

# **Pediatric Cancer Research Trust Fund Report FY 2016**



**Prepared By:**

**Division of Prevention and Quality Improvement  
Department for Public Health  
Cabinet for Health and Family Services**

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# Annual Report on the Pediatric Cancer Research Trust Fund

This report was prepared by the  
Division of Prevention and Quality Improvement  
Kentucky Department for Public Health  
Cabinet for Health and Family Services  
And  
The Pediatric Cancer Research Trust Fund Board

Date of Report: January 10, 2017

## **Pediatric Cancer Research Trust Fund Board Members**

Jamie Ennis Bloyd, MPA, Citizen-At-Large  
Kenneth G. Lucas, MD, Representing Norton Children's Hospital  
Bradley Nunn, BS, Representing the Kentucky Chapter of the Leukemia and Lymphoma Society  
Hiram C. Polk, Jr., MD, Commissioner, Department for Public Health  
James Sharp, Mid-South American Cancer Society Cancer Action Network, Inc.  
Lars Wagner, MD, Chief, Division of Pediatric Hematology/Oncology, Kentucky Children's Hospital  
April Dawn Wilhoit, Citizen-At-Large  
Heather Hood Wise, DMD, Citizen-At-Large  
Vickie Yates Brown Glisson, Secretary, Cabinet for Health and Family Services

## **Department for Public Health Contributing Staff**

Gary L. Kupchinsky, MA, Division Director, Division of Prevention and Quality Improvement  
Sue Thomas-Cox, RN, Branch Manager, Chronic Disease Prevention Branch  
Janet C. Luttrell, PCRTF Program Manager, Chronic Disease Prevention Branch

## **Report Overview**

This report is prepared pursuant to KRS 211.597, which states that a report be provided to the Governor and the Legislative Research Commission (LRC) detailing the plan developed for the expenditure of funds for the current and next fiscal year, a summary of the use and impact of prior year funds, a summary of the activities of the board during the prior fiscal year, and any recommendations for future initiatives or action regarding pediatric cancer research funding.

## **Mission**

The mission of the Pediatric Cancer Research Trust Fund (PCRTF) Board is to enhance efforts to reduce pediatric cancer incidence and mortality. The efforts of the board target the program needs and challenges of the Commonwealth.

## **History**

In 2015, legislation was enacted creating the PCRTF under KRS 211.595. The purpose of the funds is to support pediatric cancer research and treatment in Kentucky. The board is attached to the Cabinet for Health and Family Services (CHFS).

## **Needs Assessment**

A needs assessment is yet to be implemented by the board. A presentation developed by the Kentucky Cancer Registry and shared at the Health and Welfare Committee meeting on September 21, 2016 has been included as Appendix B.

## **Program Plan Summary**

KRS 211.597 authorizes the PCRTF Board to promulgate administrative regulations necessary to carry out the provisions of KRS 211.595 to 211.597, including the establishment of a competitive grant program to provide funding to organizations offering programs or services in the areas of pediatric cancer research and treatment. Accordingly, the Kentucky Department for Public Health (KDPH) is in the process of promulgating administrative regulations, which establish the requirements of the PCRTF Program.

## **Program Plan Overview**

The PCRTF program plan is being developed by the board and will be available online at the CHFS Division of Prevention and Quality Improvement (PQI) website:

<http://chfs.ky.gov/dph/info/dpqi/cd> .

## **Program Financial Summary**

Revenue for the PCRTF consists of funds collected from the state income tax check off and any other proceeds from grants, contributions, appropriations, or other money made available for the purposes of the PCRTF. Citizens may designate donations to the Trust Fund on their annual Kentucky state income tax form. Donations made through the Trust Fund check off box will be sent to CHFS from the Kentucky Department of Revenue on a monthly basis.

## **Pediatric Cancer Research Trust Fund Board Activities Summary**

The first meeting of the PCRTF Board was conducted on November 28, 2016. During this meeting, members elected Jamie Bloyd as President and April Dawn Wilhoit as Vice-President of the board. Members reviewed instructions to the board set forth in the legislation. Meeting dates were set for 2017 and topics for the next meeting discussed.

## **Recommendations for Future Initiatives or Action**

None to date.

