Childhood Cancer Fact Library 2021

All statistics below are for U.S. children from birth through age 19 unless stated otherwise. This summary relies on the most recent published data with respect to its contents, some of which dates back one or more years.

Diagnosis

- The overall incidence of childhood cancer is on the increase, averaging 0.7% increase per year since 1975. Children (0-14) increased 0.9%, while adolescents and young adults, overall cancer incidence rates increased an average of 0.9% per year from 2012 to 2016. (37, 7F)
- 1,190 children (aged 0 -14) and 540 adolescents (aged 15-19) are expected to die from cancer in 2020 (excluding benign and borderline malignant brain tumors). (1A)
- In 2020, there will be approximately 89,500 cancer cases diagnosed and about 9,270 cancer deaths in adolescents and young adults (AYAs) ages 15 to 39 years in the US. (40)
- About 1 in 285 children will develop cancer before the age of 20. (6A)
- 47 children per day or 17,293 children (aged 0-19) were diagnosed with cancer in 2018.(45)
- As of 2018, 4,317 children and teens under age 20 were diagnosed with CNS tumors, accounting for 25% of total cancer diagnoses in the age group 0-19. (45)
- The average age at diagnosis is 8 overall (ages 0 to 19), 5 years old for children (aged 0 to 14), and 17 years old for adolescents (aged 15 to 19) (9), while adults' average age for cancer diagnosis is 65 (7a)
- Childhood cancer is not one disease - there are more than 12 major types of pediatric cancers and over 100 subtypes. (1)
- Most new cancer diagnoses in children are for leukemia (28.1%) and brain/CNS cancers (26.5%), while malignant epithelial neoplasms and melanomas (23.3%) and brain/CNS cancers (21.9%) are top cancers for adolescents. (45)

Long Term Health-Effects Associated with Treatments & Survival

- Cancer in children and young adults is different from cancer that develops later in life. Some of the unwanted side effects of cancer treatments cause more harm to children than they do to adults. This is because children's bodies are still growing and developing, so cancer and its treatment are more likely to affect developing organs. (7H)
- More than 95% of childhood cancer survivors will have a significant health related issue by the time they are 45 years of age (2); these health related issues are side-effects of either the cancer or more commonly, the result of its treatment. 1/3 rd. will suffer severe and chronic side effects; 1/3rd will suffer moderate to severe health problems; and 1/3rd will suffer slight to moderate side effects. (2)
- Cognitive impairment affects up to one-third of childhood cancer survivors. (38)
- A large follow-up study of pediatric cancer survivors found that almost 10% developed a second cancer (most commonly female breast, thyroid, and bone) over the 30-year period after the initial diagnosis. (38)
- Treatment for cancer may cause infertility in childhood cancer survivors. The risk of infertility increases after treatment with chemotherapy with alkylating agents, such as cisplatin, cyclophosphamide, busulfan, lomustine, and procarbazine. (39)
- Female childhood cancer survivors who were treated with chemotherapy— even if they did not receive radiation treatments to their chest — are six times more likely than the general population to be diagnosed with breast cancer later in life. For those who did receive chest radiation, that chance increases exponentially and is on par with those who have the BRCA1 or BRCA2 mutations. (28)
- Childhood cancer survivors are at a 15-fold increased risk of developing Congestive Heart Failure and are at 7-fold higher risk of premature death due to cardiac causes, when compared with the general population. There is a strong dose-dependent relation between anthracycline chemotherapy exposure and CHF risk, and the risk is higher among those exposed to chest radiation. (33)
- Children who were treated for bone cancer, brain tumors, and Hodgkin lymphoma, or who received radiation to their chest, abdomen, or pelvis, have the highest risk of serious late effects from their cancer treatment, including second cancers, joint replacement, hearing loss, and congestive heart failure. (4)
- Beginning five years after diagnosis, those who had cancer in the 70s could expect to live 48.5 years, compared to 53.7 years among those diagnosed in the 80s and 57.1 years among people diagnosed in the 90s. (41)

- Nearly a quarter of childhood cancer survivors experience at least one debilitating neuromuscular condition 20 years post diagnosis. [47]

