can help children live a healthy life and significantly lower their risk of developing cancer later in life. Preventing cancer in adulthood involves establishing healthy habits early, protecting them from environmental toxins, and ensuring vaccination. Key measures include maintaining a healthy diet, encouraging daily physical activity, avoiding secondhand smoke, limiting sun exposure, and getting HPV and hepatitis B vaccines. While not all future cancers can be prevented, these actions may significantly reduce long-term risks.

Additional information about cancer prevention is available on the following websites:

- American Cancer Society: [Cancer Risk and Prevention at American Cancer Society](#)
- National Cancer Institute: [Cancer Prevention at National Cancer Institute](#)

Health promotion aims to enable and empower people to take control of and improve their health. It goes beyond individual behavior change to address the social, environmental, economic, and policy factors that influence health. Many health promotion initiatives focus on education. These educational initiatives address the individual's knowledge of specific risk topics such as nutrition, physical fitness, sexual practices, drugs and alcohol, tobacco, and mental health.

Genetic risk factors, exposure to high-dose ionizing radiation, and prior chemotherapy are established risk factors for childhood cancer.¹³ Other risk factors can influence a person's chance of getting cancer, but many of these risks occur over a longer duration of time. Other risk factors that could increase the chance of a childhood cancer survivor getting cancer later in life are environmental exposures, acquired or inherited gene mutations, ultraviolet (UV) radiation from tanning beds, and treatment from childhood cancer, HPV infection, and human immunodeficiency virus (HIV) infection.

It is well-known that lifestyle risk factors, such as smoking, being overweight, not exercising, and eating unhealthy foods (fried foods, soda, processed meats, candy bars, etc.), play a role in many types of adult cancers. However, most lifestyle risk factors do not play a role in the onset of childhood cancers.

Studies suggest the prenatal and early life periods are biologically vulnerable periods for the development of cancer among children.^{14,15}

Numerous factors are suspected to be associated with increased risk of childhood cancer, but studies of these factors are difficult to implement, and findings have been inconsistent. The most consistent risk factors are in

¹³ Emeny, R.T., et al., *Causes of Childhood Cancer: A Literature Review (2014-2021)-Part 3: Environmental and Occupational Factors*. Cancers (Basel), 2025. 17(21).

¹⁴ Olshan, A.F., et al., *Workshop to identify critical windows of exposure for children's health: cancer work group summary*. Environ Health Perspect, 2000. 108 Suppl 3(Suppl 3): p. 595–7.

¹⁵ Anderson, L.M., et al., *Critical windows of exposure for children's health: cancer in human epidemiological studies and neoplasms in experimental animal models*. Environ Health Perspect, 2000. 108 Suppl 3(Suppl 3): p. 573–94.

utero and early-life exposure to ionizing radiation (from X-rays and CT scans)¹⁶ and maternal smoking and exposure to pesticides during pregnancy.^{17, 18} For rarer types of cancer, very few environmental risk factors have been evaluated.

HUMAN PAPILLOMAVIRUS (HPV)

Vaccinating for the human papillomavirus (HPV) can lower children's risk of getting cancer later in life.

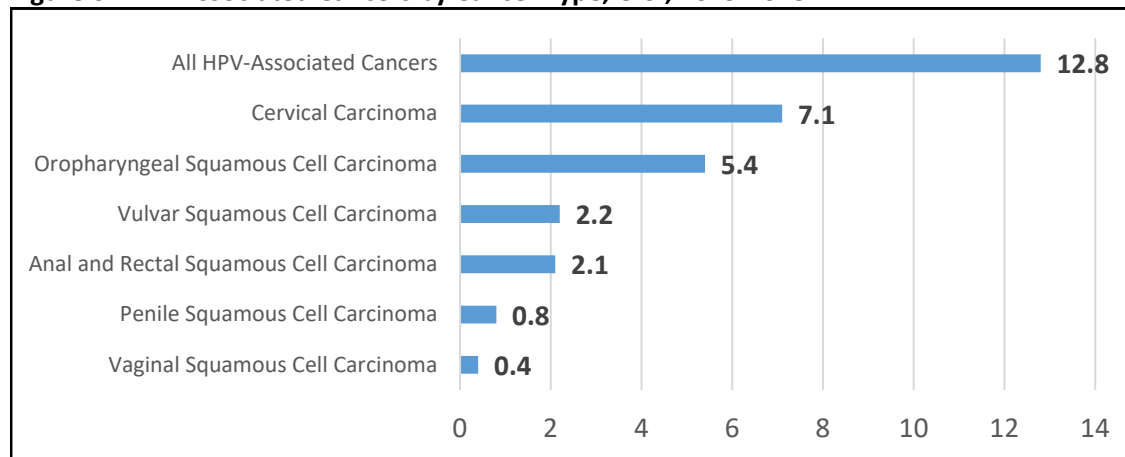
HPV is a group of more than 200 related viruses that can spread from skin-to-skin contact or through contact with the mucous membranes of the genitals or mouth. HPV infections are so common that nearly all men and women will get at least one type of HPV at some point in their lives.

HPV can cause the following types of cancer among adults:

- Cervical
- Vulvar
- Vaginal
- Penile
- Anal
- Oropharyngeal (cancers that are found at the back of the throat, base of the tongue, and tonsils)

From 2019-2023, the incidence of HPV-associated cancers was 12.6 per 100,000 people in Illinois, which is slightly lower than the U.S. incidence rate of 12.8 (Figure 6).¹⁹ Figure 9 shows the HPV-associated cancers by cancer type in the U.S. from 2019-2023.

Figure 6. HPV-Associated Cancers by Cancer Type, U.S., 2019-2023



¹⁶ Emeny, R.T., et al., *Causes of Childhood Cancer: A Literature Review (2014-2021)-Part 3: Environmental and Occupational Factors*. Cancers (Basel), 2025. 17(21).

¹⁷ Wigle, D.T., M.C. Turner, and D. Krewski, *A Systematic Review and Meta-analysis of Childhood Leukemia and Parental Occupational Pesticide Exposure*. Environmental Health Perspectives, 2009. 117(10): p. 1505–1513

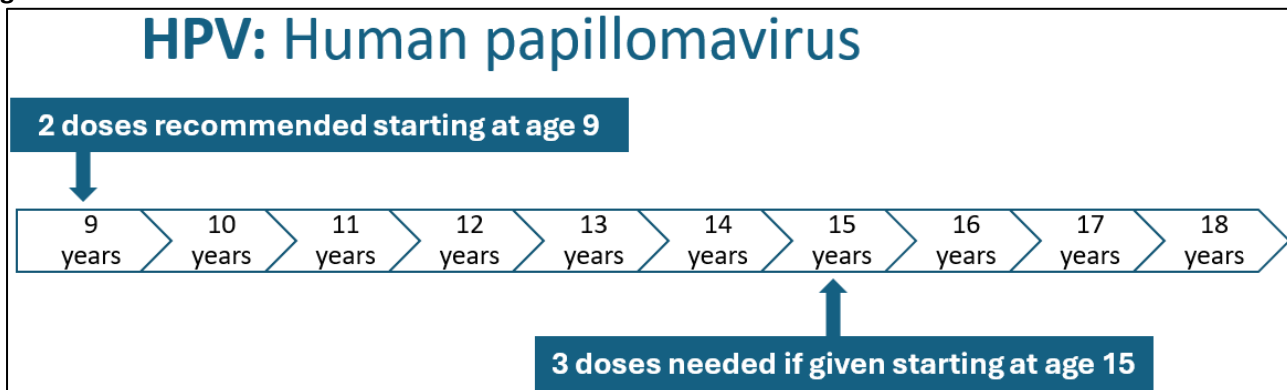
¹⁸ Rumrich, I. K., Viluksela, M., Vähäkangas, K., Gissler, M., Surcel, H. M., & Hänninen, O. (2016). Maternal Smoking and the Risk of Cancer in Early Life - A Meta-Analysis. *PloS one*, 11(11), e0165040. <https://doi.org/10.1371/journal.pone.0165040>

¹⁹ U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <https://www.cdc.gov/cancer/dataviz>, released in June 2026.

HPV Vaccination

The Illinois Department of Public Health recommends HPV vaccination for all children. HPV vaccination can be started at age 9-years (Figure 7). Vaccination is recommended through age 26 years for those who were not vaccinated earlier and may also be given at ages 27-45 years based on shared clinical decision-making. Illinois Department of Public Health immunization guidelines can be found at dph.illinois.gov/immunization.

