

Childhood Cancer in Kentucky



2008 - 2017

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Acknowledgements

The population-based childhood cancer incidence data presented in this report was made possible by the Kentucky General Assembly that passed Senate Bill 41 in April 1990. This legislation formally established the Kentucky Cancer Registry (KCR) as the official cancer surveillance program for the Commonwealth of Kentucky and mandated reporting of all cancer cases to the KCR beginning on January 1, 1991. Kentucky Revised Statute (KRS) 214.556 continues to require reporting from all health care facilities that either diagnose or treat cancer patients. Facilities include acute care hospitals, freestanding treatment centers, non-hospital (private) pathology laboratories, physician offices and genomic testing facilities. KCR gratefully acknowledges the full and active participation of facilities throughout Kentucky and a number of facilities outside of Kentucky. Their efforts are essential to complete, timely, and accurate reporting of all childhood cases occurring in Kentucky.

Beginning in 1994, the KCR was awarded funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR). This additional funding allows KCR to maintain a formal quality assurance program, implement complete death clearance follow back, and ensure that all cases of cancer are systematically reported by Kentucky's non-hospital facilities. In 2001, the KCR was awarded critical support from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, to further improve patient follow-up information and support expanded quality assurance activities. KCR has been successful in re-competing and sustaining all of these funding sources since the initial awards. KCR was awarded contract renewals to continue through 2023 as an NPCR registry and through 2028 as a SEER Program registry. KCR has recently received two competitive awards to participate in the development of the National Childhood Cancer Registry, an initiative led by the National Cancer Institute.

Finally, special recognition is given to the professional staff of the KCR. Informatics staff develop, maintain and support software, databases and technical infrastructures used throughout Kentucky. Operations staff have developed training programs and provide ongoing support to all of the reporting facilities throughout the state. Biostatistics and epidemiology faculty provide support for cancer prevention and control activities and research with KCR data. All of these individuals are highly engaged in cancer surveillance activities and standards development at the national and international levels. KCR could not be successful without the consistent contributions of these talented and dedicated individuals.

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Introduction

This report of population-based childhood cancer incidence for the Commonwealth of Kentucky represents the most accurate data available at the time of publication. KCR collects uniform, high quality data on approximately 220 new primary cases of childhood cancer occurring in Kentucky residents each year. Childhood cancer is defined as all newly diagnosed malignant neoplasms occurring among all children living in Kentucky under the age of 20. This report provides detailed information about childhood cancer in Kentucky for the most recent ten year period of complete, population-based data collected and validated by KCR. Information includes case counts by sex, age and site groups. Site groupings by body site and histologic type are defined by the International Classification of Childhood Cancer (ICCC) [1] and permit comparisons of incidence rates within and outside of Kentucky. This report also provides information about age-adjusted childhood cancer incidence rates, defined as the number of new cases diagnosed, divided by the numbers of persons at risk during the calendar year(s). Age-adjustment calculates the rates according to a standard age distribution. This is necessary to allow comparisons between regions with different age distributions. All rates in this report are per 1,000,000 (million) individuals at risk for the given cancer. It should be noted that rates per million differ from reports that include adult cancers which are typically reported per 100,000. Because of the relatively small numbers of cases, rates for small geographic regions can be deemed unstable, meaning too few cases to calculate a reliable rate. Unstable rates tend to exhibit large fluctuations with the increase or decrease of even a single case from year to year and can therefore be easily misinterpreted as representing a greatly increased or diminished risk of diagnosis. As a result, unstable rates with the number of cases less than 15 are not included in this report.

This report provides information that permits regional comparisons among Kentucky's Area Development Districts (ADD) and the Appalachian and non-Appalachian counties within the state. ADD maps display four distinct colors. Each color represents a quartile, or one-fourth of the range of incidence rates from lowest in yellow, to highest in red. Information is also provided to permit comparisons of age-adjusted rates in the U.S. with Kentucky and Appalachian Kentucky.

Overview

Childhood cancer is relatively rare, with less than 1% (2,202 / 258,083) of all cancers diagnosed in Kentucky occurring among children under the age of 20 during the years 2008-2017. However, a cancer diagnosis is severely burdensome for these children and their families. In addition to the side effects from surgeries, chemotherapeutics and/or radiation on developing body systems, there are often lifelong economic and social costs for affected families. Over 83% of children diagnosed with cancer survive at least 5 years [2], yet cancer remains the leading cause of disease-related death among U.S. children. Brain and central nervous system (CNS) tumors have recently overtaken leukemia as the leading cause of cancer-related death among children [3].

From 2008 through 2017, the most recent ten years of complete data presented in this report, 2,202 children in Kentucky were diagnosed. Cancer occurred more frequently among males (54%) than females (46%).

The frequency of cancer diagnoses varied by age, with cancers occurring most frequently among children ages 0-4, followed by children ages 15-19, 10-14 and 5-9, respectively. Males were diagnosed with more cancers across all site groups except for epithelial tumors & melanoma and renal tumors. Among all Kentucky children, leukemia occurred most frequently, followed by brain and CNS tumors, lymphoma, and epithelial tumors and melanoma.

The frequency of diagnoses by cancer site group also varied by age group. Of note, a greater proportion of hepatic tumors occurred among children ages 0-4, while more leukemia cases occurred among children ages 0-4 and 5-9. Children ages 5-9 also experienced the greatest proportion of brain and CNS tumors. Lymphoma, epithelial tumors & melanoma, and germ cell & gonadal tumors increased proportionally with age, while sympathetic nervous system tumors, renal tumors, and retinoblastoma decreased proportionally with age. The greatest proportion of soft tissue sarcomas and bone tumors occurred among children ages 10- 14. The age-adjusted incidence rates of childhood cancer have increased by over 2.5% annually among both males and females over this ten-year time period. Increasing rates of childhood cancer have been observed throughout the U.S. [2]

Regional comparisons within Kentucky indicate that the highest rates tend to occur in the eastern regions of the state with Appalachian Kentucky experiencing a higher rate than non-Appalachian Kentucky. According to the most recent national data available (2007-2018), Kentucky's age-adjusted childhood cancer incidence rate for all cancer sites is approximately the same as in the U.S. [4]. However, rates in Appalachian Kentucky are higher than in the U.S. for both males and females. Comparisons to U.S. rates by site group indicate that Appalachian children in Kentucky have higher rates across all major site groups except for soft tissue sarcomas, sympathetic nervous system tumors, and renal tumors. Of particular concern, rates of brain and CNS tumors are significantly higher in Kentucky compared to the U.S. and even higher among Appalachian children in Kentucky. Kentucky was ranked with the 11th highest rate for all invasive cancer sites combined. However, Kentucky had the 2nd highest rate of hepatic tumors, 3rd highest rate of brain and CNS tumors and 7th highest rate of retinoblastoma.

Children's Oncology Group (COG) affiliated facilities are likely to be in a position to offer the most current recommended treatment regimens for Kentucky children as well as opportunities to participate in life saving clinical trials. However, KCR data indicate that 18.7% of Kentucky children were treated outside of COG facilities in Kentucky during this reporting period.

1. Steliarova-Foucher E, Stiller C, Lacour B and Kaatsch P. International Classification of Childhood Cancer, third edition. *Cancer* 103:1457-67, 2005.