Treatment, Research, Funding

- Compared with the average stay among children and adolescents, those for cancer care were more than twice as expensive ($17,500 compared with $8,500 per stay) and about two days longer than the typical stay (6.4 versus 4.5 days). Pediatric cancer stays were also more expensive ($17,500 versus $12,100), but not any longer than adult cancer stays. [5]
- The average cost associated with childhood cancer in 2018 was $833,000 for one child for medical costs and lost parental wages. [36]
- One in four families lose more than 40% of their annual household income as a result of childhood cancer treatment-related work disruption, while one in three families face other work disruptions such as having to quit work or change jobs. [36]
- More than 90% of children and adolescents who are diagnosed with cancer each year in the United States are cared for at a children's cancer center that is affiliated with the NCI-supported Children's Oncology Group (COG). Children's Oncology Group is the world's largest organization that performs clinical research to improve the care and treatment of children and adolescents with cancer. Each year, approximately 4,000 children who are diagnosed with cancer enroll in a COG-sponsored clinical trial. COG trials are sometimes open to individuals aged 29 years or even older when the type of cancer being studied is one that occurs in children, adolescents, and young adults. [4]
- As reflected below in the National Cancer Institute's (NCI) Funded Research Portfolio, from 2008 through 2018, the NCI spent an average of 4.08% of its research funding on childhood cancers research. [7C]

Funding

There are two conflicting reporting methods available that are used to gauge federal childhood cancer research investment. A report used in the past and often cited by advocates, is the National Cancer Institute's Funded Research Portfolio (NFRP)[7C] below. It indicates that from 2008 through 2017, the NCI spent an average of 3.97% of its obligations on childhood cancer research. According to NCI's Office of Advocacy Relations (OAR), the NFRP *does not* reflect NCI's *total* investment in any one particular area of research—including childhood cancers—because it does not account for basic science awards, which are not categorized by cancer type and which may have applications to multiple types of cancer.

NCI Childhood Cancers Research Investment*

Year	Total Budget NCI Funding	Childhood Cancers Funding	Percent
2008	$4,827,552,152	$189,672,374	3.93%
2009	$4,966,926,530	$192,844,826	3.88%
2010	$5,098,146,876	$197,126,947	3.87%
2011	$5,058,104,978	$195,529,112	3.87%
2012	$5,066,969,036	$208,070,156	4.11%
2013	$4,787,897,881	$185,134,664	3.87%
2014	$4,932,807,990	$203,716,485	4.13%
2015	$4,951,675,428	$205,060,620	4.14%
2016	$5,206,169,249	$206,767,589	3.97%
2017	$5,636,393,224	$220,273,687	3.91%
2018	$5,937,729,104	$302,325,670	5.09%
Total	$56,470,372,448	$2,306,522,130	4.08%

About the NCI Funded Research Portfolio (https://fundedresearch.cancer.gov/nciportfolio/)
The NCI Funded Research Portfolio (NFRP) web site contains information about research grants, contract awards, and intramural research projects funded by the National Cancer Institute. The NFRP provides access to various NCI budget reports that contain information about research funding according to specific research categories. It also provides the ability to search the database in various ways, including text searching of project abstracts and the ability to search the NIH research categories that are assigned to projects carried out by extramural and intramural groups. [7D]

How does NCI generate NFRP funding data?
At the close of each fiscal year, NCI asks each of its scientific organizations to report their research funding according to specific research categories. The reports that NCI intramural and extramural programs provide are then combined to determine the NCI funding totals for individual research areas. The total research funding for each category is reviewed and verified before NCI publishes on the NCI web site, **Cancer.gov**. (7D)

What is scientific coding?
Scientific coding refers to the categorization of research projects according to scientific focus. In this process, research projects are analyzed and classified according to scientific topic and content. Scientific coding allows the development of science-based budget information, which can be used in portfolio analysis to examine the distribution of funds across research areas. Scientific coding is also necessary to answer inquiries about the scientific and budgetary aspects of Institute-funded research. NCI employs a sophisticated system of scientific coding in which trained professionals and/or scientific staff analyze grant applications, contracts, and intramural projects to classify each project for its degree of relevance to Special Interest Category (SIC) and Organ Site (SITE) codes. This coding structure is meant to describe in a consistent way the major scientific disciplines requested by NIH, DHHS, Congress, and the public. A critical characteristic of coded data is comparability from one fiscal year to the next. This process allows the Institute to respond quickly to requests for information from NCI staff and the broader community. The coding definitions used by the NCI intramural program are consistent with those used for extramural grants and research and development (R&D) contracts to maintain accuracy across the Institute's portfolio. (7D)

- Another report, preferred by OAR, is the NIH RePORTER, which is a congressionally-mandated system all NIH Institutes and Centers (ICs) use to report data by fiscal year (FY). This tool highlights annual support for various research, condition, and disease categories (RCDC) based on grants, contracts, and other funding mechanisms *used across* NIH.