Figure 7. Recommended Schedule for HPV Vaccination²⁰



HPV vaccination is administered as:

- A two-dose series (0, 6-12 months) for persons who initiate vaccination at ages 9 through 14 years.
- A three-dose series (0, 1-2, 6 months) for persons who initiate vaccination at ages 15 through 26 years and for immunocompromised persons.

The American Academy of Pediatrics (AAP) recommends health care providers begin routine HPV vaccination between 9 and 12 years of age to achieve higher on-time vaccination rates and because getting vaccinated earlier leads to a better immune response to the vaccine.²¹ Offering the HPV vaccine beginning at age 9 also offers the opportunity to complete the series before the other vaccines in the adolescent platform are due. Catch-up HPV vaccination is recommended for all persons through age 26 years who are not adequately vaccinated. Adults ages 27-45 years may also receive the vaccine under shared clinical decision-making.

HPV Vaccination Rates in Illinois

Overall, more adolescents in Illinois are up-to-date on the HPV vaccine compared to the U.S. average. In 2024, 66.2% of all adolescents between the ages of 13-17 years in Illinois were up-to-date for HPV vaccination, compared to 62.9% of all adolescents in the U.S. The up-to-date vaccination rate between Illinois males and females ages 13-17 years did differ (Figure 8), with 68.5% of males versus 63.8% of females who were up-to-date.²²

In Illinois, the up-to-date HPV vaccination rate differs by geographic location.²³ The most recent data from 2024 show that urban adolescent populations in Illinois have the highest up-to-date vaccination percentage (65.5%), followed by suburban adolescents (59.4%), and then rural adolescents (42.7%) (Figure 9).

²⁰ Source: Healthy Children at [HPV Vaccination Schedule at Healthy Children](https://www.healthychildren.org/HPV/Vaccination-Schedule-at-Healthy-Children)

²¹ Source: AAP. (2026). Human Papillomavirus Vaccines. [Human Papillomavirus Vaccines at American Academy of Pediatrics](https://www.aapublications.org/human-papillomavirus-vaccines)

²² Source: Centers for Disease Control and Prevention (CDC), TeenVaxView data tool.

"Up-to-date vaccination" refers to adolescents who have received all recommended HPV vaccines doses.

²³ Source: Centers for Disease Control and Prevention (CDC), TeenVaxView data tool.

Figure 8. Up-to-Date HPV Vaccination Percentages by Sex, Ages 13-17 Years, Illinois and the U.S (2024)

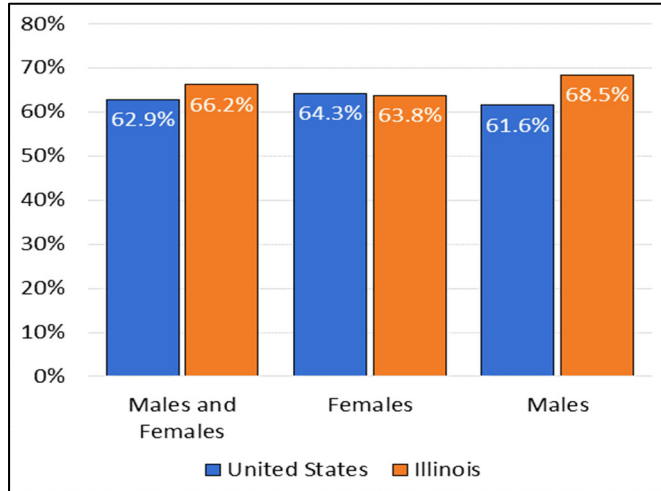
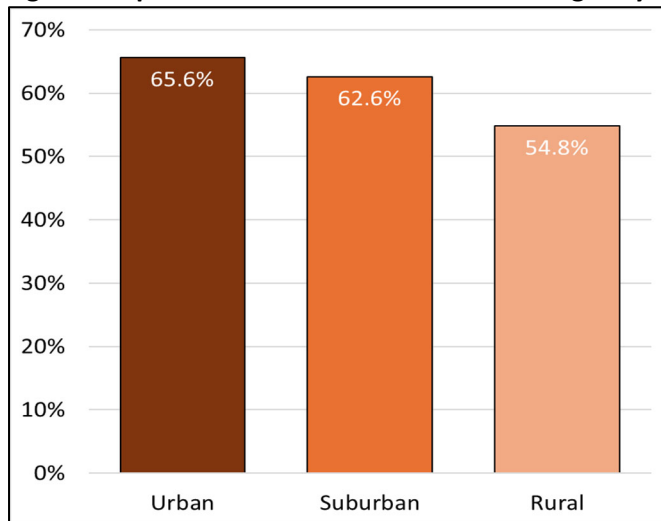


Figure 9. Up-to-Date HPV Vaccination Percentages by Urbanicity, Ages 13-17 Years, Illinois (2024)



HEPATITIS B

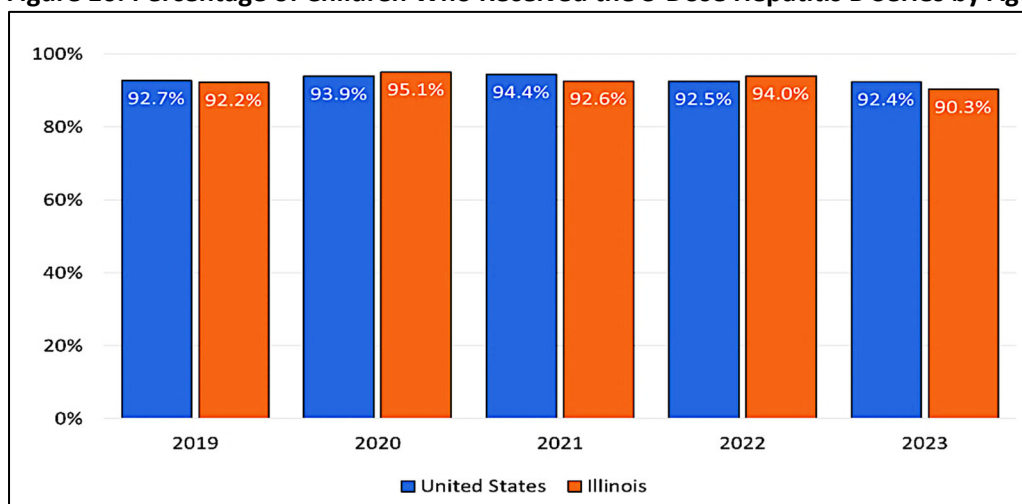
Hepatitis B is a viral infection that can cause liver inflammation and is transmitted through contact with infected blood or other bodily fluids. Chronic infection can lead to severe liver problems, including liver failure, cancer, and cirrhosis. The hepatitis B vaccine plays an invaluable role in helping children and adults prevent liver cancer and lead long, healthy lives.

Figure 10 shows the percentage of children who received the three-dose hepatitis B series by 35 months of age from 2019 to 2023.²⁴ The Illinois vaccination rates are similar to the United States rates. Illinois hepatitis B vaccination rates reached a high of 95.1% in 2020 and decreased to 90.3% in 2023.

Urban refers to Metropolitan Statistical Area (MSA) principal cities; suburban refers to MSA non-principal areas; rural refers to areas outside an MSA (U.S. Office of Management and Budget).

²⁴ Source: KFF. Hepatitis B Vaccination Coverage Among Children. [Hepatitis B Vaccination Coverage Among Children | KFF State Health Facts](#)

Figure 10. Percentage of Children Who Received the 3-Dose Hepatitis B Series by Age 35 Months



Children can get hepatitis B through mother-to-child transmission during birth and delivery or through contact with bodily fluids of people who have it. About 50% of individuals with hepatitis B in the United States do not know they are infected.²⁵

The best way to prevent hepatitis B and help prevent liver cancer is by getting vaccinated. The Illinois Department of Public Health recommends universal hepatitis B vaccination at birth and completion of the full vaccination series according to the child and adolescent immunization schedule found at dph.illinois.gov/immunization. The hepatitis B vaccine is recommended as follows:²⁶

- All infants, including all infants at birth
- All children and adolescents younger than 19 who have not been vaccinated
- Adults 19–59
- Adults 60 and older with risk factors for hepatitis B or who request vaccination

Children through 18 years of age may be eligible to receive vaccines through the Vaccines for Children (VFC) program if they are enrolled in or eligible for Medicaid, uninsured, American Indian or Alaska Native, or under-insured (having insurance that does not cover vaccination). To locate VFC providers, go to [Illinois Department of Public Health Vaccines for Children Provider Search](#) or [Illinois Department of Public Health Vaccine Locator Dashboard](#). Contact the provider to check eligibility and availability.