2. Noone AM, Howlander N, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2015, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2015/, based on November 2017 SEER data submission, posted to the SEER web site, April 2018.

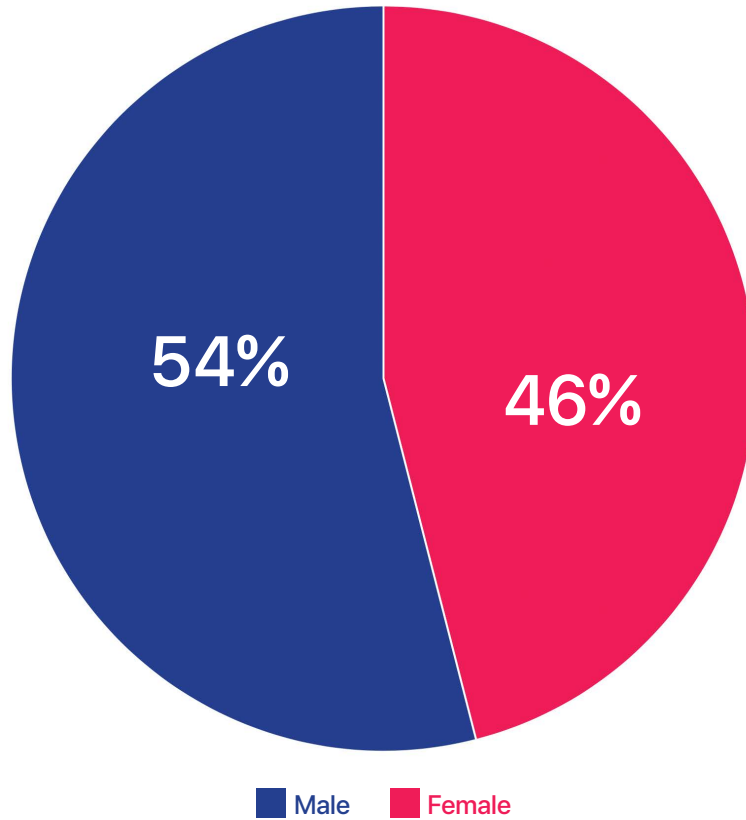
3. Curtin SC, Minino AM, Anderson RN. Declines in cancer death rates among children and adolescents in the United States, 1999-2014. *National Center for Health Statistics Data Brief* 2016; 257:1-8.

4. United States Cancer Statistics: 1999 - 2017 Incidence, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2020. Accessed at <http://wonder.cdc.gov/cancer-v2017.html>.