NIH RePORT Categorical Spending (RCDC)
NCI – Pediatric Cancer Category

Fiscal Year	NCI Pediatric Cancer $ Amount	Total NCI Obligations	% of Total Obligations
2016	$289,845,271	$5,206,169,272	5.57%
2017	$351,782,326	$5,636,392,678	6.24%
2018	$413,099,150	$5,927,729,104	6.97%
2019	**$437,681,409**	**$5,992,439,908**	**7.30%**

According to OAR, like the NFRP, the NIH RePORTER also does not account for the totality of NCI's investment in a given area of research because basic science awards cannot be categorized by individual cancer type. Using Total NCI Obligations, without making allowances for NIH items included in the Pediatric Cancer Amount, would distort the percentage of Total Obligations.

While both of the above reports, The NFRP and the NIH RePORTER, seem unable to capture a completely accurate measure of childhood cancer research expenditure as it relates to total research dollars, perhaps a better method to measure progress may be to compare NIH RePORTER pediatric dollars (c) to the Total NIH Dollars (d) for each fiscal year. This method would show changes from one year to the next. Note that the chart below shows that the pediatric cancer expenditures are growing from 2016 to 2019.

	NCI (a) Funded Research Portfolio		NCI (b) Obligations	NIH (c) RePORTER			NIH (d) Obligations
Fiscal Year	Dollars	% to NCI	Total Dollars	Dollars	% to NCI	% to NIH	Total Dollars
2016	$206,767,589	3.97%	$5,206,169,272	$289,845,271	5.57%	0.90%	$32.311 Billion
2017	$220,273,687	3.91%	$5,636,392,678	$351,782,326	6.24%	1.03%	$34.301 Billion
2018	$302,325,670	5.09%	$5,927,729,104	$413,099,150	5.97%	1.11%	$37.311 Billion
2019	Unavailable		$5,992,439,908	$437,681,409	7.30%	1.11%	$39.313 Billion
a. NCI Funded Research Porfolio			https://fundedresearch.cancer.gov/nciportfolio/				
b. NCI Obligations			https://www.cancer.gov/about-nci/budget/fact-book/archive				
c. NIH RePORTER			https://projectreporter.nih.gov				
d. NIH Obligations			https://www.everycrsreport.com/reports/R43341.html				

Survival

Pediatric Cancer 5-Year Observed Survival Rates, Ages Birth to 19 Years (1)The table below is a representation of the estimated 5-year survival rates for various types of childhood cancers for years 2009 through 2015. It should be noted the survival rates listed below reflect general rates and in no way are a representation of an anticipated actual survival outcome for any individual child. (1A)

