

Childhood Cancer Realities

How Big is the Problem?

- Childhood cancer is the # 1 disease killer of children in the U.S [9].
- Globally, it is estimated that there are more than 400,000 cases of childhood cancer annually [19].
- One in five children diagnosed with cancer in the U.S. will die [17].
- Approximately 1 in 263 children in the US will be diagnosed with the disease before the age of 20 [13].
- In 2024 in the U.S., an estimated 9,620 children (ages 0 to 14 years) and 5,290 adolescents (ages 15-19 years) will be diagnosed with cancer, and 1,040 children and 550 adolescents will die from the disease [1].

Progress

NOTE: Stats about the tremendous progress made over the last few decades show the power of research and the hope it brings. But we must also remember that for some types of childhood cancer, there are still no cures.

- In the mid 1970's, 58% of children (0-14 years) and 68% adolescents (15-19 years) with cancer survived at least 5 years. Today that number is 85% overall [9].
- The progress in survival rates can be largely attributed to the treatment advancements made as a result of decades of high participation in pediatric cancer clinical trials [9].
- While great progress has been made in curing some types of childhood cancers, for others progress has been limited, and for some there is still no cure [9].
- The vast majority of drugs approved to treat childhood cancer are approved for adults first, and kids often have to wait years to have access to these same therapies.
- In total, there are 81 FDA-approved drugs to treat pediatric cancer, including supportive therapies. 59 of these drugs have been approved since 2000. However, of these 59 drugs, only 22 were initially approved for kids. The rest were approved for kids years after they were approved for adults. And of those 22, only a few were approved specifically for kids first or for kids exclusively [18].

Ages

- The average age of diagnosis for childhood cancer is 6. There are 71 potential life years lost on average. (Note: These figures differ by a year or two depending on the source.)
- Cancer is diagnosed at all ages, from newborn infants, to children, teens and young adults [9].
- Survival rates for adolescents and young adults have lagged behind that of younger children in some cancer types [9].
- Among children and adolescents (ages 0 to 19) in the United States, the most common types of cancer are leukemias, brain and central nervous system tumors, and lymphomas [9].

Childhood Cancers vs. Adult Cancers

- Most types of cancers that strike children are very different from the types that strike adults. Childhood cancers are often the result of DNA changes in cells that take place very early in life, sometimes even before birth. Research shows that in some cases even when a child has the same type of cancer as an adult, the disease behaves differently and requires altered treatment. For best outcomes, children must be treated by pediatric oncologists, who have the specific expertise needed [9].
- Unlike many cancers in adults, childhood cancers are not strongly linked to lifestyle or environmental risk factors [9].
- Much of what we know about treating adult cancers has been learned from childhood cancer research.
- Most kids are treated on clinical trials if one is available for them; most adults are not [6].

Funding of Childhood Cancer Research

- Thanks to greater advocacy and awareness, the federal investment in childhood cancer research has more than doubled in recent years. In 2022, the National Cancer Institute invested more than \$555 million in childhood cancer research, an 8.24% portion of the Institute's total budget.
- The St. Baldrick's Foundation is the largest charity funder of childhood cancer research grants.

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Survivorship & Late Effects

Note: When a child survives cancer, he or she faces a lifetime that is forever changed, due to the increased risks that result from their treatment. Standard survival statistics count those alive 5 years after diagnosis, but many children are still in treatment or die of cancer after that milestone. Surviving five years is not enough.

• Survivors stats:

- » There are about 500,000 survivors of childhood cancer in the United States [9].
- » 1 in 680 young adults (age 20 to 50) in the United States is a childhood cancer survivor [4].
- » Overall, an estimated 1 in 900 people in the United States is a survivor of childhood cancer [4].
- By the age of 50, more than 99% of survivors have had a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more. By the time a child in treatment for cancer today reaches the age of 50, we want these statistics to be far less grim [5].
- People who have had cancer during childhood or adolescence need follow-up care and enhanced medical surveillance for the rest of their lives because of the risk of complications related to the disease or its treatment that can last for, or arise, many years after they complete treatment for their cancer. It's important for people who had cancer during childhood or adolescence to have regular medical follow-up examinations so any health problems can be identified and treated as soon as possible [9].

A Few Disease-Specific Stats

- Acute Lymphoblastic Leukemia (ALL) is a “liquid” tumor, a cancer of the blood and bone marrow. It is the single greatest killer of children with cancer, accounting for about 25% of all childhood cancer diagnoses [10].
- Cancers of the brain and brain stem are the most common “solid” tumors of childhood and they have the highest mortality rate of the childhood cancers [16].
- Neuroblastoma is the most common type of cancer in infants (younger than 1 year old). The average age of diagnosis is 1-2, and it is rare in children over 10 [2].
- The average age of diagnosis for osteosarcoma, a type of bone cancer, is 15 [15]. Big dogs often get this cancer too, so research to find cures helps both people and pet dogs.
- A rare disease is defined as “any disease or condition that affects fewer than 200,000 people in the United States, or about 1 in 1,500 people. By that definition, all pediatric cancers – and in fact most adult cancers -- are rare. But some are rare, even within childhood cancers. These include thyroid cancer, melanoma and nonmelanoma skin cancers, and multiple types of carcinomas (e.g., adrenocortical carcinoma, nasopharyngeal carcinoma, and most adult-type carcinomas such as breast cancer, colorectal cancer, etc.). These diagnoses account for about 4% of cancers diagnosed in children aged 0 to 14 years, compared with about 20% of cancers diagnosed in adolescents aged 15 to 19 years [11].
- Children with Down syndrome have an increased risk of developing leukemia [9].
- 8% to 18% of all cancers in children overall are caused by an inherited pathogenic variant (harmful alteration) in a cancer predisposition gene, although the percentage varies across cancer types [7].