Childhood Cancer in Kentucky

CHILDHOOD CANCER INCIDENCE IN KENTUCKY ALL SITES, 2008-2017

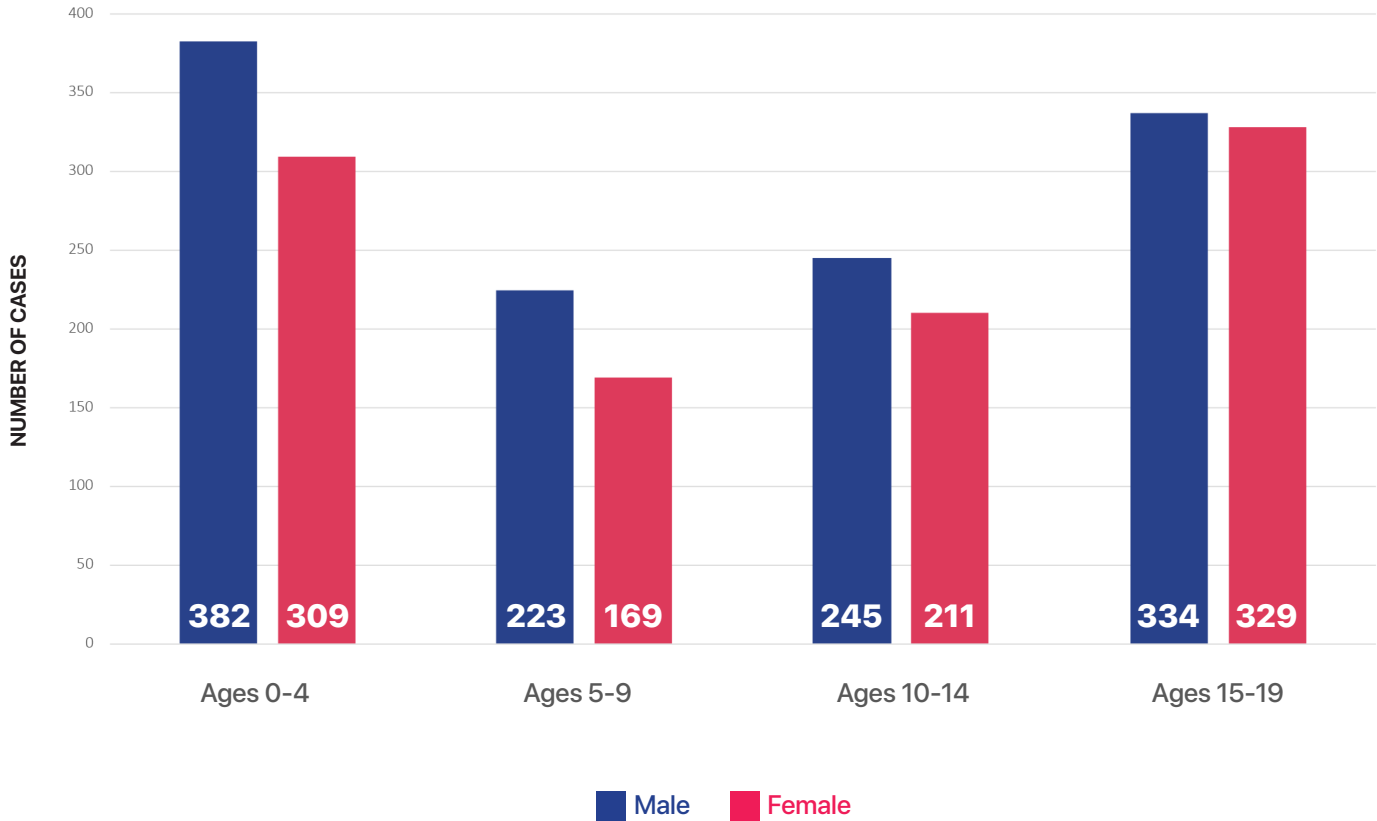
PROPORTION OF CASES BY SEX



Sex	Number of Cases (Percent)
Male	1,184 (54%)
Female	1,018 (46%)
Total	2,202

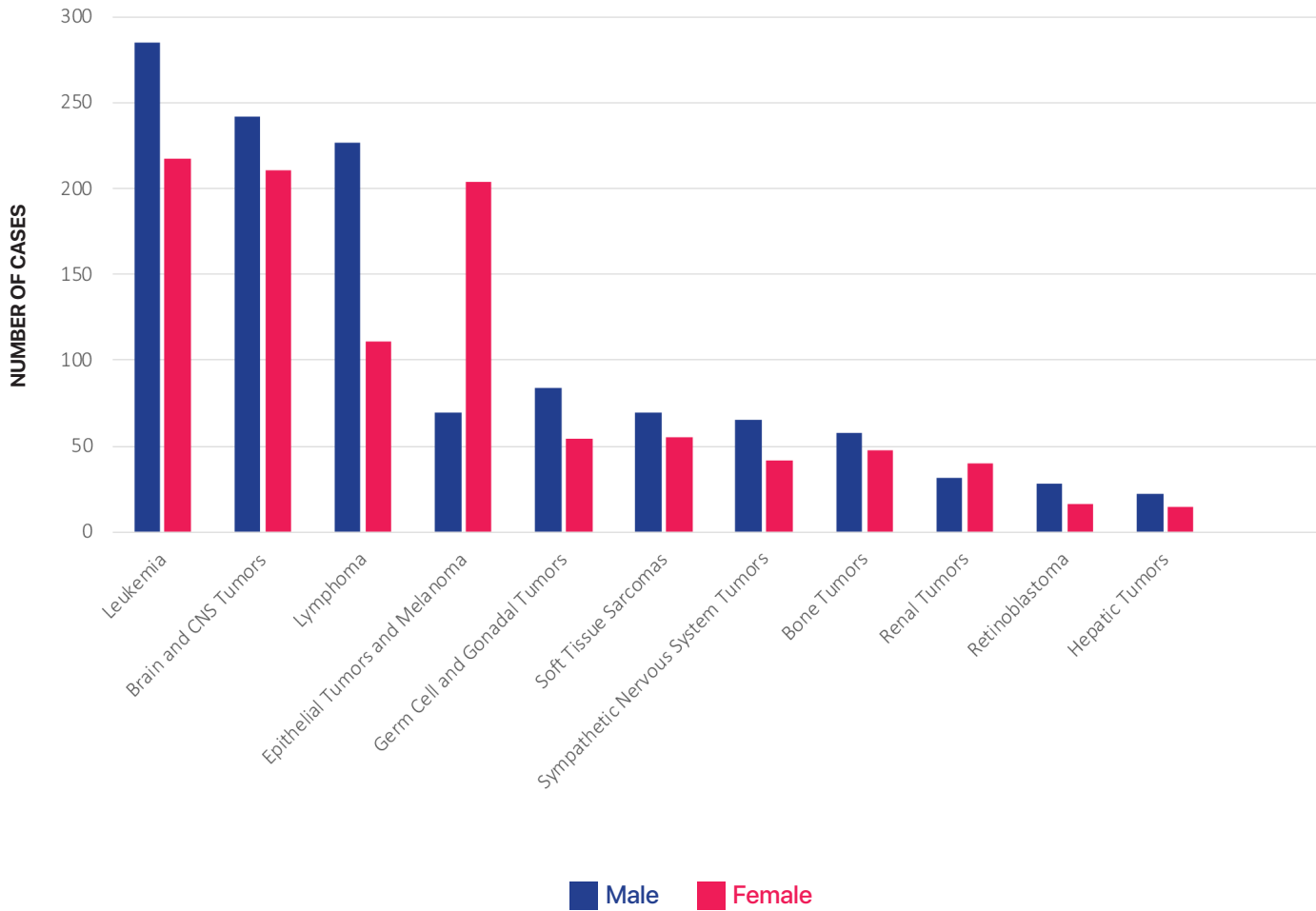
CHILDHOOD CANCER INCIDENCE IN KENTUCKY ALL SITES, 2008-2017

CASES BY SEX AND AGE AT DIAGNOSIS



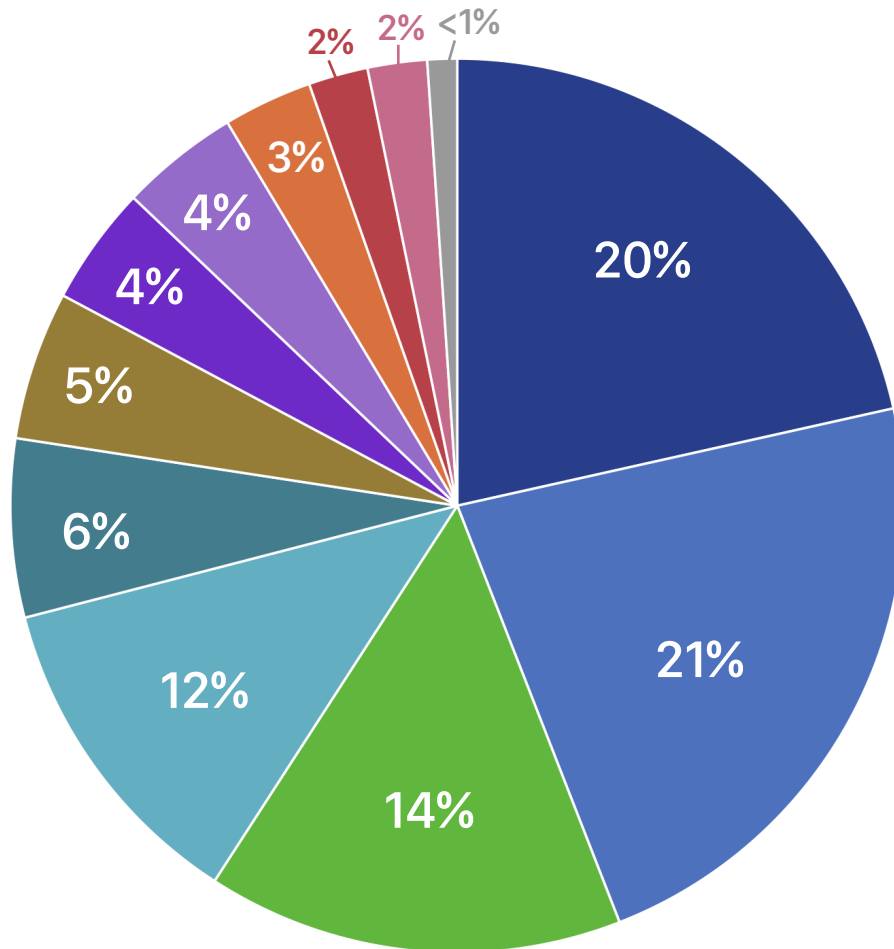
CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2008-2017