5-Year Relative Survival % Ages 0-19

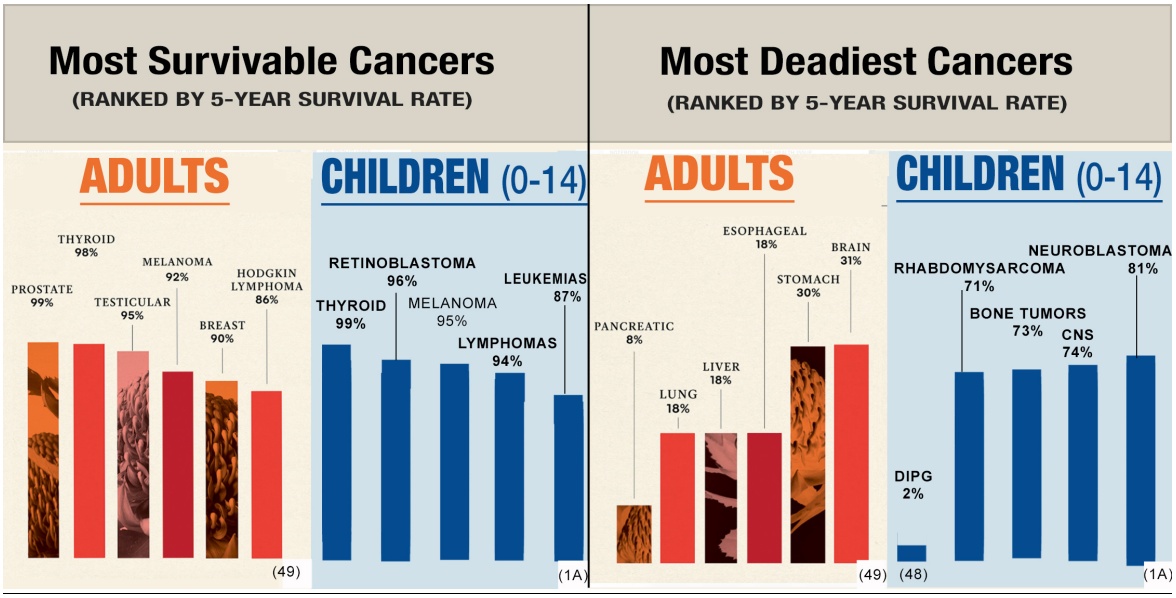
(1A) 5-Year Relative Survival (2009 through 2015) ICCC Type, United States	Birth to 14 Survival %	15 to 19 Survival %
All ICCC groups combined	**84**	**85**
Leukemias, myelopfroliferative & myelodysplastic diseases	87	73
Lymphoid leukemia	91	74
Acute myeloid leukemia	66	66
Lymphomas and reticuloendothelial neoplams	94	94
Hodgkin lymphoma	98	97
Non-Hodgkin lymphoma (including Burkitt lymphoma)	91	88
Central Nervous System neoplasms (d.)	74	77
Benign/borderline malignant tumors	97	98
Neuroblastoma & other peripheral nervous cell tumor	81	57
Retinoblastoma	96	_b
Nephroblastoma & other nonepithelial renal tumors	93	_b
Heptic tumors	79	44c
Hepatoblastoma	83	_b
Malignant bone tumors	73	68
Osterosarcoma	69	67
Ewing tumor & related bone sarcomas	76	58
Rhabdomyosarcoma	71	45
Germ cell & gonadal tumors	91	93
Thyroid carcinoma	99	99
Malignant melanoma	95	95

Footnotes:

Abbreviation: ICCC, International Classification of Childhood Cancer
Survival rates are adjusted for normal life expectancy and are based on follow-up of patients through 2016.
a. Benign and borderline brain tumors were excluded from survival calculations except where specified.
b. Statistic could not be calculated due to fewer than 25 cases during 2009 through 2015.
c. The standard error of the survival rate is between 5 and 10 percentage points.
d. Includes Astrocytoma, Ependymoma, Medullioblastoma, Germ Cell, Brain Stem Glioma

- The average 5-year survival rate for childhood cancers when considered as a whole is 84%. [1A, 3]
- Cancer survival rates vary not only depending upon the type of cancer, but also upon individual factors attributable to each child. [6]
- The average 5-year survival rate, not including children with ALL, is 80%. [1]
- Five year survival rates can range from almost 0% for cancers such as DIPG (2.2%[48]) , a type of brain cancer, to as high as 90% for the most common type of childhood cancer known as Acute Lymphoma Leukemia (ALL). [1]
- Diffuse intrinsic pontine glioma (DIPG) represents approximately 80% of the malignant brainstem tumors occurring in children. [34]
- Despite numerous clinical trials, the outcome of children with DIPG continues to remain dismal, with a median survival of only 11 months, while only 10% of DIPG patients have ≥2-year overall survival (OS) rate. [48]
- 12.2% of all newly diagnosed brain tumors occur under age 20. [7G]
- In 2015 there were nearly 429,000 childhood cancer survivors in the United States. This number is projected to grow to more than 500,000 by 2020. [27]
- Approximately 1 in 530 young adults between the ages of 20 and 39 is a survivor of childhood cancer. [1]
- Long-term follow-up analysis of a cohort of survivors of childhood cancer treated between 1970 and 1986 has shown that cancer survivors remain at risk of complications and premature death as they age, with more than half of survivors having experienced a severe or disabling complication or even death by the time they reach age 50 years. Children treated in more recent decades may have lower risks of late effects due to modifications in treatment regimens to reduce exposure to radiotherapy and chemotherapy, increased efforts to detect late effects, and improvements in medical care for late effects. [4]

Mortality



- Cancer is the number one cause of death by disease among children.[4] Cancer alone represents nearly half of the top seven causes of death by disease in children aged 0-19 yrs. [35]
- 1/3 of childhood brain and CNS cancers occur among those aged 5-9, median age at death is age 9. [7i]
- On average, about 16% of children die within 5 years of diagnosis. Among those children who survive to five years from diagnosis, 18% of them will die over the next 25 years. [8]
- Overall cancer death rates among children ages 0 to 14 years decreased an average of 1.4% per year. Among adolescents and young adults ages 15 to 39 years, overall cancer death rates decreased an average of 1.0% per year. [37]
- Those that survive the five years have an eight times greater mortality rate due to the increased risk of liver and heart disease and increased risk for reoccurrence of the original cancer or of a secondary cancer. [8]
- There are 70 potential life years lost on average when a child dies of cancer compared to 15 potential life years lost for adults. [7B]