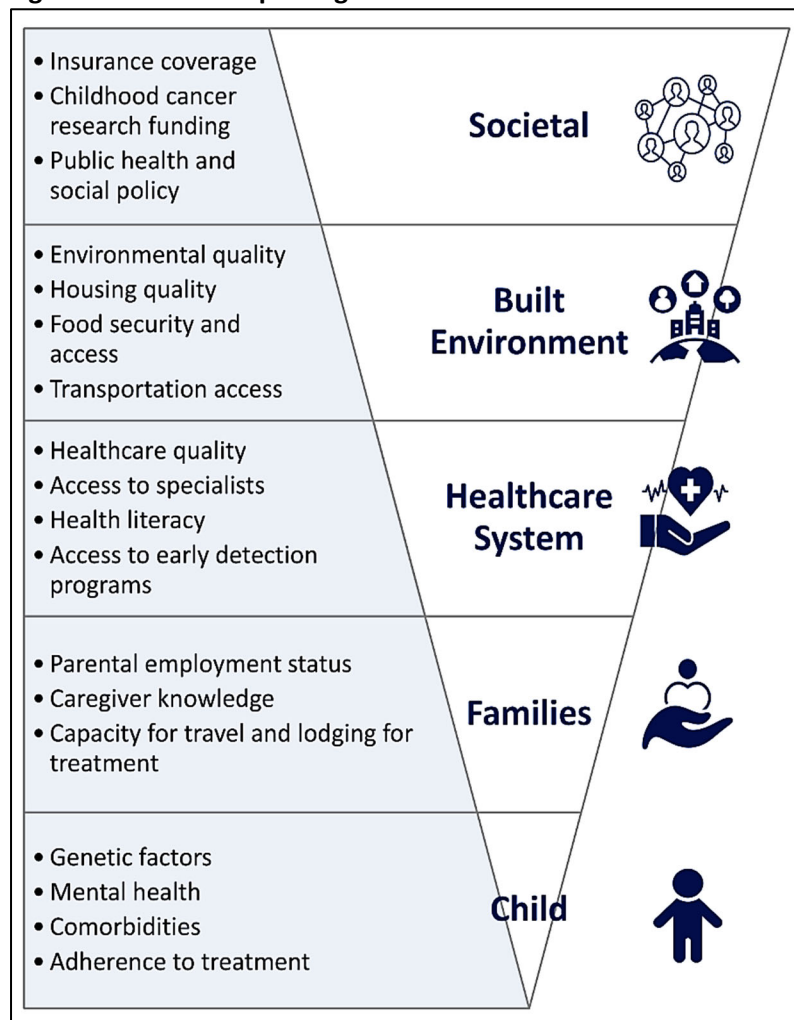
²⁵ [Hepatitis B Basics | Hepatitis B | CDC](#)

²⁶ American Academy of Pediatrics. (2026). *Hepatitis B*. [Hepatitis B at American Academy of Pediatrics](#)

SOCIAL DRIVERS OF HEALTH AND CHILDHOOD CANCER OUTCOMES

Factors That Impact Childhood Cancer Outcomes

Figure 11. Factors Impacting Cancer Outcomes^{26, 27, 28}



Childhood cancer outcomes are shaped by more than medical treatment (Figure 11). Non-clinical factors also shape the experiences that children and families face throughout a cancer journey. Recognizing the impact of these factors helps us identify opportunities to strengthen support for Illinois children with cancer and their families. Addressing these factors is essential for reducing cancer health disparities, improving quality of life, and survival rates for children.

Families also impact a child's mental health, as studies show that a caregiver's mental state or expression of anxiety can influence the emotional well-being and thus the treatment process of that child.²⁷ Families can experience financial hardship, transportation challenges, and childcare burdens that may lead to interruptions in

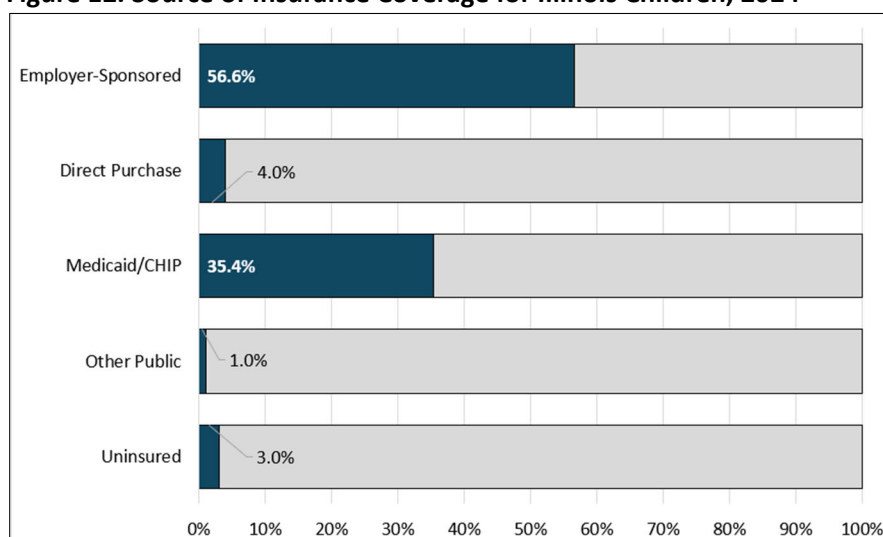
²⁷ Sim, J.-a., Horan, M. R., Choi, J., Srivastava, D. K., Armstrong, G. T., Ness, K. K., Hudson, M. M., & Huang, I.-C. (2024). Multilevel social determinants of patient-reported outcomes in young survivors of childhood cancer. *Cancers*, 16(9), 1661. doi: <https://www.mdpi.com/2072-6694/16/9/1661>

treatment and worse survival outcomes.²⁸ Amongst these stressors, internal conflict within family dynamics can also impact survival outcomes as these conflicts can impact a survivor’s sleep, stress levels, and quality of life.²⁶

Access to quality healthcare is a factor that is significantly influential in determining the survival of a pediatric cancer patient. The availability of supportive services and resources often impacts a family’s ability to adhere to the patient’s designed treatment plan.^{26, 28} Beyond access to care upon diagnosis, quality of healthcare systems also determines the extent to which early cancer detection programs or initiatives may be available to families.²⁸ As a dependent, most of a child’s individual health care accessibility factors are tied to their familial resources. Insurance coverage, for example, influences a child’s survival, as publicly insured or uninsured patients have been reported in studies to have worse survival outcomes when compared to patients covered by private insurance plans.²⁹

Figure 12 shows the sources of insurance coverage for children in Illinois in 2024.³⁰ The majority of Illinois children, 56.6%, are covered by employer-sponsored insurance, followed by 35.4% of children covered by Medicaid or Children Health Insurance Program (CHIP).