CASES BY SITE GROUP AND SEX



CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2008-2017

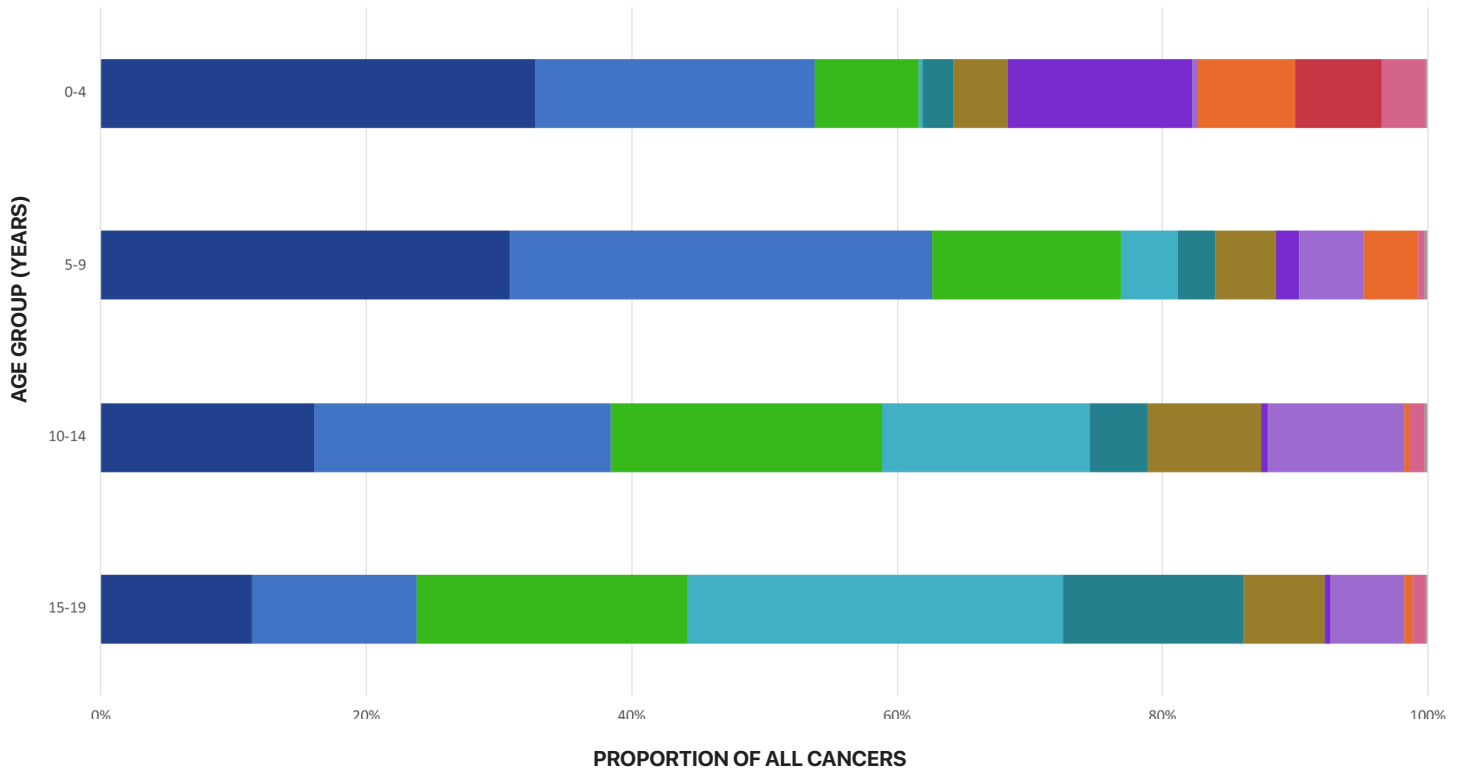
PROPORTION OF CASES BY SITE GROUP



- Leukemia ■ Brain and CNS Tumors ■ Lymphoma ■ Epithelial Tumors and Melanoma
- Germ Cell and Gonadal Tumors ■ Soft Tissue Sarcomas ■ Sympathetic Nervous System Tumors ■ Bone Tumors
- Renal Tumors ■ Retinoblastoma ■ Hepatic Tumors ■ Other and Unspecified

CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2008-2017

PROPORTION OF CASES BY SITE GROUP AND AGE GROUP



- Leukemia
- Brain and CNS Tumors
- Lymphoma
- Epithelial Tumors and Melanoma
- Germ Cell and Gonadal Tumors
- Soft Tissue Sarcomas
- Sympathetic Nervous System Tumors
- Bone Tumors
- Renal Tumors
- Retinoblastoma
- Hepatic Tumors
- Other and Unspecified

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY BY SITE GROUP, 2008-2017

MALE AND FEMALE

Site Group	Male Cases	Male Age-Adjusted Rate	Female Cases	Female Age-Adjusted Rate
All Sites	1,184	202.9	1,018	183.3
Leukemia	285	48.9	217	39.0
Brain and CNS Tumors	242	41.6	211	38.1
Lymphoma	227	39.0	111	20.0
Epithelial Tumors and Melanoma	70	12.0	204	36.7
Germ Cell and Gonadal Tumors	84	14.2	54	9.7
Soft Tissue Sarcomas	70	12.0	55	9.9
Sympathetic Nervous System Tumors	65	11.0	42	7.5
Bone Tumors	58	10.0	48	8.7
Renal Tumors	32	5.4	40	7.2
Retinoblastoma	28	4.7	16	2.8
Hepatic Tumors	22	3.7	15	2.7

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

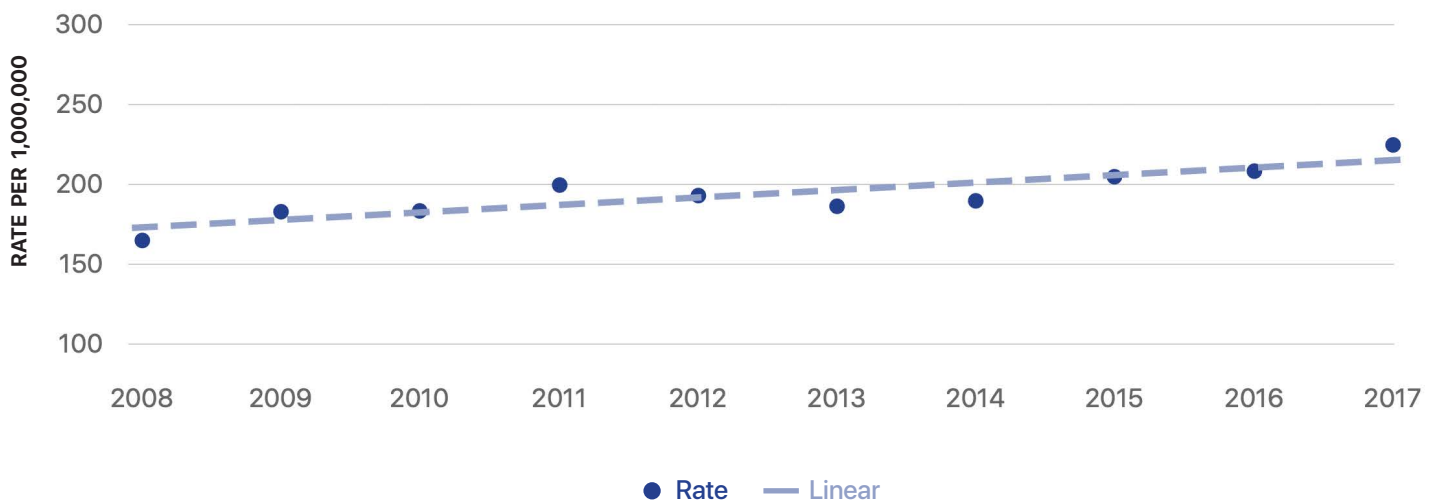
CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2008-2017

BOTH SEXES

Year	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2008-2017
Population at Risk	1,142,982	1,144,346	1,146,045	1,140,703	1,134,260	1,132,659	1,127,781	1,125,892	1,125,914	1,126,133	11,346,715
Total Cases	189	210	211	228	219	211	214	231	235	254	2,202
Crude Rate	165.4	183.5	184.1	199.9	193.1	186.3	189.8	205.2	208.7	225.6	194.1
Age-Adjusted Rate	164.5	182.5	183.0	199.2	192.6	185.9	189.3	204.4	207.9	224.3	193.3
95% CI Lower	141.9	158.7	159.1	174.2	167.7	161.7	164.8	178.9	182.2	197.6	185.3
95% CI Upper	189.7	209.0	209.4	226.8	219.9	212.8	216.5	232.6	236.2	253.6	201.5