- Brain cancer represents 29.9% of total childhood cancer deaths while leukemia accounts for 24.9%(7E)
- A diagnosis of diffuse intrinsic pontine glioma (DIPG) is normally terminal with less than 25% of children surviving even two years. (29)
- Worldwide, 100,000 children lose their lives every year to cancer. (33A)

FDA Approved Drugs for Childhood Cancers

Highlighted drugs below were approved in the first instance for use in cancer treatment for children

FDA Approved Drugs For Childhood Cancers * updated 06/10/2021

Drug	Approved for	Type	Original Approval	Pediatric Approval	Indication
Mercaptopurine	Adults/Peds	Chemo	9/11/1953	4/28/2014	ALL
Cyclophosphamide	Adults/Peds	Chemo	11/16/1959	****	Leukemia, lymphoma, NBL, retinoblastoma 💗
Vincristine	Adults/Peds	Chemo	7/10/1963	***	ALL, lymphomas, Wilms, rhabdomyosarcoma, NB
Dactinomycin	Adults/Peds	Chemo	12/10/1964	8/23/2013	Ewing Sarcoma, sarcoma botryoides
Cytarabine	Adults/Peds	Chemo	6/17/1969	***	Acute non-lymphocycic leukemia
Procarbazine	Adults/Peds	Chemo	7/22/1969	***	Hodgkin lymphoma
Daunorubicin	Adults/Peds	Chemo	12/19/1979	1/30/1998	ALL 💗
Pegaspargase	Peds/AYA	NME**	2/2/1994	4/24/2006	ALL *ct
*FDAMA, enacted Nov. 21, 1997, amended the Federal Food, Drug, and Cosmetic Act relating to the regulation of food, drugs, devices, and biological products					
Clofarabine	Pediatrics	NME**	12/28/2004	9/1/2017	Refactory ALL *ct
Nelarabine	Adults/Peds	NME**	10/28/2005	9/1/2017	T-cell ALL *ct
Dasatinib	Adults/Peds	Targeted Therapy	6/28/2006	11/9/2017 12/21/2018	Ph+CML in the chronic phase *ct PH+ ALL
Imatinib	Adults/Peds	Targeted	9/27/2006	11/9/2017	PH+ ALL and PH+ CML *ct
Nilotinib	Adults/Peds	Targeted	10/29/2007	3/22/2018	Ph+CML in the chronic phase
Ipilimumab	Adults/Peds	MAB***	3/25/2010	7/21/2017	Unresectable or metastatic melanoma ≥ 12 yrs
Everolimus	Adults/Peds	Chemo	10/29/2010	9/25/2012	SEGA / subependymal giant cell astrocytoma.
Asparaginase Erwinia	Adults/Peds	NME**	11/18/2011	11/18/2011	ALL *ct
Pembrolizumab	Adults/Peds	MAB***	9/4/2014	3/14/2017 5/232017 6/13/2018 12/19.2018 6/6/2020 10/14/2020	refractory classical cHL Micosatellite instability-high (MSI-H) or mismatch repair deficient solid tumor Adult and pediatric patients with refractory primarymediastinal largeB-cell lymphoma MatasticMerkel cell carcinoma(≥12years) *ct Tumor mutational burden-high (TMB) solid tumors Relapsed or refractory classical Hodgkin lymphoma (cHL)
Dinutuximab *PRV	Pediatrics	NME**	3/10/2015	3/10/2015	High risk NB See *NB basic research note below *ct
Avelumab	Adults/Peds	MAB***	3/23/2017	3/23/2017	MatasticMerkel cell carcinoma(≥12years)
Blinatumomab	Adults/Peds	MAB***	7/12/2017	7/12/2017	B-cell acute lymphoblastic leukemia
Tisagenleclcucel *PRV	Pediatrics	NME**	8/30/2017	8/30/2017	Relapsed or refractory ALL *ct
Nivolumab	12 yrs or older	MAB***	7/11/2018	7/11/2018	mismatch repair-deficient and microsatellite instability-high colorectal cancer
Iobenguane I 131	12 yrs or older		7/30/2018	7/30/2018	malignant pheochromocytoma paraganglioma
Calaspargase Pegol-mkl	1mo -21 yrs.	Multi-Agent Component		12/20/2018	ALL Used with combination chemotherapy *ct
Tagraxofusp-erzs	Adults/Peds	Targeted	12/21/2018	12/21/2018	Blastic plasmacytoid dendritic cell neoplasm
Larotrectinib	Adults/Peds	NME**	11/26/2018	11/26/2018	Solid tumor with (NTRK) gene fusion *ct
entrectinib	Adults/Peds	Targeted	8/15/2019	8/15/2019	12 years or older to treat solid tumors that have certain changes in a gene called NTRK
tazemetostat hydrobromide	Adults/Peds		1/23/2020	1/23/2020	epithelioid sarcoma 16 years and older whose cancer cannot be removed by surgery.
selumetinib sulfate *PRV	Pediatrics	Targeted	4/10/2020	4/10/2020	2 yrs and older who have plexiform neurofibromas
selpercatinib	Adults/Peds	Targeted	5/8/2020	5/8/2020	12 years or older to treat advanced or metastatic RET-mutant medullary thyroid cancer (MTC)
naxitamab *PRV	Pediatrics	MAB***	11/25/2020	11/25/2020	1 yr & older with certain types of high-risk neuroblastoma
pralsetinib	Adults/Peds	Targeted	12/1/2020	12/1/2020	12 years or older to treat advanced or metastatic RET-mutant medullary thyroid cancer (MTC)
Gemtuzumab	Adults/Peds	MAB***	5/17/2000	6/16/2020	1 mo. & older Relapsed or refractory CD33+AML
crizotinib	Peds/AYA	Targeted	3/11/2016	1/14/2021	1 yr. & Young Adults ALK-positive systemic anaplastic large cell lymphoma