Figure 12. Source of Insurance Coverage for Illinois Children, 2024



The neighborhood and built environment that a child with cancer resides in can also impact their survival outcomes. Children with cancer residing in impoverished or socially deprived communities face a higher risk of mortality and lower quality of survivorship.^{27, 31} When a child with cancer has access to a reliable transportation source, quality housing, and a quality-built environment, families can mitigate some of the harm that is associated with neighborhood poverty.³²

²⁸ Wolfson, J. A. (2021). Poverty and survival in childhood cancer: A framework to move toward systemic change. *JNCI: Journal of the National Cancer Institute*, 113(3), 227–230. <https://academic.oup.com/jnci/article/113/3/227/5998640>

²⁹ Tran, Y. H., Coven, S. L., Park, S., & E. A. (2022). Social determinants of health and pediatric cancer survival: A systematic review. *Pediatric Blood & Cancer*, 69(5), e29546. doi: <https://doi.org/10.1002/pbc.29546>

³⁰ U.S. Census Bureau. (2023). *American Community Survey 1-year estimates*. Retrieved from [United States Census Bureau](https://www.census.gov/data/tables/2020/acs/1-year.html)

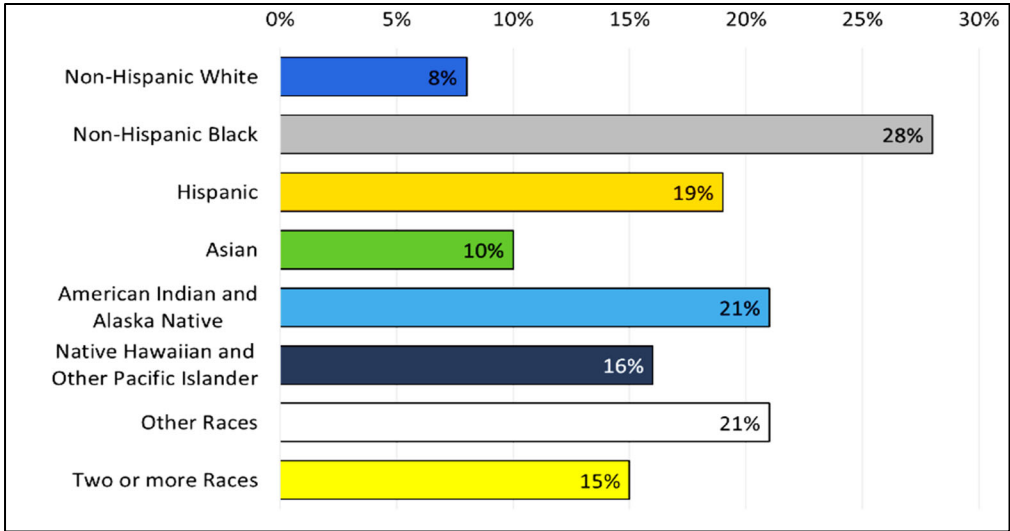
³¹ Chalfant, V., Riveros, C., Bradfield, S. M., & Stec, A. A. (2023). *Impact of social disparities on 10 year survival rates in paediatric cancers: a cohort study*. *The Lancet Regional Health – Americas*, 20, Article 100454. doi: <https://doi.org/10.1016/j.lana.2023.100454>

³² Erdmann, F., Feychting, M., Mogensen, H., Schmiegelow, K., & Zeeb, H. (2019). Social inequalities along the childhood cancer continuum: An overview of evidence and a conceptual framework to identify underlying mechanisms and pathways. *Frontiers in Public Health*, 7, 84. <https://www.frontiersin.org/articles/10.3389/fpubh.2019.00084/full> (Frontiers)

Social conditions such as income and educational opportunities, racism, and segregation heavily influence what a child’s cancer journey may look like.³² Beyond the family level, poverty is connected to structural forces that create disparities in survival outcomes across populations.^{28,31} To address these challenges, policy-level changes that mitigate financial hardships, increase healthcare access, and improve the availability of social supports are necessary.

In 2023, poverty (defined as an income below \$23,940 for an individual household or below \$83,580 for an eight-person household³³) among children in Illinois varied substantially across racial and ethnic groups, as shown in Figure 13. Non-Hispanic Black children had the highest poverty rate at 28%, followed by American Indian and Alaska Native children (21%), children classified as other races alone (21%), and Native Hawaiian and Other Pacific Islander children (16%). Poverty also affected 19% of Hispanic children and 15% of children of two or more races. Lower poverty rates were observed among Asian children (10%) and non-Hispanic White children (8%). These differences indicate clear racial and ethnic disparities in childhood poverty across the state.³⁴

Figure 13. Percentage of Children (Age < 18 Years) Below Poverty Level, by Race/Ethnicity, Illinois, 2023



³³ U.S. Department of Health and Human Services. (2026). 2026 Federal Poverty Level Standards. Retrieved from [2026 Federal Poverty Level Standards | Guidance Portal](#)

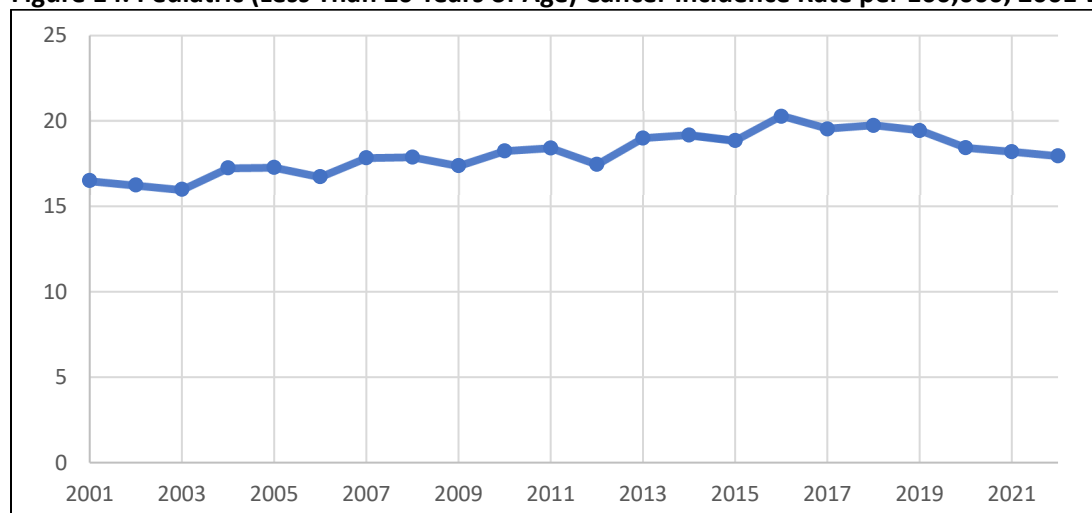
³⁴ U.S. Census Bureau. (2023). *American Community Survey 1-year estimates*. Retrieved from [United States Census Bureau](#)

IMPORTANT STATISTICS OF CHILDHOOD CANCER

This section will describe important statistics regarding the burden of childhood cancer. Rates and counts are suppressed if fewer than 16 cases are reported in a specific category, such as cancer type, race and/or ethnicity, age, and state. Due to the small number of childhood cancer cases, data is not available by county.³⁵

From 2001 to 2022, Illinois' age-adjusted pediatric cancer incidence rate, the number of new cases of disease during a specified period of time, for children less than 20 years remained stable overall, fluctuating only slightly from year to year (Figure 14).³⁶

Figure 14. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rate per 100,000, 2001-2022, Illinois

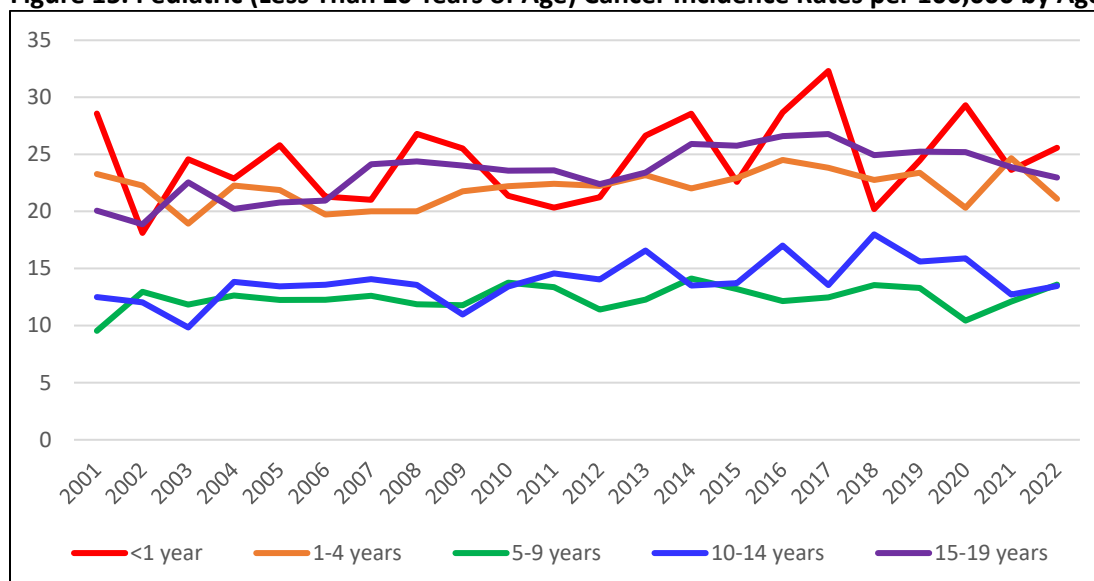


Across 2001–2022, pediatric cancer incidence in Illinois showed stable but distinct age-related patterns (Figure 15). Infants (less than 1 year of age) and adolescents ages 15 to 19 years consistently had the highest incidence rates, while children ages 5 to 9 years had the lowest.³⁵

³⁵ When the numbers of cases (or deaths) used to compute the incidence (and death) rates (and trends) are small, those rates (and trends) tend to have poor reliability. Therefore, to discourage misinterpretation and misuse of counts, rates, and trends that are unstable because of the small number of cases or deaths, these statistics are not shown in tables, figures, and maps if the counts are less than 16 for the time period. Another important reason for employing a cell suppression threshold value is to protect the confidentiality of patients whose data are included in a report by reducing or eliminating the risk of identity disclosure. These rules are set forth by the US Census Bureau.