## **Appendix A**

# **Kentucky Revised Statutes Related to Pediatric Cancer Trust Fund and Pediatric Cancer Trust Fund Board**

**211.595 Pediatric cancer research trust fund.**

- (1) The pediatric cancer research trust fund is hereby created as a separate trust fund. The fund shall be administered by the Cabinet for Health and Family Services.
- (2) The fund shall receive amounts collected from the income tax checkoff created in KRS 141.445, and any other proceeds from grants, contributions, appropriations, or other moneys made available for the purposes of this fund.
- (3) Notwithstanding KRS 45.229, trust fund amounts not expended at the close of a fiscal year shall not lapse but shall be carried forward to the next fiscal year.
- (4) Any interest earned on moneys in the trust fund shall become a part of the trust fund and shall not lapse.
- (5) Trust fund moneys shall be used to support pediatric cancer research and treatment for Kentucky patients. Funds shall be administered and distributed by the Pediatric Cancer Research Trust Fund Board established by KRS 211.596 for the purposes directed in this section and KRS 211.596 and 211.597.
- (6) Moneys transferred to the trust fund pursuant to KRS 141.445 are hereby appropriated for the purposes set forth in KRS 211.597.

**Effective:** June 24, 2015

**History:** Created 2015 Ky. Acts ch. 96, sec. 3, effective June 24, 2015; and ch. 108, sec. 2, effective June 24, 2015.

**Legislative Research Commission Note** (6/24/2015). This statute was created with identical text in 2015 Ky. Acts chs. 96 and 108, which were companion bills. These Acts have been codified together.

**Legislative Research Commission Note** (6/24/2015). During codification, the Reviser of Statutes has corrected the name of the Pediatric Cancer Research Trust Fund Board in this statute from the way it appeared in 2015 Ky. Acts ch. 96, sec. 3 and 2015 Ky. Acts ch. 108, sec. 2, by inserting the inadvertently omitted word "Research" in subsection (5).

**211.596 Pediatric Cancer Research Trust Fund Board -- Membership -- Terms -- Meetings.**

- (1) The Pediatric Cancer Research Trust Fund Board is hereby created for the purpose of administering and distributing funds from the trust created under KRS 211.595. The board shall be composed of nine (9) members to be appointed as follows:
  - (a) A specialist in pediatric oncology nominated by the Kosair Children's Hospital to be appointed by the Governor;
  - (b) A specialist in pediatric oncology nominated by the University of Kentucky Children's Hospital to be appointed by the Governor;
  - (c) A representative nominated by Kentucky Chapters of the Leukemia and Lymphoma Society to be appointed by the Governor;
  - (d) A representative nominated by Kentucky offices of the American Cancer Society to be appointed by the Governor;
  - (e) Three (3) citizens, one (1) of whom shall be a pediatric cancer survivor, or parent thereof, to be appointed by the Governor from a list of six (6) citizens nominated by Kentucky offices of the American Cancer Society;
  - (f) The secretary of the Cabinet for Health and Family Services, or the secretary's designee; and
  - (g) The commissioner of the Department for Public Health, or the commissioner's designee.

(2) The board shall be attached to the Cabinet for Health and Family Services for administrative purposes.

(3) The secretary of the Cabinet for Health and Family Services shall convene the first meeting of the board within sixty (60) days of June 24, 2015.

(4) Board members shall serve without compensation, but may receive reimbursement for their actual and necessary expenses incurred in the performance of their duties.

(5) The term of each appointed member shall be four (4) years.

(6) A member whose term has expired may continue to serve until a successor is appointed and qualifies. A member who is appointed to an unexpired term shall serve the rest of the term and until a successor is appointed and qualifies. A member may serve two (2) consecutive four (4) year terms and shall not be reappointed for four (4) years after the completion of those terms.

(7) A majority of the full membership of the board shall constitute a quorum.

(8) At the first meeting, the board shall elect, by majority vote, a president who shall preside at all meetings and coordinate the functions and activities of the board. The president shall be elected or reelected each calendar year thereafter.

(9) The board shall meet at least two (2) times annually, but may meet more frequently, as deemed necessary, subject to call by the president or by request of a majority of the board members.

**Effective:** June 24, 2015

**History:** Created 2015 Ky. Acts ch. 96, sec. 4, effective June 24, 2015; and ch. 108, sec. 3, effective June 24, 2015.