* Source: https://www.cancer.gov/research/areas/childhood/fda-approved-drugs-childhood-cancers?cid=eb_govdel
*ct = Data from NCI-sponsored clinical trials were used to support the approval
*PRV = Priority Review Voucher issued
** NME = New Molecular Entities
*** MAB= Monoclonal Antibody
****Exact pediatric-specific approval date is unknown.
💗 Possible late-onset cardiotoxicity https://www.uspharmacist.com/article/chemotherapy-agents-that-cause-cardiotoxicity
*NB Dinutuximab - NCI basic research 1960-2015 https://www.cancer.gov/research/areas/childhood/childhood-cancer-basic-cancer-research

Information Below Supplied by the FDA:

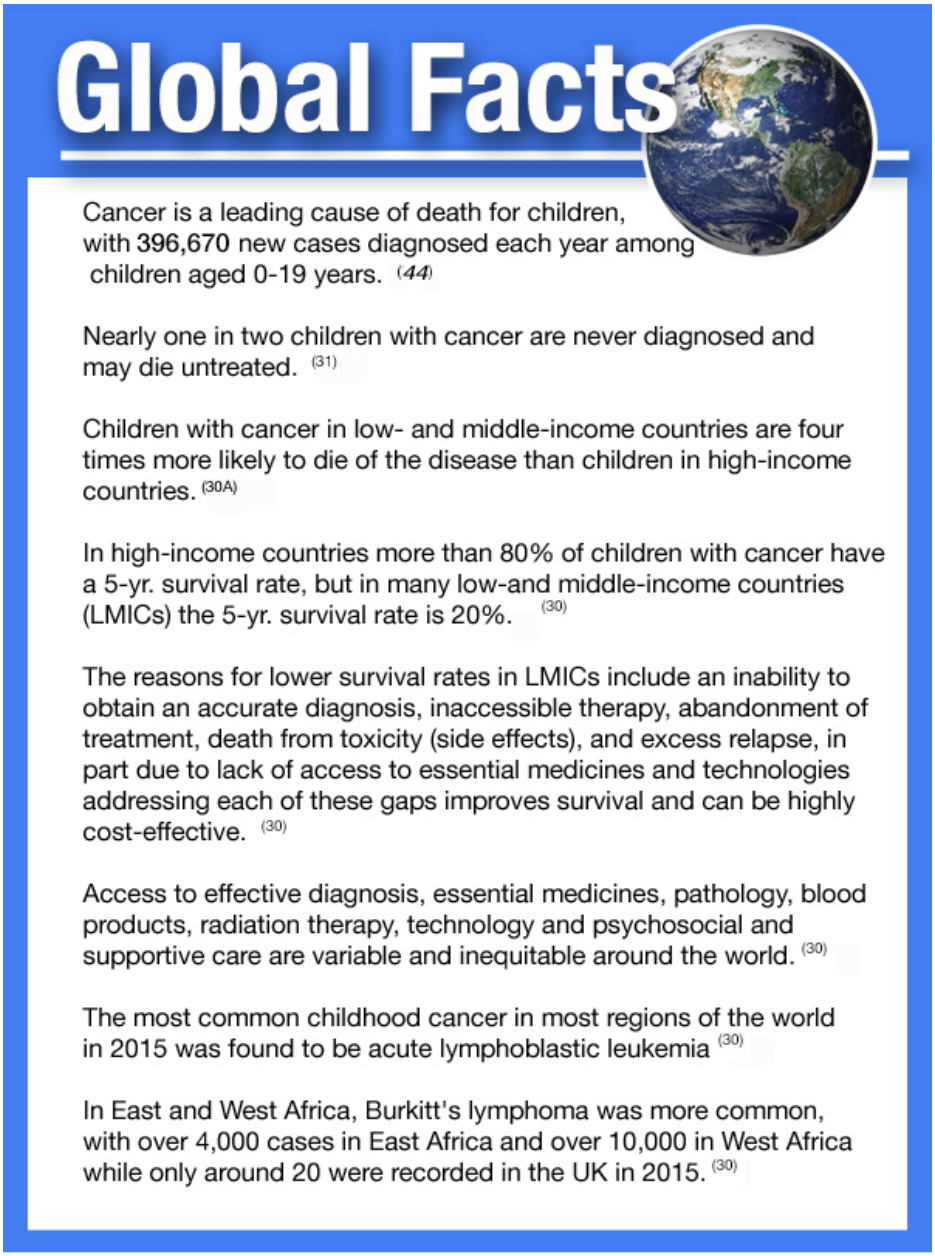
Supportive Care Oncology Drugs to treat pediatric patients with toxicty associated with cancer treatment

Drug	Approved for	Type	Original Approval	Pediatric Approval	Indication
Pegfilgrastim	Adults/Peds		1/31/2002	11/13/2015	Decrease incidence of infection,increases survival in patients acutely exposed ot myelossuppressive doses of radiation
Rasburicase	Adults/Peds	NME*	7/12/2002	7/12/2002	Management of plasma uric acid levels in patients at riask for tumor lysis syndrome
Palifermin	Adults/Peds		12/15/2004		Decreased incidence and duration of severe oral musositis
Levolcucovorin	Adults/Peds		3/7/2008	3/7/2008	Rescue after HD-MTX
Tocilizumab	Adults/Peds	MAB***	1/8/2010	8/30/2017	Treatment of chimertic antigen receptor (CAR) T cell-induced cytokine release syndrome
Voraxaze	Adults/Peds		1/17/2012	1/17/2012	Treatment of toxic plasma methotrexate concentration based on delayed MTX clearance

Drug Development

- Between the years of 2009 and 2019, nine of the 11 drugs used to treat acute lymphoblastic leukemia — which is the most common childhood cancer — were in and out of shortage. [32]
- While hundreds of cancer drugs have been developed and approved for adults, the FDA, through 2020 has approved a total of 34 drugs for use in the treatment of childhood cancers. 28 of the drugs were originally approved only for adult use. Today we have only six drugs that were approved in the first instance for use in cancer treatment for children: Teniposide (1992 for ALL) use now discontinued by NCI, clofarabine (2004 for ALL), dinutuximab (2015 for NB), tisagenlecleucel (2017 for ALL), calaspargase pegol-mk (2018 for ALL), selumetinib (2020 for NF1) and naxitamab (2020 for NB). [7]
- The FDA awarded Priority Review Vouchers (PRV) for four of the six drugs originally approved in the first instance for cancer treatment for children. PRV's are transferable and are desired incentives for developers of drugs for rare pediatric diseases. Holders of a PRV get a faster FDA drug approval process for a future drug of their choice. The vouchers are transferable and may be sold or traded. [42]