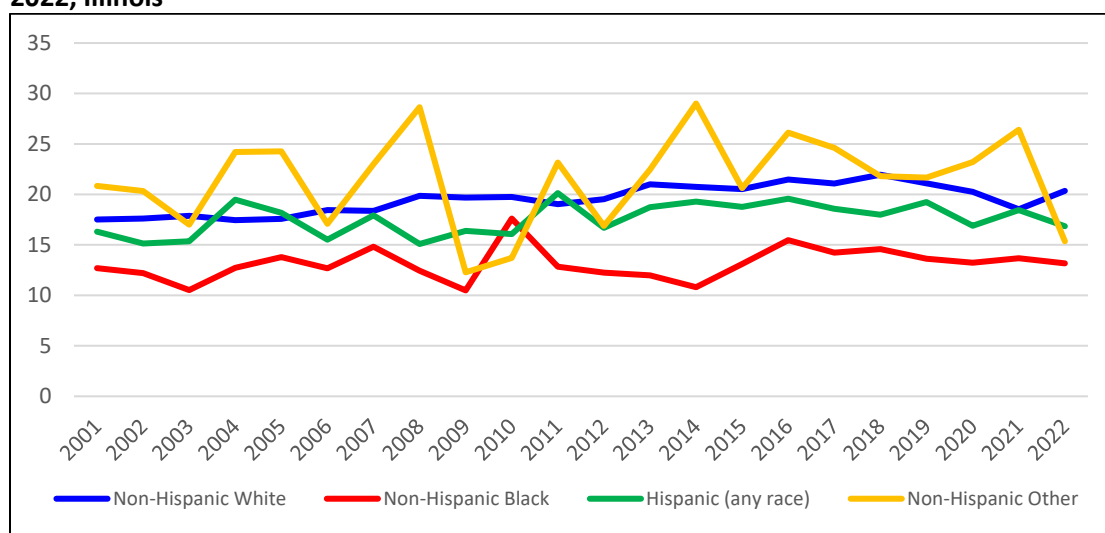
³⁶ Case Data: Illinois Department of Public Health, Illinois State Cancer Registry, Public Data Set V32, 1986–2022, data as of November 2024. Population Data: Surveillance, Epidemiology, and End Results (SEER) Program Populations (1969–2023) <Katrina/Rita Adjustment> – Linked to County Attributes – Total U.S., released Feb 2025.

Figure 15. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rates per 100,000 by Age, 2001-2022, Illinois



From 2001 to 2022, pediatric cancer incidence in Illinois remained relatively stable across racial and ethnic groups, but clear differences in magnitude were evident (Figure 16). Non-Hispanic White children consistently had one of the highest incidence rates, aligning with national patterns. Hispanic children and those in the non-Hispanic Other race category showed moderate incidence levels, with noticeable year-to-year fluctuation. Non-Hispanic Black children consistently had the lowest incidence, mirroring national data. The non-Hispanic Other group, which combines several small racial categories (Asian, American Indian/Alaska Native, Pacific Islander, and multiracial children), exhibited greater variability across the years.³⁵

Figure 16. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rates per 100,000 by Race/Ethnicity, 2001-2022, Illinois



From 2001 to 2022, pediatric cancer incidence rates in Illinois remained relatively stable for both males and females, with only modest year-to-year fluctuations (Figure 17). Males exhibited slightly higher incidence rates than females across most years.³⁵

Figure 17. Pediatric (Less Than 20 Years of Age) Cancer Incidence Rates by Sex, 2001-2022, Illinois

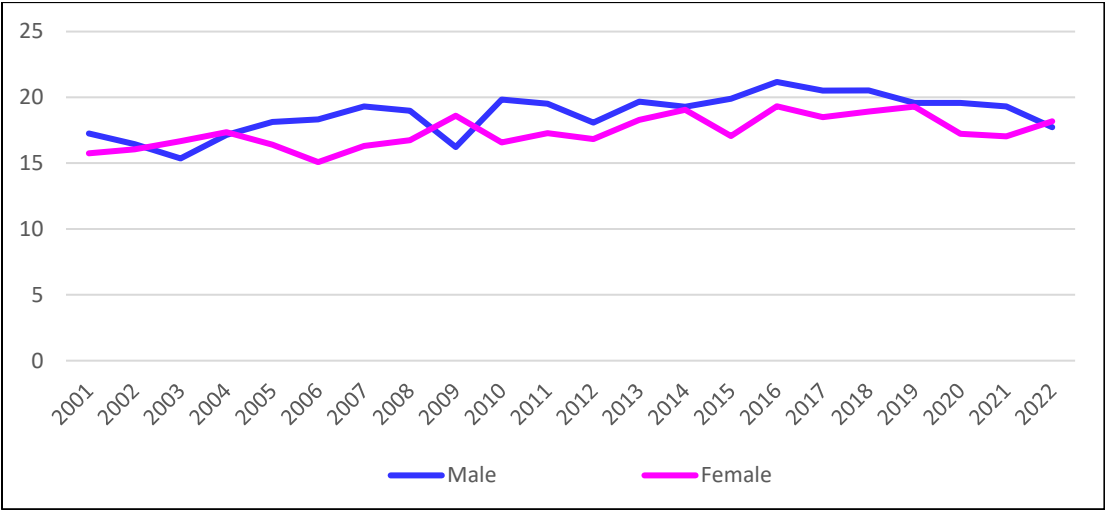
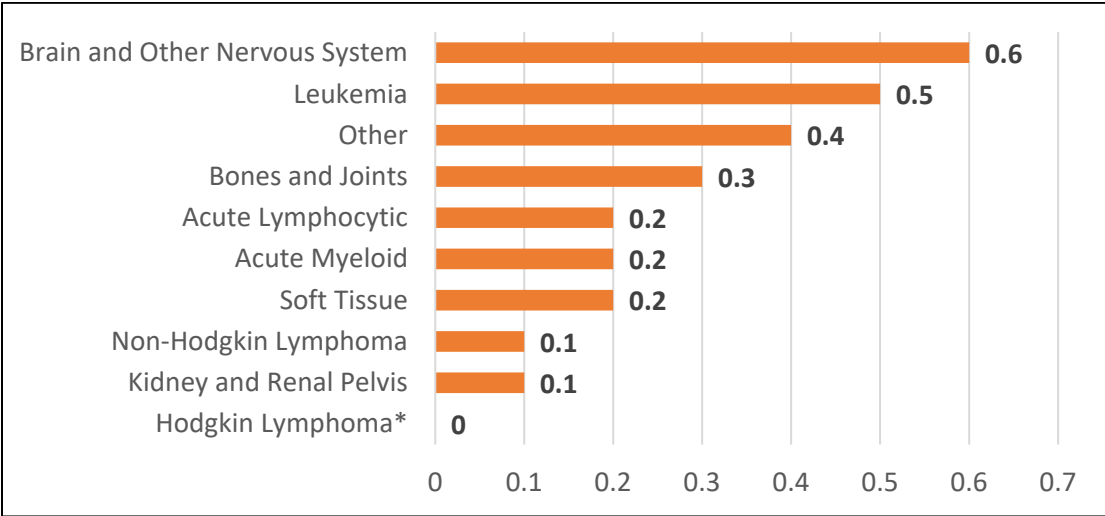


Figure 18 shows the pediatric cancer deaths by primary site for 2020-2024 in the U.S.³⁷ Brain and other nervous system cancers had the highest rate of deaths nationally at 0.6 per 100,000 children. The following figures show U.S. pediatric death and survival rates. Illinois-specific data is unavailable.