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED INCIDENCE RATE TREND



Incidence rates have increased approximately 2.5% annually over this ten year time period. The trend line shown in the figure is based on a linear regression. The 2.5% annual percent change (APC) is calculated using the Joinpoint Trend Analysis software package developed by NCI SEER (<https://surveillance.cancer.gov/joinpoint/>)

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2008-2017

MALE

Year	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2008-2017
Population at Risk	585,519	586,178	586,999	584,707	581,456	580,842	578,129	577,092	576,748	576,819	5,814,489
Total Cases	96	94	127	128	124	122	110	130	119	134	1,184
Crude Rate	164	160.4	216.3	218.9	213.3	210.0	190.3	225.3	206.3	232.3	203.6
Age-Adjusted Rate	162.4	160.0	214.4	218.6	212.7	209.6	189.9	224.3	205.6	231.2	202.9
95% CI Lower	131.5	129.3	178.7	182.3	176.9	174.1	156.1	187.4	170.3	193.7	191.5
95% CI Upper	198.3	195.8	255.1	259.9	253.5	250.3	228.9	266.4	246.0	273.8	214.8

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2008-2017

FEMALE

Year	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2008-2017
Population at Risk	557,463	558,168	559,046	555,996	552,804	551,817	549,652	548,800	549,166	549,314	5,532,226
Total Cases	93	116	84	100	95	89	104	101	116	120	1,018
Crude Rate	166.8	207.8	150.3	179.9	171.8	161.3	189.2	184	211.2	218.4	184.0
Age-Adjusted Rate	166.7	206.4	150.1	178.9	171.6	161.1	188.8	183.4	210.3	217.1	183.3
95% CI Lower	134.6	170.5	119.7	145.6	138.8	129.3	154.3	149.4	173.8	180.0	172.2
95% CI Upper	204.3	247.6	185.8	217.6	209.7	198.2	228.8	222.9	252.3	259.6	194.9

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2008-2017

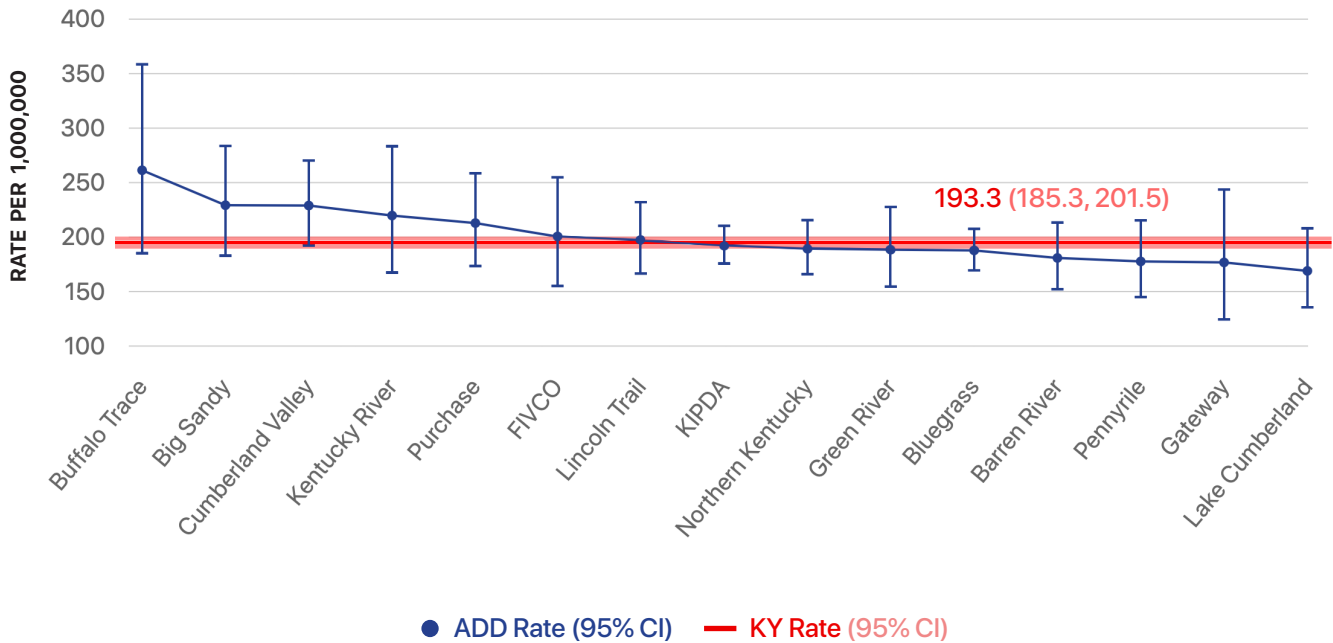
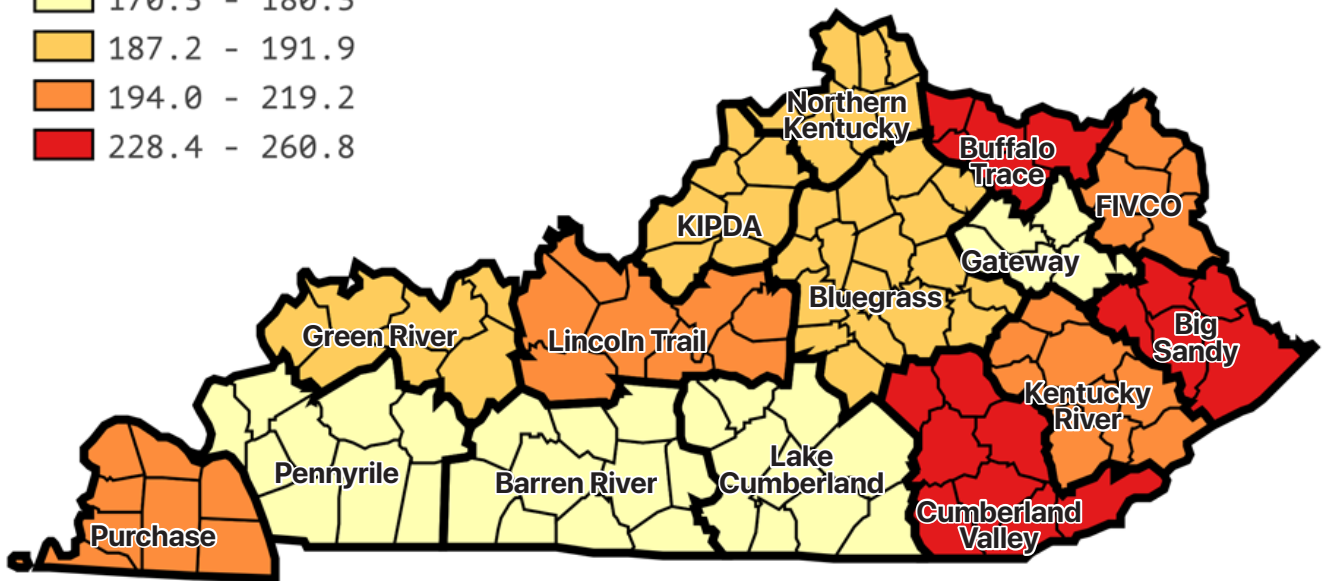
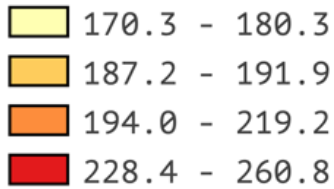
BY AREA DEVELOPMENT DISTRICT