**Legislative Research Commission Note** (6/24/2015). This statute was created with identical text in 2015 Ky. Acts chs. 96 and 108, which were companion bills. These Acts have been codified together.

**Legislative Research Commission Note** (6/24/2015). During codification, the Reviser of Statutes has corrected the name of the Pediatric Cancer Research Trust Fund Board in this statute from the way it appeared in 2015 Ky. Acts ch. 96, sec. 4 and 2015 Ky. Acts ch. 108, sec. 3, by inserting the inadvertently omitted word "Research" in subsection (1).

### **211.597 Duties of Pediatric Cancer Research Trust Fund Board.**

The Pediatric Cancer Research Trust Fund Board created by KRS 211.596 shall:

(1) Develop a written plan for the expenditure of trust funds made available under KRS 211.595.

The initial plan shall be completed on or before October 1, 2015, and shall be updated on an annual basis on or before October 1 of each year thereafter. The plan shall, at a minimum, include the following:

(a) A summary of existing pediatric cancer research, awareness, treatment, and funding programs provided to children of Kentucky;

(b) A needs assessment for the pediatric cancer patients of the Commonwealth of Kentucky that identifies additional research funding needs by cancer type and geographic area, with support for why the identified programs are needed; and

(c) A prioritized list of programs and research projects that the board will address with funding available through the competitive grant program established under subsection (2) of this section;

(2) (a) Promulgate administrative regulations to establish a competitive, open grant program to provide funding to not-for-profit entities, academic medical centers and government agencies



offering research funding and treatment for pediatric cancer to Kentucky children impacted by the disease.

(b) The grant program shall provide funding to research projects and programs in accordance with the priorities established in the plan developed under subsection (1) of this section.

(c) The administrative regulations shall, at a minimum:

1. Establish an application process and requirements;
  2. Set forth program and outcome measurement requirements;
  3. Establish an application review and award process; and
  4. Provide monitoring, oversight, and reporting requirements for funded programs;
- (3) Promulgate administrative regulations necessary to carry out the provisions of this section and KRS 211.596; and
- (4) Provide to the Governor and the Legislative Research Commission an annual report by October 1 of each year. The report shall include:
1. The plan developed under subsection (1) of this section for the expenditure of funds for the current and next fiscal year;
  2. A summary of the use and impact of prior year funds;
  3. A summary of the activities of the board during the prior fiscal year; and
  4. Any recommendations for future initiatives or action regarding pediatric cancer research funding.

**Effective:** June 24, 2015

**History:** Created 2015 Ky. Acts ch. 96, sec. 5, effective June 24, 2015; and ch. 108, sec. 4, effective June 24, 2015.

**Legislative Research Commission Note** (6/24/2015). This statute was created with identical text in 2015 Ky. Acts chs. 96 and 108, which were companion bills. These Acts have been codified together.

**Legislative Research Commission Note** (6/24/2015). During codification, the Reviser of Statutes has corrected the name of the Pediatric Cancer Research Trust Fund Board in this statute from the way it appeared in 2015 Ky. Acts ch. 96, sec. 5 and 2015 Ky. Acts ch. 108, sec. 4, by inserting the inadvertently omitted word "Trust" in the sentence preceding subsection (1).

**Legislative Research Commission Note** (6/24/2015). During codification, the Reviser of Statutes has changed the way subsection (2) of this statute is subdivided from the way it appeared in 2015 Ky. Acts ch. 96, sec. 5 and 2015 Ky. Acts ch. 108, sec. 4. None of the text of that subsection was changed

## **Appendix B**

# **Childhood Cancers in Kentucky Presentation to Interim Joint Committee on Health and Welfare**

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# Childhood Cancer in Kentucky

Eric B. Durbin, DrPH, MS  
Director of Cancer Informatics  
Kentucky Cancer Registry

Lars Wagner, MD  
Chief, Division of Pediatric Hematology/Oncology  
Kentucky Children's Hospital  
Professor of Pediatrics, Children's Miracle Network Research Chair in Pediatrics  
University of Kentucky