Global Facts



- In 2018, The World Health Organization (WHO) launched the Global Initiative for Childhood Cancer with partners to provide leadership and technical assistance to support governments in building and sustaining high-quality childhood cancer programs. The goal is to achieve at least 60% survival rate globally by 2030, for all children with cancer. This represents an approximate doubling of the current cure rate and will save an additional one million lives over the next decade. The objectives are to increase capacity of countries to deliver best practices in childhood cancer care and also to prioritize childhood cancer and increase available funding at the national and global levels. (30)
- It is estimated that there will be 13.7 million cases of childhood cancer between 2020-2050. Unless there are major improvements in diagnosis and treatments, of this, 45% will go undiagnosed and 11.1 million will die if no further investments in interventions are made. The vast majority, almost 85%, will be concentrated in developing countries. (33A)
- Global 5-year net childhood cancer survival is currently estimated at 37.4%. (46)

Psychosocial Care (20)

- Childhood cancer threatens every aspect of the family's life and the possibility of a future, which is why optimal cancer treatment must include psychosocial care. [11]
- The provision of psychosocial care has been shown to yield better management of common disease-related symptoms and adverse effects of treatment such as pain and fatigue.[12]
- Depression and other psychosocial concerns can affect adherence to treatment regimens by impairing cognition, weakening motivation, and decreasing coping abilities. [13]
- For children and families, treating the pain, symptoms, and stress of cancer enhances quality of life and is as important as treating the disease. [14]
- Childhood cancer survivors reported higher rates of pain, fatigue, and sleep difficulties compared with siblings and peers, all of which are associated with poorer quality of life. [15]
- Changes in routines disrupt day-to-day functioning of siblings .[16] Siblings of children with cancer are at risk for emotional and behavioral difficulties, such as anxiety, depression, and post traumatic stress disorder.[17]
- Symptoms of posttraumatic stress disorder are well documented for parents whose children have completed cancer treatment. [18]
- Chronic grief has been associated with many psychological (e.g., depression and anxiety) and somatic symptoms (e.g., loss of appetite, sleep disturbances, fatigue), including increased mortality risk. [19]
- Cancer survivors in the United States reported medication use for anxiety and depression at rates nearly two times those reported by the general public, likely a reflection of greater emotional and physical burdens from cancer or its treatment. [21]
- Financial hardship during childhood cancer has been found to affect a significant proportion of the population and to negatively impact family wellbeing. [22]
- Adolescents with cancer experienced significantly more Health Related Hindrance (HRH) of personal goals than healthy peers, and their HRH was significantly associated with poorer health-related quality of life, negative affect, and depressive symptoms. [23]
- Peer relationships of siblings of children with cancer are similar to classmates, though they experience small reductions in activity participation and school performance. [24]
- Chronic health conditions resulting from childhood cancer therapies contribute to emotional distress in adult survivors. [25]
- Parents have been found to report significant worsening of all their own health behaviors, including poorer diet and nutrition, decreased physical activity, and less time spent engaged in enjoyable activities 6 to 18 months following their child's diagnosis. [26]

Factors Affecting Access to Follow-up Care (43)

Stakeholders GAO interviewed and studies GAO reviewed identified three factors that affect access to follow-up care for childhood cancer survivors—individuals of any age who were diagnosed with cancer from ages 0 through 19. These factors are care affordability, survivors' and health care providers' knowledge of appropriate care, and proximity to care. Childhood cancer survivors need access to follow-up care over time for serious health effects known as late effects—such as

developmental problems, heart conditions, and subsequent cancers—which result from their original cancer and its treatment.

- **Affordability:** Survivors of childhood cancer may have difficulty paying for follow-up care, which can affect their access to this care. For example, one study found that survivors were significantly more likely to have difficulty paying medical bills and delay medical care due to affordability concerns when compared to individuals with no history of cancer.

- **Knowledge:** Survivors' access to appropriate follow-up care for late effects of childhood cancer can depend on both survivors' and providers' knowledge about such care, which can affect access in various ways, according to stakeholders GAO interviewed and studies GAO reviewed:

    - Some survivors may have been treated for cancer at an early age and may have limited awareness of the need for follow- up care.

    - Some primary or specialty care providers may not be knowledgeable about guidelines for appropriate follow-up care, which can affect whether a survivor receives recommended treatment. Follow-up care may include psychosocial care (e.g., counseling), and palliative care (e.g., pain management).

- **Proximity:** Survivors may have difficulty reaching appropriate care settings. Stakeholders GAO interviewed and studies GAO reviewed noted that childhood cancer survivors may have to travel long distances to receive follow-up care from multidisciplinary outpatient clinics—referred to as childhood cancer survivorship clinics. The lack of proximity may make it particularly difficult for survivors with limited financial resources to adhere to recommended follow-up care.

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