The Following Info on Childhood Cancer Types is Provided in Case it is Helpful

Acute Lymphoblastic Leukemia (ALL) is the most common type of childhood cancer. It is a cancer of the blood and bone marrow. Normally the bone marrow makes stem cells that mature into blood cells over time. In ALL, too many stem cells turn into immature white blood cells (lymphoblasts) that don't mature into the normal blood cells (lymphocytes) that fight infection by attacking germs and other harmful bacteria.

Central Nervous System (CNS) tumors are cancers of the brain and brain stem. They are the most common solid tumors of childhood and they have the highest mortality rate of the childhood cancers. Types include medulloblastoma, PNET, germ cell tumors, high-grade and low-grade gliomas, ependymoma, astrocytoma and more.

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The Following Info on Childhood Cancer Types is Provided in Case it is Helpful *(continued)*

Clear Cell Sarcoma of the Kidney (CCSK) is a very rare type of kidney tumor. It is not recognizable as different from Wilms tumor before removal of the tumor, but requires a different treatment.

Ewing Sarcoma is a less common form of bone tumor, affecting mostly children ages five and older. These tumors form in the cavity of the bone.

Hodgkin disease is a type of lymphoma, a cancer of the lymph nodes. It affects teens most commonly, but also younger children. The lymph system is present throughout the body and helps fight infections. Hodgkin disease can start almost anywhere and then spread to almost any organ or tissue, including the liver, bone marrow and spleen.

Myeloid leukemias are more rare and difficult to cure than the more common Acute Lymphoblastic Leukemia. In leukemia, the bone marrow produces large numbers of abnormal blood cells, which flood the bloodstream and lymph system and may invade vital organs. The most common cancer of the myeloid cells is Acute Myeloid Leukemia (AML). Others include Juvenile Myelomonocytic Leukemia (JMML), Chronic Myelogenous Leukemia (CML), Acute Promyelocytic Leukemia (APL), and Myelodysplastic Syndromes (MDS).

Neuroblastoma is a cancer of the sympathetic nervous system, a message network between the brain and other parts of the body. Neuroblastoma tumors can grow in the abdomen, neck or pelvis. It is the most common type of cancer in infants, and can form before birth. The average age of diagnosis is 1-2, and it is rare in children over 10.

Osteogenic sarcoma (or Osteosarcoma) is the most frequently diagnosed type of bone tumor, usually found in adolescents and young adults. Tumors are most often in the large bones of the upper arm (humerus) and the leg (femur and tibia).

Non-Hodgkins Lymphomas (NHL) are cancers of the cells of the immune system (T and B lymphocytes, natural killer cells). Cells of the immune system are produced in the bone marrow and then travel to all the lymph glands, the thymus gland, areas of the intestinal tract, tonsils, and spleen, so a lymphoma can develop in any of those sites. The four major

subtypes of NHL in children are Lymphoblastic, Burkitts, Large B cell, and Anaplastic large cell.

Retinoblastoma is a cancer of the retinoblasts, or “baby” cells in the retina, responsible for vision. Retinoblastoma occurs most often in children from birth to age 3. About 25% of these children have the genetic form of the disease; with every cell in the retina susceptible to tumor formation, usually both eyes are affected [12]. The other 75% have the non-genetic type, affecting only one eye [12]. Since removal of the eye can cure most children research is now focused on preserving vision.

Rhabdoid Tumor of the Kidney is a very rare type of kidney tumor, and rhabdoid tumors can occur in other places of the body, as well. Researchers have found a specific gene mutation that leads to rhabdoid tumors.

Rhabdomyosarcoma is the most common of the soft tissue sarcomas which can be found anywhere in the body. Rhabdomyosarcoma is a tumor that arises in the muscle cells, and is the most common type in children under age ten. The other soft tissue tumors are more rare and tend to be found in adolescents. They include fibrosarcomas, synovial sarcomas, malignant peripheral nerve tumors, leiomyosarcoma, liposarcoma, and others even more rare. Some soft tissue tumors are similar to those found in adults, while others are very unique to children.

Wilms Tumor accounts for about 90% of kidney tumors in children. About 95% of children with this tumor have a “favorable histology” (better cure rate with less treatment) as determined by the pattern the pathologist sees in the tumor cells. The other 5% have anaplastic Wilms tumor, which is much more resistant to treatment [3].

Other Rare Childhood Cancers are actually not so rare, when added together, as they account for about Wilms Tumor accounts for about 90% of kidney tumors in children. About 95% of children with this tumor have a “favorable histology” (better cure rate with less treatment) as determined by the pattern the pathologist sees in the tumor cells. The other 5% have anaplastic Wilms tumor, which is much more resistant to treatment [3].

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