Katie Bathje, MA, LPCC  
Program Director  
Kentucky Cancer Consortium

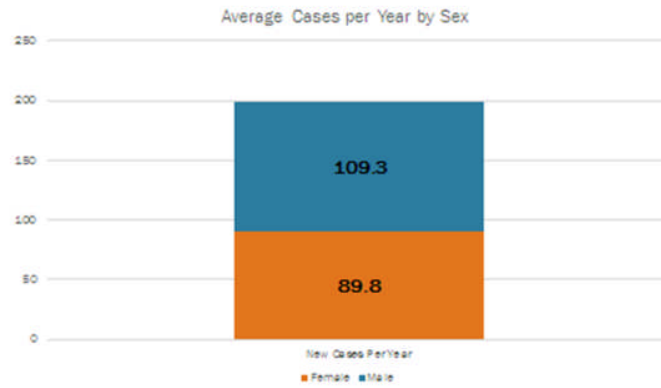
Interim Joint Committee on Health and Welfare  
September 21, 2016

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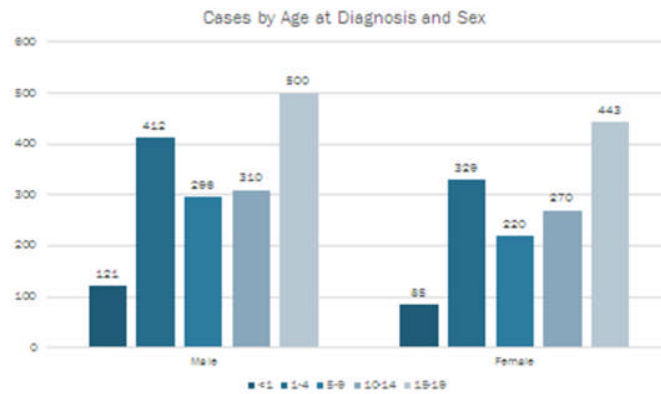
## Overview

- Childhood cancer incidence in Kentucky
- Regional burden of childhood cancer in Kentucky
- Comparisons of childhood cancer incidence rates in Kentucky, Appalachian Kentucky and the United States
- Childhood cancer survival in Kentucky
- Kentucky Cancer Action Plan

## Childhood Cancer Incidence in Kentucky All Sites, 1999-2013



## Childhood Cancer Incidence in Kentucky All Sites, 1999-2013



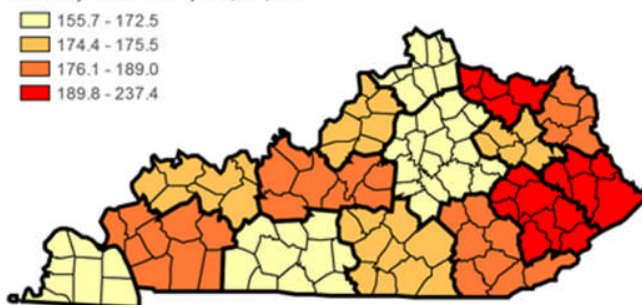
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## Cancer Incidence Rates

- Defined as the number of new cases diagnosed in the population at risk over a specific time period

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Age-Adjusted Childhood Cancer Incidence Rates in Kentucky  
All Sites, 1999 - 2013  
By Area Development District  
Age-Adjusted to the 2000 U.S. Standard Million Population  
Kentucky Rate: 176.0 / per 1,000,000



All rates per 1,000,000.  
Data accessed September 12, 2016. Based on data released Jan 2016.  
© 2016 Kentucky Cancer Registry.