Figure 18. Pediatric (Less than 20 Years of Age) Cancer Deaths by Primary Site per 100,000 Children, 2020-2024, U.S.



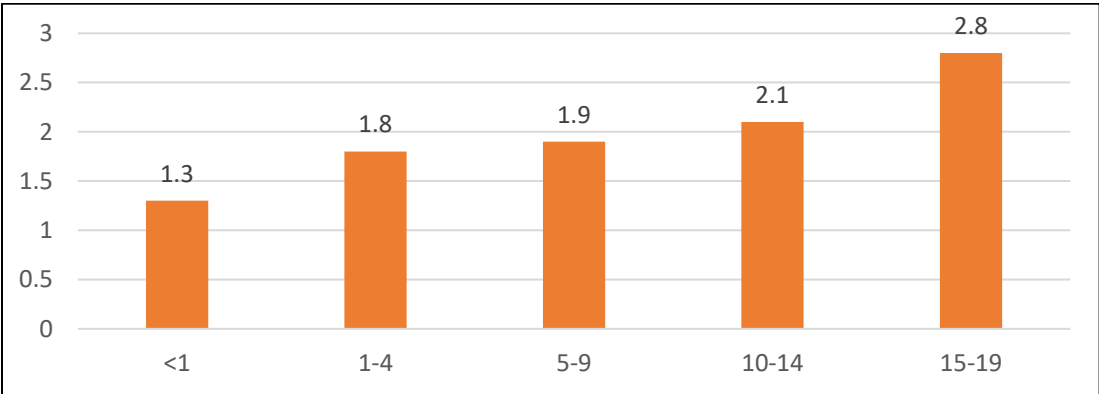
*Data not presented.

Rates are the number of cases (or deaths) per 100,000 people and are age-adjusted to the 2000 U.S. standard population.

Figure 19 shows the pediatric cancer deaths by ages for 2020-2024 in the U.S.³⁶ Children ages 15-19 years had the highest rate of deaths at 2.8 per 100,000 children nationally. Illinois-specific data is unavailable.

³⁷ U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <https://www.cdc.gov/cancer/dataviz>, released in June 2026.

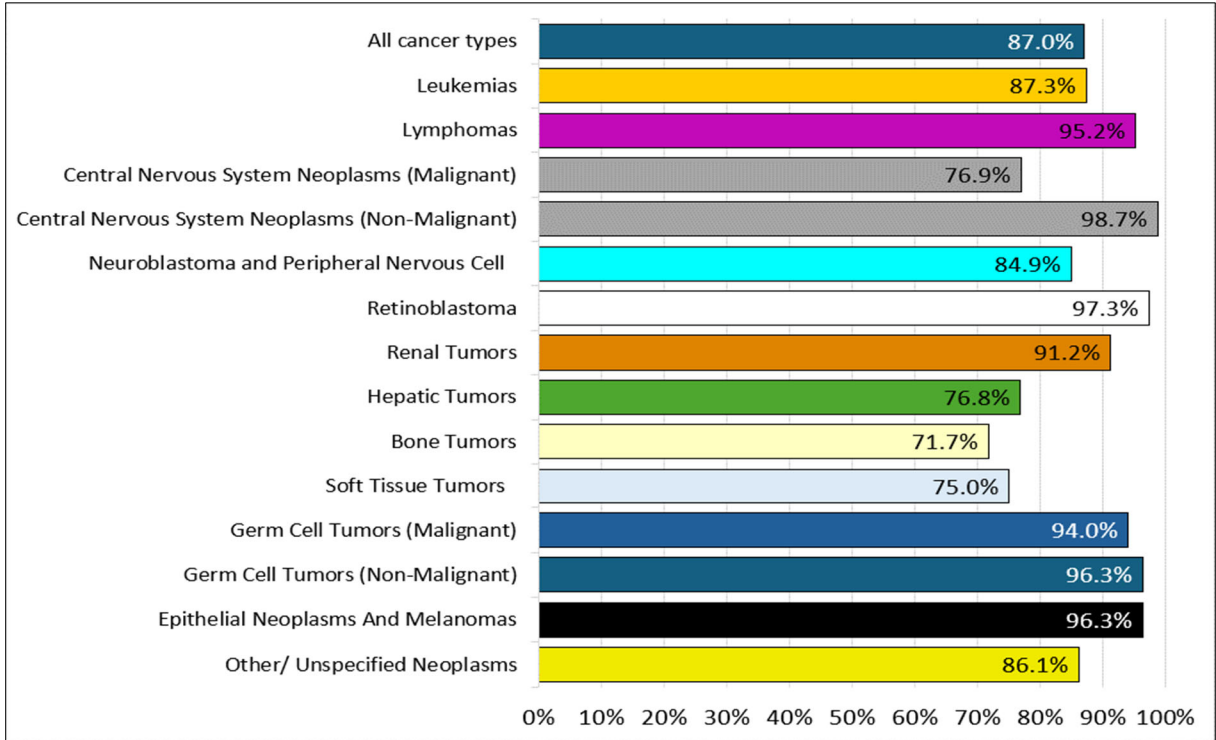
Figure 19. Pediatric (Less than 20 Years of Age) Cancer Deaths by Age per 100,000 Children, 2020-2024, U.S.



Rates are the number of cases (or deaths) per 100,000 people and are age-adjusted to the 2000 U.S. standard population.

Figure 20 shows the estimated percentage of U.S. patients who are expected to survive the effects of their cancer five years or more after cancer diagnosis.³⁸ Survival data specifically for Illinois is not available.

Figure 20. Five-Year Survival Rates, Comparison by Childhood Cancer Types (Less Than 20 Years), 2015–2021, U.S.



³⁸NCCR*Explorer: An interactive website for NCCR cancer statistics. National Cancer Institute; 2025 Sep 24. Available from: [Information at Childhood Cancer Data Initiative at the National Cancer Institute](#). Note: The data covers diagnoses from 2015–2021, but the values shown represent 5-year survival rates using NCCR*Explorer’s method for summarizing survival over multiple years.

CALL TO ACTION - WHAT YOU CAN DO

Whether you are a cancer survivor, caregiver of a cancer patient, community member, employer, health care professional, or policymaker, everyone can play a role in helping with early detection, treatment, and survivorship of childhood cancer in Illinois.

The 2022-2027 Illinois Comprehensive Cancer Control Plan provides details on different actions by role. The plan is available at [Illinois Department of Public Health Cancer Plan Call to Action](#).

Individuals

- Quit smoking or never start smoking and avoid/reduce exposure to secondhand smoke.
- Maintain a healthy diet by eating the recommended amounts of fruits and vegetables.
- Schedule exercise or be active at least 30 minutes per day.
- Get vaccinated against diseases that can cause cancer, such as human papillomavirus (HPV) and hepatitis B.
- Test your home for radon and implement mitigation strategies, such as sealing cracks and other openings in the foundation and modifying house or room pressure and ventilation.
- Collect family health history and share with your health care provider.
- Reduce exposure to UV radiation and wear sunscreen.
- Ask about genetic counseling services.
- Support cancer survivors.
- Get a copy of the cancer treatment plan and instructions on what to do after treatment.
- Get recommended cancer screenings.
- Ask about support groups.
- Explore clinical trials.

Community Organizations

- Ensure equitable access to educational opportunities for children with cancer.
- Increase awareness of childhood cancer among families, health care professionals, schools, and society.
- Identify and address family medical education needs (diagnosis, treatment, late-effects, support programs, sibling support, and respite care).
- Encourage participation in wellness programs.
- Provide healthy foods and drinks at events.
- Provide information on ways to prevent cancers.
- Provide at-home radon kits.
- Assist community members with signing up for insurance.
- Collaborate to address and to remove barriers to care.
- Provide family health history tools.
- Establish partnerships with local health care organizations to raise awareness and to educate community members.
- Establish partnerships with local health care organizations to raise awareness, educate, and increase access to screening and early detection services for community members.
- Provide information for cancer patients and survivors.
- Provide information about genetic services.