Area Development District	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Buffalo Trace	146,415	38	259.5	260.8	184.6	358.0
Big Sandy	365,884	84	229.6	228.7	182.4	283.1
Cumberland Valley	605,250	139	229.7	228.4	192.0	269.7
Kentucky River	269,153	59	219.2	219.2	166.9	282.8
Purchase	476,519	101	211.9	212.3	172.9	258.0
Fivco	329,964	66	200.0	199.9	154.6	254.3
Lincoln Trail	738,028	143	193.8	194.0	163.5	228.5
Kipda	2,512,928	483	192.2	191.9	175.2	209.8
Northern Kentucky	1,223,519	230	188.0	188.1	164.6	214.1
Green River	568,064	107	188.4	187.9	154.0	227.1
Bluegrass	2,026,529	383	189.0	187.2	168.9	207.0
Barren River	773,848	140	180.9	180.3	151.6	212.8
Pennyrile	578,435	103	178.1	177.1	144.4	214.8
Gateway	212,726	37	173.9	176.2	123.9	243.1
Lake Cumberland	519,453	89	171.3	170.3	136.8	209.6
Kentucky	11,346,715	2,202	194.1	193.3	185.3	201.5

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2008-2017

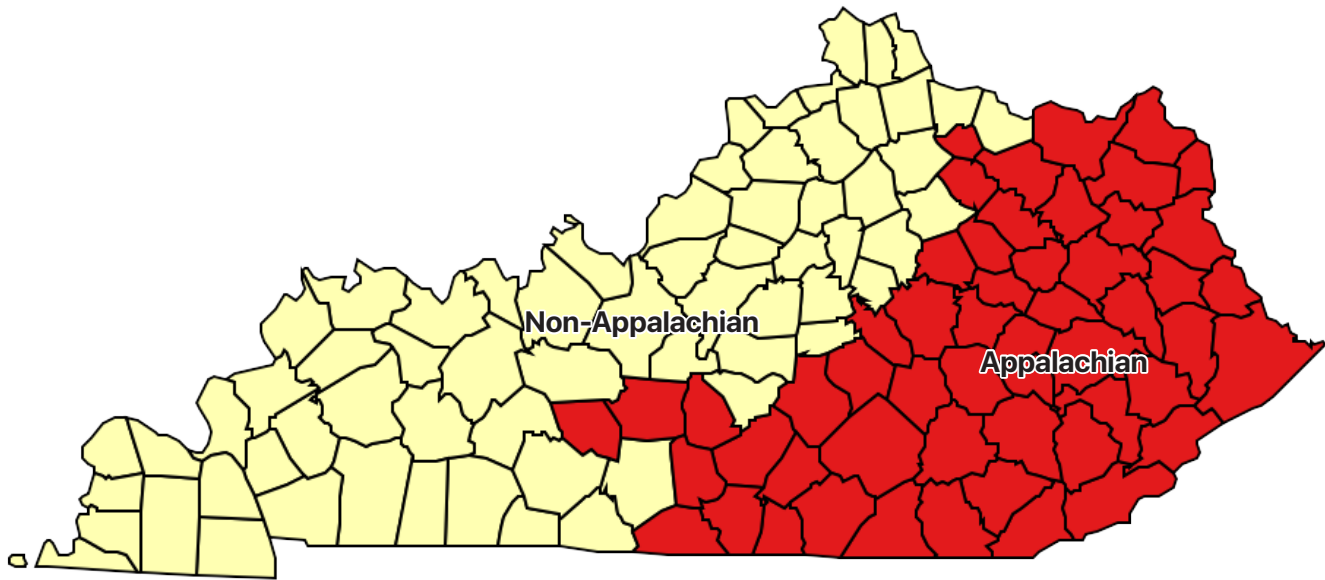
AGE-ADJUSTED RATES BY AREA DEVELOPMENT DISTRICT



Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE IN KENTUCKY ALL SITES, 2008-2017

AGE-ADJUSTED RATES BY APPALACHIAN REGION

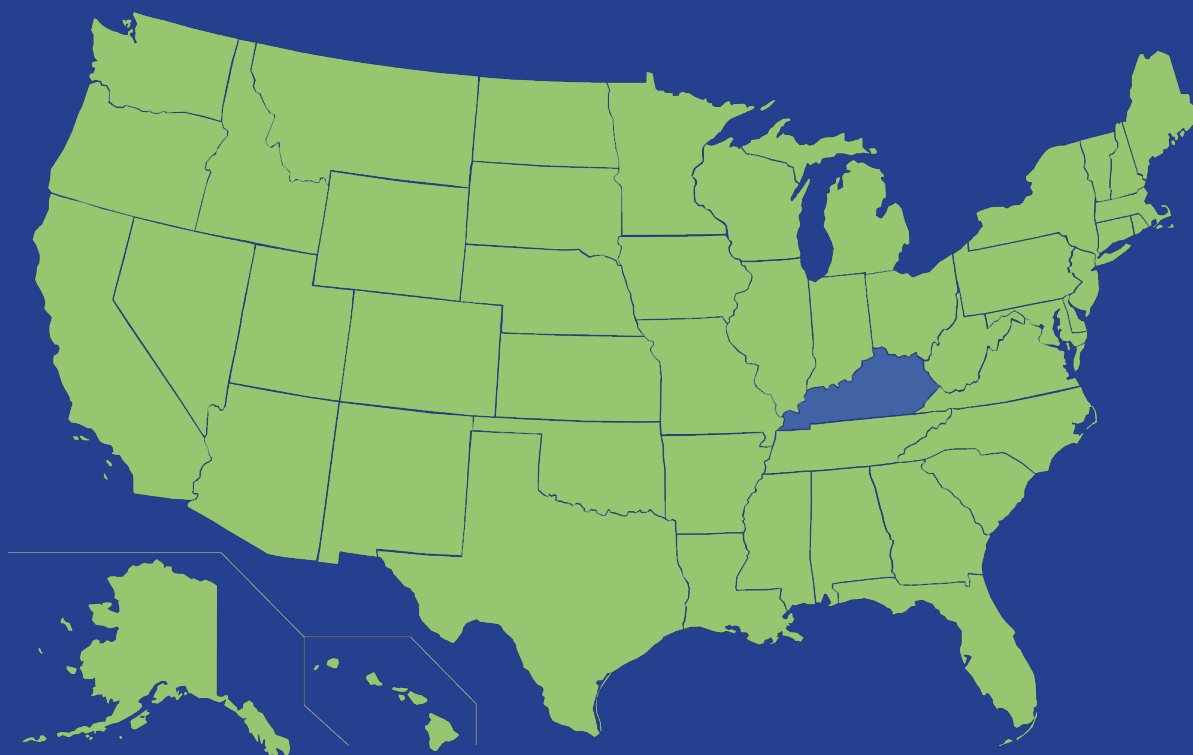


Region	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Appalachian	2,958,408	621	209.9	208.6	192.5	225.7
Non-Appalachian	8,388,307	1,581	188.5	187.8	178.6	197.2
Kentucky	11,346,715	2,202	194.1	193.3	185.3	201.5

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

Childhood Cancer Incidence Rates in Kentucky Compared to U.S.