### Age-Adjusted Childhood Cancer Incidence Rates in Kentucky All Sites, 1999 - 2013

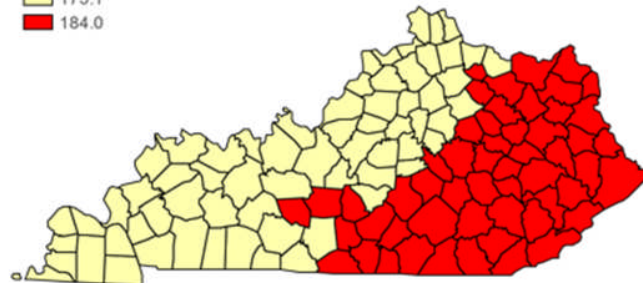
By Appalachian Region

Age-Adjusted to the 2000 U.S. Standard Million Population

Kentucky Rate: 176.0 / per 1,000,000

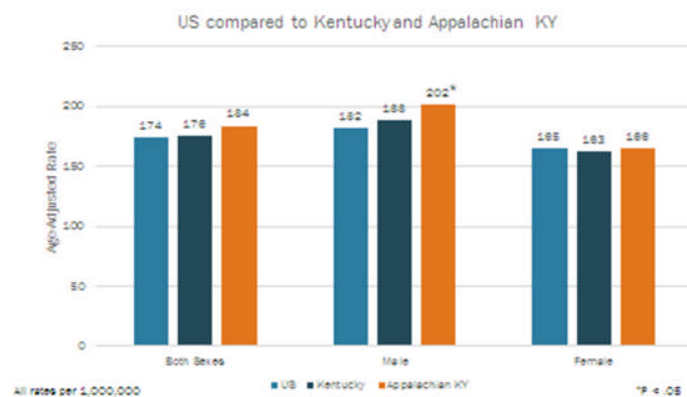
173.1

184.0

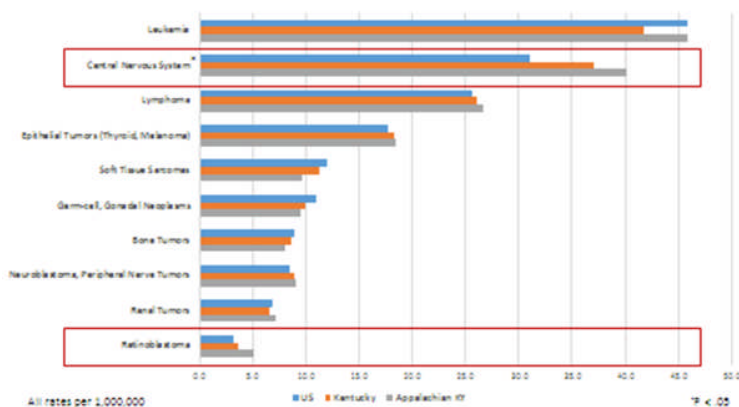


All rates per 1,000,000.  
Data accessed September 12, 2016. Based on data released Jan 2016.  
© 2016 Kentucky Cancer Registry.

### Age-Adjusted Childhood Cancer Incidence Rates All Sites, 1999-2013

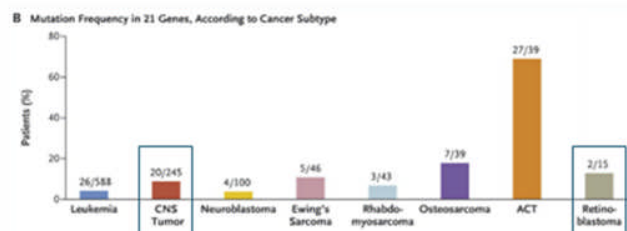


## Age-Adjusted Childhood Cancer Incidence Rates Top Ten US Sites, 1999-2013



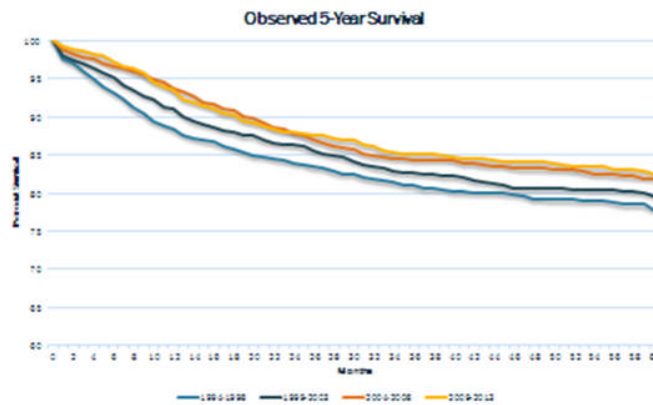
## Predisposition Genes in Pediatric Cancer

- Germline mutations in cancer-predisposing genes identified in 8.5% of 1120 pediatric cancer patients
- Rate much higher than expected



Zhang J, Walsh MF, Wu G, et al. Germline Mutations in Predisposition Genes in Pediatric Cancer. *New England Journal of Medicine* 373:2336-46, 2015.