Schools

- Provide education about healthy foods and physical activity.
- Test buildings for radon.
- Implement HPV vaccination campaigns in conjunction with school nurses and other school health staff.
- Work with school intervention specialists to raise awareness among patients, families, educators, and administrators of the support that should be available through the school system.
- Educate staff and personnel on cancer treatment and survivorship.
- Provide counseling services for students and parents going through cancer treatment.

Employers

- Educate human resource professionals as to the full extent of resources available to pediatric cancer caregivers through the Family Medical Leave Act.
- Offer employee insurance benefits for wellness programs.
- Provide breaks to encourage health behaviors.
- Provide education on cancer prevention.
- Adopt smoke-free policies.

Health Care Professionals

- Ensure children diagnosed with cancer (and their families) have equitable access to quality health care and psychosocial programs.
- Ensure children (and their families) have knowledge of the long-term effects of childhood cancer treatment and have equitable access to high-quality follow-up care.
- Identify and address family medical education needs (diagnosis, treatment, late-effects, support programs, sibling support, and respite care).
- Increase awareness of childhood cancer among families, health care professionals, schools, and society.
- Educate patients on recommendations for healthy eating habits and physical activity.
- Educate on the HPV vaccine and hepatitis B vaccine.
- Encourage sun safety behaviors.
- Collect family health history annually and assess risks; refer to genetic counseling/testing when appropriate.
- Utilize community/patient navigators to conduct outreach to community members and stakeholders to educate and raise awareness of cancer prevention.
- Use electronic medical record systems and other reminder systems to keep individuals up to date on screenings and vaccinations.
- Provide appropriate medical care for cancer patients and survivors.
- Encourage patients to participate in clinical trials.
- Establish referral pathways for palliative and hospice care to be used as needed.
- Refer patients to mental health services when needed.

Health Insurers and Policy Makers

- Support the implementation of policies for healthier environments.
- Support collection of family health history, risk assessment, and appropriate genetic counseling/testing services.
- Ensure no cost sharing for recommended cancer screenings and immunizations.
- Support coverage of genetic counseling/testing services.

CLINICAL TRIALS

Clinical trials are research studies conducted for doctors to find new ways to improve treatments and the quality of life for people with certain diseases. Researchers design cancer clinical trials to test new ways to treat cancer, find and diagnose cancer, prevent cancer, and manage cancer symptoms and treatment side effects.

Information about current clinical trials may be found through the following sites:

Illinois Clinical Trials

- Ann & Robert H. Lurie Children's Hospital of Chicago and Stanley Manne Children's Research Institute: [Clinical Trials at Ann and Robert H. Lurie Children's Hospital of Chicago and Stanley Manne Children's Research Institute](#)
- UChicago Medicine Comer Children's Hospital: [Clinical Trials at University of Chicago Medicine Comer Children's Hospital](#)

National Clinical Trials

- MD Anderson: [Clinical Trials at The University of Texas MD Anderson Cancer Center](#)
- National Cancer Institute: [Clinical Trials at the National Cancer Institute](#)
- National Library of Medicine: [Clinical Trials at the National Library of Medicine](#)
- Siteman Cancer Center: [Clinical Trials at Siteman Cancer Center](#)
- St. Jude Children's Research Hospital: [Clinical Trials at St. Jude Children's Research Hospital](#)
- University of California San Francisco: [Clinical Trials at University of California San Francisco](#)

RESOURCES

This section provides a sampling of resources for childhood cancers in the following areas:

- Pediatric Oncology Data Resources
- Pediatric Cancer Units in Illinois
- Support Organizations
 - Central Illinois Organizations
 - Chicago/Cook County/Northern IL
 - Non-Illinois/National Organizations
- Related Reports
- Resource Guides

Please contact the organizations below for more information, availability, and requirements for services.

This is not an all-inclusive list. Many other resources and organizations may be available that are not listed below. Additional resources and support systems may be available through the child's oncology provider.

Pediatric Oncology Data Resources

- Childhood Cancer Data Initiative Data Catalog (CCDC): A searchable database of pediatric data resources, sharing clinical care and research data generated by the pediatric cancer research community. [CCDC](#).
- Illinois Youth Survey: The IYS (IYS) is a self-report survey of 8th, 10th, and 12th graders administered in school settings every other year. It is designed to gather information about a variety of health and social indicators including substance use and perceptions, bullying, school climate, nutrition, and physical activity. [Illinois Youth Survey](#).
- Kids First Data Resource Portal: The Gabriella Miller Kids First Data Resource Center (Kids First DRC) is a collaborative pediatric research effort with the goal to understand the genetic causes and links between childhood cancer and congenital disorders. [Kids First](#).
- National Childhood Cancer Registry (NCCR): The National Childhood Cancer Registry (NCCR) is a component of NCI's Childhood Cancer Data Initiative (CCDI) Data Ecosystem. The goal of CCDI is to build a community of pediatric cancer researchers, advocates, families, hospitals, and networks committed to sharing clinical care, registry, and research data. By gathering and integrating data from every child, adolescent, and young adult diagnosed with childhood cancer, CCDI aims to improve our understanding of cancer biology, prevention measures, treatment, quality of life, and survivorship. [NCCR](#).
- Pediatric Cancer Data Commons (PCDC): The Pediatric Cancer Data Commons (PCDC) harnesses pediatric, AYA, and adult cancer clinical data from around the world into a single unified platform for research. [PCDC](#).
- St. Jude Cloud: This database includes information on pediatric cancer data across thousands of datasets. Specifically offers gene expression data based on analysis for thousands of tumor samples. [St. Jude](#).
- Youth Risk Behavior Surveillance System (YRBSS): The Youth Risk Behavior Surveillance System (YRBSS) measures health-related behaviors and experiences that can lead to death and disability among youth and adults. [YRBSS](#).

Pediatric Cancer Units in Illinois

- AdventHealth Hinsdale (Hinsdale): [AdventHealth Hinsdale](#).
- Advocate Christ Medical Center (Chicago): [Advocate Christ Medical Center](#).

- Advocate Good Shepherd Hospital (Barrington): [Advocate Good Shepherd Hospital](#).
- City of Hope Chicago (Chicago): [City of Hope Chicago](#).
- Edward-Elmhurst Health Integrated Cancer Program (Chicago): [Endeavor Health](#).
- HSHS St. John's Hospital (Springfield): [HSHS St. John's](#).
- John H. Stroger Hospital (Chicago): [Cook County Health](#).
- Loyola University Medical Center (Chicago): [Loyola Medicine](#).
- Northwestern Memorial Hospital (Chicago): [Northwestern](#).
- OSF Saint Francis Medical Center (Peoria): [OSF Healthcare](#).
- Rush University Medical Center (Chicago): [Rush University Medical Center](#).
- University of Chicago Medical Center (Chicago): [University of Chicago Medicine](#).
- University of Illinois Hospital (Chicago): [University of Illinois Hospital](#).

Support Organizations

Central Illinois Organizations

- OSF HealthCare Children's Hospital (Peoria): Provides critical, non-treatment related, medical and support programs and services, to help oncology patients live life beyond a cancer diagnosis. [OSF Healthcare](#).
- Ronald McDonald House Charities (RHMC) of Central Illinois: Provides essential services that remove barriers, strengthen families, and promote healing when children need healthcare. [Ronald McDonald House](#).

Chicago/Cook County/Northern IL

- Advocate Children's Hospital: Offers medical services, psychosocial and financial support, education, research, and survivorship programs. [Advocate Children's Hospital](#).
- American Cancer Society (Chicago): Supports cancer survivors and their families through advocacy, research, and patient support. [American Cancer Society](#).
- Bear Necessities Pediatric Cancer Foundation: Programming for granting wishes for patients, financial (\$500 diagnosis and relapse assistance eligibility), counseling through the Bear Necessities Counseling Program offers cost assistance for pediatric cancer patients. The webpage includes specific restrictions and eligibility criteria, scholarship opportunities for pediatric cancer patients and/or a sibling. [Bear Necessities](#).
- Cal's Angels: Provides wish granting, comfort kits, hospital parties, research and awareness programs. [More information at Cal's Angels](#).
- Camp One Step by Children's Oncology Services: Provides free camps and experiences for pediatric cancer patients and their families providing accommodations, transportation, and medical support for all campers. [More information at Camp One Step](#).
- Cancer Support Center: Provides virtual and in-person programs as resources; including specific reoccurring group meetings, counselling and stress management programs (some in-person, some virtual), fitness programs, nutrition programs, body image wig boutique. [More information at Cancer Support Center](#).
- Cancer Wellness Center: Provides free counseling services, support groups, health and nutrition programs, educational programs. [More information at Cancer Wellness Center](#).
- Children's Place Association: Provides vital services often lacking in under-resourced neighborhoods, such as early education, trauma therapy, support groups, and primary healthcare. [More information at Children's Place Association](#).
- Compass to Care Childhood Cancer Foundation: Provides transportation services. [More information at Compass to Care](#).