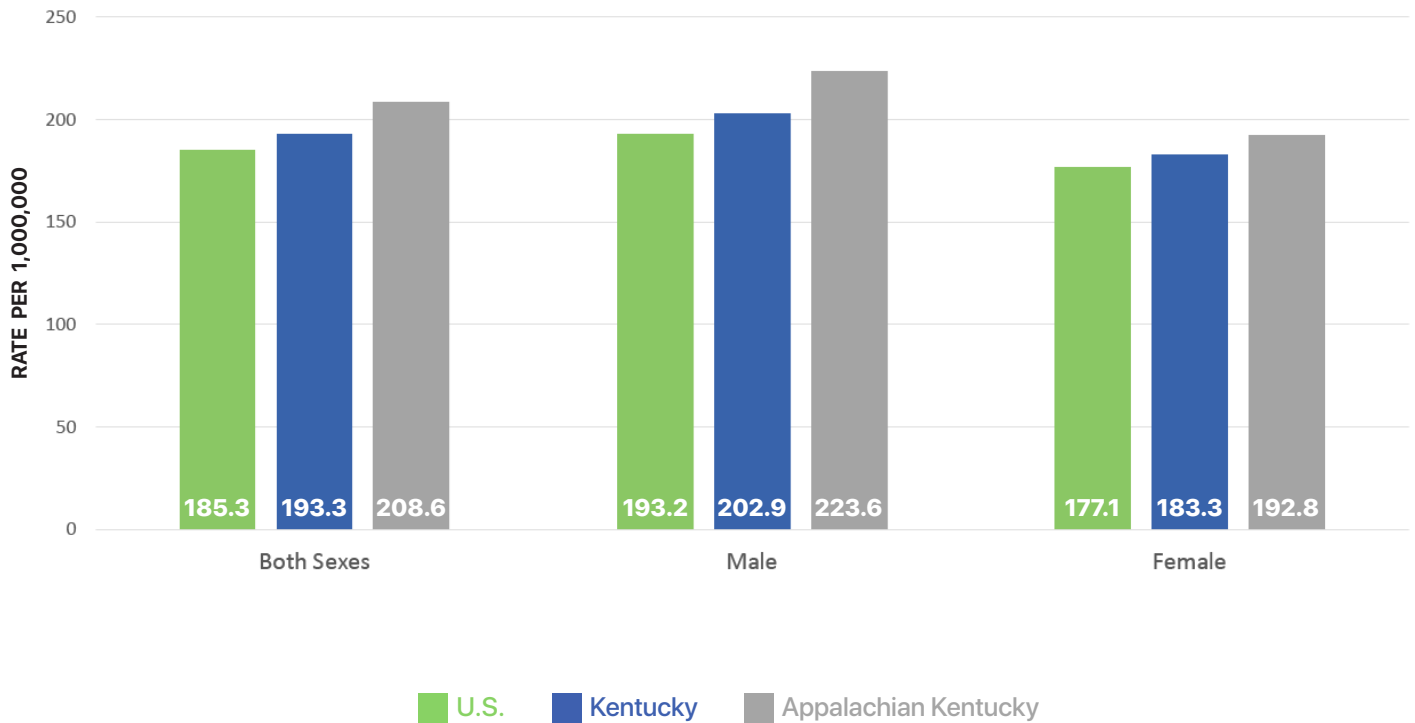
2008 - 2017



All U.S. rates and rankings were extracted from the CDC Wonder Cancer Statistics - <https://wonder.cdc.gov/cancer.html>

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES ALL SITES, 2008-2017

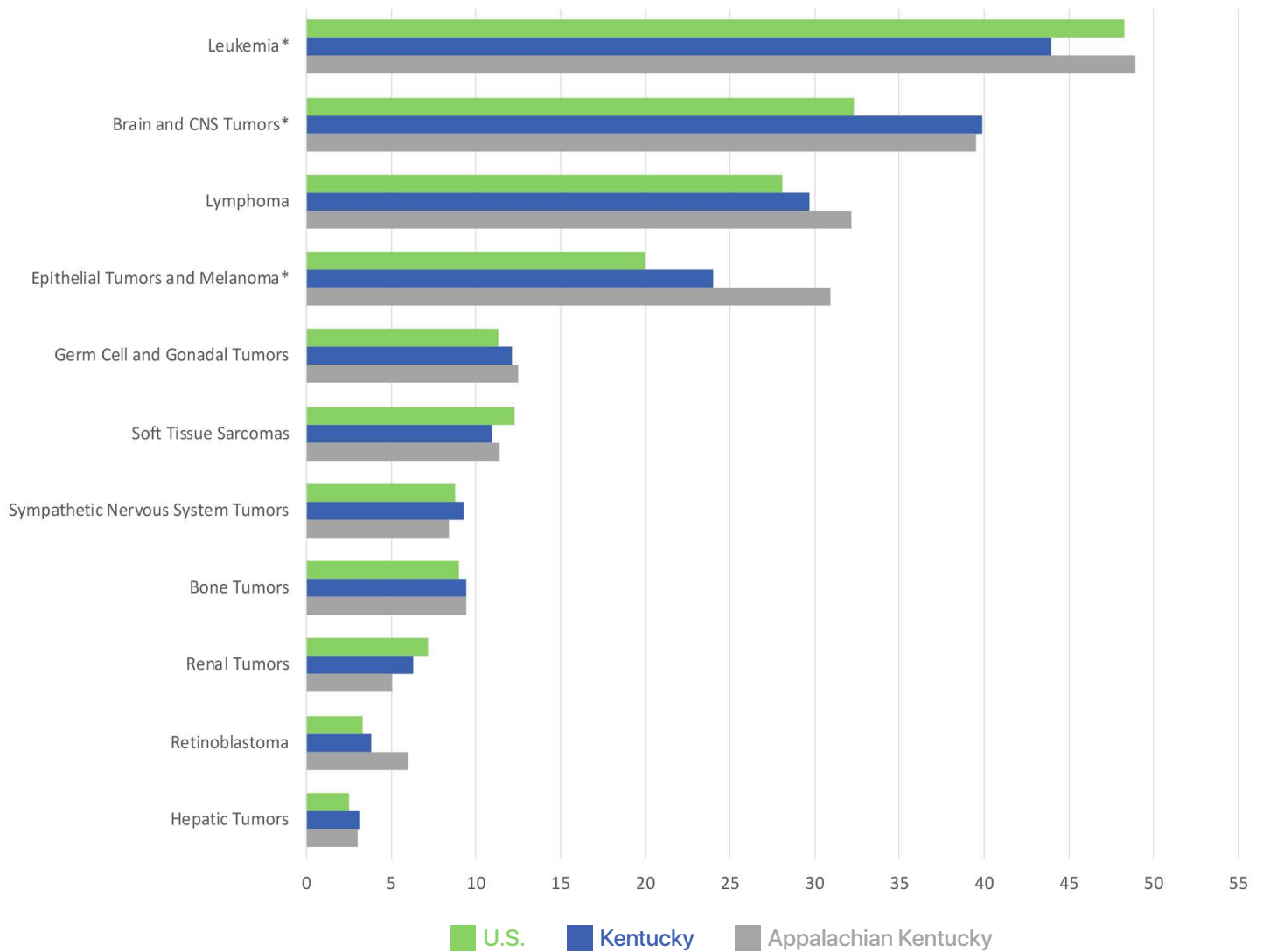
KENTUCKY COMPARED TO U.S.



Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES BY SITE GROUP, 2008-2017

KENTUCKY COMPARED TO U.S.



***Rates are significantly different**

Leukemia $P < 0.05$ (Kentucky rate compared to the U.S. rate)

Brain and CNS Tumors $P < 0.01$ (Kentucky rate compared to the U.S. rate)

Epithelial Tumors and Melanoma $P < 0.01$ (Kentucky and Appalachian Kentucky rates compared to the U.S. rate)

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES BY SITE GROUP, 2008-2017

KENTUCKY RANKINGS COMPARED TO ALL U.S. STATES

Site Group	Highest Ranking
Leukemia	34th
Brain and CNS Tumors	3rd
Lymphoma	15th
Epithelial Tumors and Melanoma*	11th
Germ Cell and Gonadal Tumors*	15th
Soft Tissue Sarcomas	41st
Sympathetic Nervous System Tumors	16th
Bone Tumors*	16th
Renal Tumors*	39th
Retinoblastoma*	7th
Hepatic Tumors*	2nd
All Sites	11th

*One or more states outside of KY not available for comparison due to unstable rates.

Supplemental Information

Definitions

Age-Adjusted Rate	A statistical adjustment applied to crude rates to permit comparisons of populations with different age structures. The 2000 Standard U.S. Million Population is commonly used in age-adjusted rates for cancer research in U.S.
Annual Percent Change (APC)	Change in annual rates over time. The APC in this report was calculated through a log-transformation of the age-adjusted rates using the Joinpoint Trend Analysis software. https://surveillance.cancer.gov/joinpoint/
Appalachian Region	Groups of counties designated by the Appalachian Regional Commission's authorizing legislation. The region follows the spine of the Appalachian Mountains from southern New York to northern Mississippi. The current Kentucky Appalachian region includes 54 Kentucky counties https://www.arc.gov/appalachian_region/TheAppalachianRegion.asp
Area Development Districts	Groups of contiguous counties in Kentucky, comprising 15 area development districts. https://www.kyatlas.com/kentucky-adds.html
Cases	Total number of new incident cancer cases diagnosed in a given year or time period.
Childhood Cancer	A malignant cancer diagnosed in an individual under the age of 20.
Children's Oncology Group (COG)	A large group of researchers, hospitals, and cancer centers that get support from the National Cancer Institute (NCI) to study childhood cancer. https://www.childrensoncologygroup.org/index.php/aboutus
Crude Rate	An unadjusted incidence rate, calculated as the number of newly diagnosed cases divided by the population at risk.
Diagnosis Year	Year in which a cancer is first diagnosed.
Incidence Rate	Rate of new cancer diagnoses in a given year or time period.
P-value	The P-value, or calculated probability under the null hypothesis is used to quantify the idea of statistical significance of evidence. $P < 0.05$ is a convention generally accepted as representing a statistically significant finding.
Population at Risk	Number of individuals living in a geographical region and at risk of being diagnosed with cancer for a given year or time period.
Site Group	Type of cancer, grouped by topography and histology, as defined by the International Classification of Childhood Cancer. [1]
US Standard Million Population	The age distribution of individuals living in the U.S. in a given year, per million residents, as defined by the U.S. Census.
95% Confidence Interval (CI)	Specifies the precision of the age-adjusted rate measurement, resulting in a 95% certainty that the confidence interval includes the true value of the measurement.

1. Steliarova-Foucher E, Stiller C, Lacour B and Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 103:1457-67, 2005.

Staff of the Kentucky Cancer Registry

Director	Eric B. Durbin, DrPH, MS
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Epidemiologist/Research Coordinator	Jaclyn K. McDowell, DrPH, MPH
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Senior Regional Coordinators	Shelly Hodge, CTR Michele Hoskins, CTR Marynell Jenkins, CTR
Regional Abstractors	Leslie Benningfield, CTR Becky Bruno, CTR Danielle Darcy, CTR Jennifer Denham, CTR
Non-Hospital Abstractors	Lindsey Baker, CTR Stephanie Carmack, MS, CTR Kim Kimbler, MS, CTR Shannon Ladd, MSW, CTR Pam Shaw, CTR Robin Walls Marilyn Wooten, CTR
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Software and Database Developers	Chaney Blu Clay Campbell Roger Chui Jason Jacob, MS Luan Pham, MS Pete Ransdell, MS David Rust, MS
Information Technology Support	Joel Wheeler John Williams, MA
Budget Analysts	Sarah Dickerson Cindy Pearce
Administrative Assistants	Paula Cole Cheryl Nicholson
Staff Biostatistician	Quan Chen, DrPH

Additional Resources

American Cancer Society

<https://www.cancer.org/cancer/cancer-in-children.html>

American Childhood Cancer Organization

<https://www.acco.org/types-of-childhood-cancer>

Childhood Cancer Data Initiative

<https://www.cancer.gov/research/areas/childhood/childhood-cancer-data-initiative>

Children's Hospital of Philadelphia

<https://www.chop.edu/centers-programs/cancer-center>

Children's Oncology Group

<https://www.childrensoncologygroup.org>

Cincinnati Children's Hospital

<https://www.cincinnatichildrens.org/service/c/cancer-blood/cancer>

DanceBlue

<http://www.danceblue.org>

Jarrett's Joy Cart

<http://thejoycart.com>

Kids Cancer Alliance

<https://kidscanceralliance.org>

Kentucky Children's Hospital – Pediatric Hematology & Oncology

<https://ukhealthcare.uky.edu/kentucky-childrens-hospital/services/cancer/hematology-oncology-pediatric>

Kentucky Pediatric Cancer Research Trust Fund

<https://chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/pctrf.aspx>

National Cancer Institute Center for Cancer Research Pediatric Oncology Branch

<https://ccr.cancer.gov/Pediatric-Oncology-Branch>

National Childhood Cancer Registry

<https://cancercontrol.cancer.gov/research-emphasis/childhood-cancer-registry>

NIH Kids First Data Resource Center

<https://kidsfirstdrc.org>

Norton Children's Cancer Institute

<https://nortonchildrens.com/services/cancer>

Tracking Pediatric and Young Adult Cancer Cases

<https://www.cdc.gov/cancer/npcr/pediatric-young-adult-cancer.htm>

Vanderbilt University Medical Center Pediatric Cancer Program

<https://www.childrenshospitalvanderbilt.org/service-line/pediatric-cancer-program>

Why Not Kids?

<http://whynotkids.com>