### Childhood Cancer in Kentucky Survival by Diagnosis Cohort All Sites, 1994-2013



### Kentucky Cancer Action Plan: Childhood Cancer

- The childhood cancer section of the Cancer Action Plan is provided in your folders today.
- Measurable objectives include:
  - Percentage of Kentucky pediatric oncology patients seen at Children's Oncology Group facilities.
  - Five-year survival rate of Kentucky childhood cancer patients.
  - Number of Kentucky-specific resource guides available to pediatric cancer patients and their families/caregivers.



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### **Kentucky Cancer Action Plan: Childhood Cancer, cont.**

- Number of statewide networking and professional development meetings of childhood cancer advocates and professionals.
- Number of Kentucky pediatric oncology patients evaluated at Long-Term Follow-Up Clinics.
- Number of instructional hours offered under Kentucky's home/hospital instruction programs.

## Appendix C

# **Kentucky Cancer Consortium Cancer Action Plan Childhood Cancer Section**



*Kentucky Cancer Consortium*

# CANCER ACTION PLAN

a blueprint for cancer prevention  
and control in our state



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## Goal 10: Quality of Life

Promote overall health of Kentucky cancer survivors from diagnosis onward, to increase quality of life.

### Childhood Cancer Survivors

#### Focus Areas

- Public Health Needs of Adult Cancer Survivors
- **Childhood Cancer Survivors**
- Hospice and Palliative Care

#### Objectives

Measure	Baseline	Target
% of KY pediatric oncology patients seen at Children's Oncology Group facilities	79% <sup>1</sup>	90% by 2021
Number of KY pediatric oncology patients evaluated at Long-Term Follow Up Clinics.	XX <sup>2</sup> : TBD by Fall 2017	XX by 2021
Five year survival rate of KY childhood cancer patients.	84% <sup>3</sup>	87% by 2021
Number of KY-specific resource guides available to pediatric cancer patients and their families/caregivers.	0 <sup>4</sup>	1 by 2021
Number of instructional hours offered under KY's home/hospital instruction programs.	Minimum of two (2) one (1) hour visits per week. <sup>5</sup>	Minimum of five (5) hours per week by 2021.
Number of statewide networking & professional development meetings of childhood cancer advocates & professionals.	0 <sup>6</sup>	One meeting annually (five total) by 2021.

#### Policy, Systems, and Environmental Changes

- Work with childhood cancer advocacy organizations to support efforts aimed at improving Kentucky pediatric cancer patients' quality of life from diagnosis onward.
- Educate patients, parents and educators on academic challenges faced by childhood cancer patients, and educate legislators as to the importance of comprehensive home/hospital instruction administrative regulations in Kentucky.
- Expand workforce training in pediatric palliative care.
- Promote increased access to integrated palliative care services for children facing any stage of cancer.
- Work with public health economists to calculate the financial impact of childhood cancer in Kentucky (loss of income by parents; out of pocket costs for care; data on financial hardships/medical bankruptcy; long-term financial impact on pediatric cancer survivors such as employability and insurability).

#### Health Equity

- Increase research to better understand and address differences in childhood cancer occurrence and survival between Appalachian and Non-Appalachian regions.

#### Communication/Education

- Increase education about long-term consequences of cancer treatment for pediatric, adolescent/young adult, and adult cancer patients.
- Educate patients and their families about the need for long term follow-up care to monitor for late effects of childhood cancer treatment and promote healthy survivorship.
- Encourage families of children with cancer to utilize treatment summaries and survivorship care plans.
- Conduct website research to identify available childhood cancer educational resources.
- Work with Kentucky Children's Alliance, Kentucky COG facilities staff, and other interested partners and advocates to create a list of childhood cancer resources utilized by pediatric cancer patients and their families.
- Support and promote awareness for programs that provide psychosocial, physical, logistical, and emotional support for patients and their families.
- Identify and address need for consumer friendly explanations of pediatric clinical trials, informed consent, and referral patterns.
- Identify and address family educational needs (diagnosis, treatment, late-effects, psychosocial support programs, sibling support, respite care).
- Work with school intervention specialists to raise awareness among Kentucky patients, families, educators and administrators as to support that should be available through the school system (IEP, educational consultants, etc.).