- Gilda's Club Chicago: Provides virtual and in-person programs. [More information at Gilda's Club Chicago.](#)
- Lurie Children's Hospital: [Lurie Children's Hospital.](#)
- The Dragonfly Foundation: Offers families battling pediatric cancer a holistic, uncompromising, fighting chance at well-being. [More information at Dragonfly Foundation.](#)
- Wellness House: Offers a variety of programs and services — exercise classes, nutrition seminars, support groups and more — that complement the treatment from your medical team. [More information at Wellness House.](#)

Non-Illinois/National Organizations

- Alex's Lemonade Stand Foundation for Childhood Cancer: Offers financial and logistical support, sibling support programs, education, community support. [Alex's Lemonade Stand Foundation.](#)
- Amanda Hope Rainbow Angels: Offers psychosocial support, financial support, education, community support. [Amanda Hope.](#)
- American Childhood Cancer Organization: Offers information; patient services (e.g., free rides, lodging via Hope Lodge, ACS CARES app, helpline); education materials; advocacy; research funding. Programs include Cancer Survivors Network, educational brochures, training for professionals, and the helpline. [American Childhood Cancer Organization.](#)
- Band of Parents: A grassroots, nonprofit organization that funds innovative research and clinical trials for neuroblastoma, helping increase the survival rate for this childhood cancer. [Band of Parents.](#)
- Candlelighters Childhood Cancer Family Alliance: Provides emotional, educational and practical support to families of children with cancer. [Candlelighters.](#)
- Cardinal Glennon Children's Hospital: Provides pediatric oncology care and related support services. [Cardinal Glennon.](#)
- Childhood Cancer Coalition: Provides advocacy, educational support, and family support. [Childhood Cancer Coalition.](#)
- Friends of Kids with Cancer: Provides free services. [Friends of Kids with Cancer.](#)
- His Kids Cancer Support: Treatment camp for children (7-14) undergoing cancer treatment or in remission, sibling camp (7-14) for siblings of childhood cancer patients, Lit camp (15-17) for current patients or siblings who wish to become a camp/community leader for children or siblings of children with cancer. [His Kids Cancer Support.](#)
- Journey Like June: Provides financial support and assistance as well as individual family support. [Journey Like June.](#)
- Kellsie's Hope Foundation: Provides financial and emotional support. [Kellsie's Hope.](#)
- Leukemia Research Foundation: Provides educational conferences and webinars, online and one-on-one mentorship programs, financial grant of up to \$1,500 for leukemia patients, curated external resources. [Leukemia Research Foundation.](#)
- Make a Wish Foundation: Provides wish granting, comfort kits, hospital parties, research and awareness programs. [Make a Wish Foundation.](#)
- National Children's Cancer Society: Provides legislative, financial, psychosocial (grief and emotional support), education/information (clinical trials, disability, medical/insurance, camps, transplant), wish foundations, and transportation resources. [NCCS.](#)
- Passport for Care: Provides a data entry platform, algorithm-based screening recommendation generator. Offers information on adolescent and young adult survivorship, financial, legal, and college and scholarship resources. Provides clinicians with access survivorship data. [Passport for Care.](#)
- SMART ALACC (Oncolink): Provides an informative survivorship care plan. [SMART ALACC.](#)

- St. Baldrick's Foundation: Provides information on cancer types, treatment options, risk and prevention, transition of care into adulthood, worksheets for health care providers to build patient treatment binders. Primarily an information-based resource. [St. Baldrick's](#).
- St. Jude Children's Research Hospital: Provides psychosocial (counseling), in-person and online groups for caregivers, in-person groups for siblings, parent mentorship program of past patient parents, information based coping and educational resource, couples/relationship connectedness resource. [St. Jude](#).
- St. Louis Children's Hospital: Provides programs for children with cancer (programs for treatments and children with specialized cancer types such as brain tumor and neuro-oncology programs), survivorship programs (aid with managing side effects of treatment). [St. Louis Children's Hospital](#).

Related Reports

- [Childhood Cancer in South Carolina: 25-Year Trends in Incidence, Survival and Mortality](#): South Carolina provides a report of a 25-year analysis of incidence, survival, and mortality. It uncovers persistent racial/ethnic disparities and urban–rural differences. The report sets priority areas: addressing inequities, enhancing survivorship care, and monitoring changing incidence patterns.
- [Child and Adolescent Cancer Statistics Report](#) from the Illinois State Cancer Registry (ISCR): This website includes a report that covers current statistics related to childhood and adolescent cancers in Illinois.
- [Cancer in Adolescents and Young Adults](#): The American Cancer Society provides this report with an overview of trends in cancer incidence, mortality, and survival and some of the unique challenges among adolescents and young adults. Cancer occurrence in this report is also described separately by age.

Resource Guides

- A Parent's Guide to School and Childhood Cancer: Support for pediatric cancer patients within the educational setting and educational planning support. [Blood Cancer United](#).
- Adapted Resource and Implementation Application (ARIA) Guide: Tool aimed at helping health care professionals all over the world with the necessary information in their efforts to safely diagnose, treat and manage childhood cancer. [St. Jude Children's Research Hospital](#).
- Adolescent and Young Adult Cancers Caregiver Resource Guide: Information and resources for caregivers of cancer patients. [American Cancer Society](#).
- Childhood Cancer Survivors Guide: Provides references and resources. [Alex's Lemonade Stand Foundation for Childhood Cancer](#).
- Childhood Leukemia Support: Guide with information and links about childhood leukemia. [Leukemia Research Foundation](#).
- **Children with Cancer: A Guide for Parents**: Resource guide for parents. [National Cancer Institute at National Institute of Health](#).
- Children's Cancer Cause Advocacy Toolkit: Information related to childhood cancer advocates. [Children's Cancer Cause](#).
- Children's Oncology Group Patient and Family Resources: Practical guides for patients and parents. [Children's Oncology Group](#).
- Children's Oncology Group Survivorship Guide: Detailed information about long-term health effects after treatment. [Children's Oncology Group](#).
- **Defining Essential Psychosocial Care**: Evidenced based standards for psychosocial care. [Mattie Miracle Cancer Foundation](#).
- Diagnosis and Testing: Understanding the tests involved in diagnosis, treatment selection and monitoring of Leukemia and MDS. [Leukemia Research Foundation](#).

- Helping Your Child Transition from Treatment to Survivorship: Information and resources for caregivers and parents of childhood cancer survivors. [American Cancer Society](#).
- Long-Term Follow-Up Guidelines for Survivors of Childhood: Tool aimed at providing health care professionals all over the world with the necessary information in their efforts to safely diagnose, treat, and manage childhood cancer. [Children's Oncology Group](#).
- Navigating Life During and After a Blood Cancer Diagnosis: Survivorship workbook that patients can fill out. [Blood Cancer United](#).
- Next Steps Survivorship Program: Helps patients and caregivers identify and monitor late effects. [Children's Wisconsin](#).
- National Comprehensive Cancer Network Guidelines for Patients and Caregivers:
 - [Guidelines for Pediatric acute lymphoblastic leukemia \(ALL\)](#)
 - [Guideline for AYA patients](#)
 - [Patient and caregiver guidelines for several lymphoma types and other cancers](#)
- Psychosocial Support and Research Program-Educational Materials: Psychosocial educational and therapeutic materials to support children who have been diagnosed with cancer. [National Cancer Institute at the National Institute of Health](#).
- Smart Adult Living After Childhood Cancer (Smart ALACC): Survivorship care plan. [Smart Adult Living After Childhood Cancer](#).
- The Survivorship Checklist: Checklist for patients and caregivers. [National Coalition for Cancer Survivorship](#).
- Together Teens and 20s: Comprehensive online resource for patients and survivors. [St. Jude Children's Research Hospital](#).