<sup>1</sup>Kentucky Cancer Registry, 2009-2013, accessed September 2016; <sup>2</sup>Baseline data to be collected by Fall 2017, from Children's Oncology Group facilities in Kentucky with Long-Term Follow-Up Clinics.; <sup>3</sup>National Cancer Institute, SEER\*Stat database, 2009-2013; <sup>4</sup>Meeting of Kentucky Cancer Consortium childhood Cancer member organizations, August 2016; 5704 KAR 7:120; <sup>6</sup>Kentucky Cancer Consortium program records, 2001-2016.

## Goal 10: Quality of Life

Promote overall health of Kentucky cancer survivors from diagnosis onward to increase quality of life.

### Childhood Cancer Survivors

#### Focus Areas

- Public Health Needs of Adult Cancer Survivors
- Childhood Cancer Survivors
- Hospice and Palliative Care

**“** In the U.S. in 2016, an estimated 10,380 new cases of cancer will be diagnosed among children from birth to 14 years, and about 1,250 children are expected to die from the disease.<sup>1</sup>

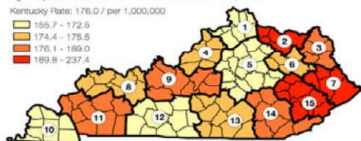
In Kentucky, approximately 200 children are diagnosed with invasive cancer each year.<sup>2</sup>

**”**

Although pediatric cancer death rates have declined by nearly 70% over the past four decades, cancer remains the leading cause of death from disease among children.<sup>1</sup>



Age-Adjusted Childhood Cancer Incidence Rates in Kentucky  
All Sites, 1999 - 2013  
By Area Development District  
Age-Adjusted to the 2000 U.S. Standard Million Population  
Kentucky Rate: 176.0 / per 1,000,000



All rates per 1,000,000.  
Data accessed August 29, 2016. Based on data released Jan 2016.  
© 2016 Kentucky Cancer Registry.

- |                     |                      |
|---------------------|----------------------|
| 1 Northern Kentucky | 9 Lincoln Trail      |
| 2 Buffalo Trace     | 10 Purchase          |
| 3 Flaco             | 11 Pennyville        |
| 4 Kipda             | 12 Barren River      |
| 5 Bluegrass         | 13 Lake Cumberland   |
| 6 Gateway           | 14 Cumberland Valley |
| 7 Big Sandy         | 15 Kentucky River    |
| 8 Green River       |                      |

#### Communication/Education (cont.)

- Increase general awareness of incidence and impact of pediatric cancer on America's children.
- Increase awareness of clinical trials in the pediatric/adolescent population.
- Increase awareness of need for novel pediatric cancer therapies.
- Increase awareness of the impact of pediatric cancer on survivors and their families.

#### Healthcare Professionals

- Promote utilization of recommendations/standards for follow-up care (e.g., COG Passport for Care; Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)), including baselines for neuro-cognitive status and follow-up screening.
- Increase continuing education opportunities for pediatricians and primary care providers regarding diagnosis of childhood cancer and importance of referrals to COG facilities.
- Adopt a standardized neuro-cognitive baseline and follow up assessments as established by COG.
- Increase collaborations among Kentucky partner organizations to develop childhood cancer awareness continuing education modules for tele-health and online use.

#### Insurers

- Work to increase access and coverage of treatment at COG facilities for all childhood cancer patients.
- Educate decision makers on the need for adequate reimbursement for pediatric home, hospice and palliative care.
- Advocate for coverage of appropriate psychosocial services for parents and siblings of children with cancer.

#### Worksite Wellness

- Educate human resource professionals as to the full extent of resources available to pediatric cancer caregivers through the Family Medical Leave Act.

#### Data & Research

- Support research leading to new therapies targeted specifically for children with cancer that are effective and less toxic.
- Promote basic/molecular research leading to understanding the causes of pediatric cancers.
- Increase access to all phases of pediatric oncology clinical trials.
- Promote research to improve the quality of life for survivors that address the physical, cognitive and psychosocial consequences of treatment from diagnosis through late effects.
- Work with state and national partners to support funding for pediatric cancer research.
- Support development of funding mechanisms to support non-profits providing quality educational materials to children with cancer and their families.

<sup>1</sup>National Cancer Institute; <sup>2</sup>Kentucky Cancer Registry