



## Media Backgrounder

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### Overview

Childhood Cancer Guides is a charitable organization located in Bellingham, Washington dedicated to writing, updating, and publishing books that help families of children with cancer and survivors of childhood cancer. Childhood Cancer Guides aims to make the future brighter for children with cancer, from diagnosis through survivorship, one step at a time. Childhood Cancer Guides was founded in 2003 by two parents of children who survived childhood cancer: Nancy Keene and Catherine Woodman. Childhood cancer is the number one cause of death by disease in children and teens. Nancy's daughter had high-risk acute lymphoblastic leukemia and Catherine's son had medulloblastoma, a type of brain cancer.

Childhood Cancer Guide's books are reviewed by well-known experts in childhood cancer from places such as the Children's Hospital of Philadelphia, Children's Hospital of Los Angeles, St. Jude Children's Research Hospital, and many others. In fact, of the 160 experts Childhood Cancer Guide has asked to review texts, none have said no and all have been voluntary. The books are distributed in over 100 hospitals and support groups. As well as being a part of the Coalition Against Childhood Cancer, Childhood Cancer Guides also received a Bronze level award with Guidestar. Guidestar is internationally recognized for its non-profit reporting services.



## Social Media

Facebook: Childhood Cancer Guides, For Book Purposes

[www.facebook.com/childhoodcancerguides/](http://www.facebook.com/childhoodcancerguides/)

Facebook: Childhood Cancer Survivors, For Survivors of Childhood Cancer

[www.facebook.com/survivors.of.childhood.cancer/](http://www.facebook.com/survivors.of.childhood.cancer/)

## Current Activities:

Childhood Cancer Guides is currently working on updating Childhood Leukemia: A Guide for Families, friends & Caregivers, 4th Edition. That is scheduled to come out in Spring of 2018, but Keene has begun work on that already to begin to get drafts off to editors. They are not currently engaged in any campaigns but they are always looking to spread knowledge about childhood cancer and helping survivors of childhood cancer.

One of the main goals that Keene hopes to accomplish is to educate survivors of childhood cancer. To instruct them that continuing to get checked out once a year, even by a primary care doctor will be beneficial in the long run. Keene says that so many survivors do not continue to seek treatment and it can have dangerous consequences.

## The Books

Childhood Cancer Guides is part of a large community of people that love someone that has or had childhood cancer. Strong bonds of caring, shared experience, and support tie this group together. Throughout the text of the books are stories from more than 500 parents, children with cancer, and survivors. More than 160 health care professionals including well-known pediatric oncologists, nurse practitioners, psychologists, educators review and improve the books.



The following books were written to help families and survivors cope, one step at a time.

- **Childhood Leukemia**
- **Childhood Cancer**
- **Childhood Brain & Spinal Cord Tumors**
- **Childhood Cancer Survivors**
- **Your Child in the Hospital**

## Key Terms

Acute lymphoblastic leukemia: *Type of cancer of the blood and bone marrow.*

Medulloblastoma: *The most common type of pediatric malignant primary brain tumor (cancer), originating in the part of the brain that is towards the back and the bottom, on the floor of the skull.*

## Facts

*All Childhood Cancer Guides books are published books at an eleventh-grade literacy level.*

### National

- Although cancer in children is rare, it is the leading cause of death by disease past infancy among children in the United States.
- In 2014, it is estimated that 15,780 children and adolescents ages 0 to 19 years were diagnosed with cancer. (NCI)
- An estimated 1,960 will die of the disease in the United States. (NCI)
- Every day 43 children and teens are diagnosed with cancer.
- More than 40,000 children and teens are in cancer treatment each year.
- About 420,000 survivors of childhood cancer live in the United States.
- By the time they are 45 years old, 95% of survivors have a major health problem.



## State of Washington

- Childhood Cancer rates in Washington in children under the age of 15 (16.1%) are slightly higher than that of the nation (16%). (SCP)
- Of the 2,233 children in the United States who died from cancer in 2003, 53 lived in Washington. (CHE)
- The state death rate from all childhood cancers combined was 3.1 per 100,000 population, as compared to a national rate of 2.8. (CHE)
- Washington had the fifth highest childhood cancer death rates in the country in 2003. Only Idaho, New Mexico, California and Oregon had higher rates. (CHE)

## Industry

- In the last 20 years, only three drugs have been approved specifically to treat children with cancer.
- Less than 4% of National Cancer Institute funding is used for childhood cancer research.
- On average, pediatric hospitalizations principally for cancer were eight days longer and cost almost five times as much as hospitalizations for other pediatric conditions in 2009. (AHRQ)
- The most expensive pediatric cancer hospitalization in 2009 was for leukemia. A \$55,700 mean cost per stay. (AHRQ)
- From 2000 to 2009, the mean cost per stay for pediatric cancer hospitalizations rose 36%. (AHRQ)

## Organization Bios

Childhood Cancer Guides has 5 members in its board of directors:

### Nancy Keene



Nancy Keene is the mother of a long-term survivor of high-risk acute lymphoblastic leukemia. A well-known writer and advocate for children with cancer, she has written and co-authored many books on topics ranging from childhood cancers to working with your doctor. She was the first chair of the Children's Cancer Group (CCG) Patient Advocacy



Committee, and then the first chair of the Patient Advocacy Committee of the Children's Oncology Group (COG)—consortiums of researchers from more than 250 children's hospitals.

### Catherine Woodman, MD

Catherine Woodman received her BA in biology and her MD from Brown University, and she completed her residency at the University of California, San Francisco. Her young adult son is a survivor of medulloblastoma. She has been on the faculty at the University of Iowa in the departments of psychiatry and family medicine for more than 20 years. She has served as a member of COG for 10 years and is on its Patient Advocacy Committee, Ethics Steering Committee, and Central Nervous System Tumors Steering Committee. In addition, Dr. Woodman is currently a member of the Phase I/Phase II Data Safety Monitoring Committee, and she served on the National Cancer Institute's Pediatric Central Institutional Review Board for 6 years.



### Gib Smith, JD

Long-term survivor of childhood cancer; attorney; advocate.

### Patty Feist, MS

Parent of a long-term survivor of childhood cancer; webmaster of [www.ped-onc.org](http://www.ped-onc.org); administrator of online support groups. ([www.acor.org](http://www.acor.org))

### Wendy Hobbie, RN, MSN, CRNP, FAAN

Associate Director of the Cancer Survivorship Program at Children's Hospital of Philadelphia; writer; advocate.



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## Boilerplate

Childhood Cancer Guides (CCG) – headquartered in Bellingham, Washington – was founded in 2003 by Nancy Keene and Catherine Woodman. This nonprofit organization is dedicated to improving the lives and access to health care for those affected by childhood cancer through publishing and distributing books on childhood cancer, survivorship, coping mechanisms and objective information about the disease. CCG has six authors and five people on the board of directors

[www.childhoodcancerguides.org](http://www.childhoodcancerguides.org)

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## Top 10 Frequently Asked Questions

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### 1. Who is Childhood Cancer Guides?

We are a 501(c)(3) charitable organization dedicated to improving the lives and access to health care for those affected by childhood cancer through the publication of books, guides for families experiencing a child with cancer.

### 2. What do you do?

We write books that help families of children with cancer and survivors of childhood cancer. There are currently five books: “Childhood Leukemia,” “Childhood Cancer,” “Childhood Brain & Spinal Cord Tumors,” “Childhood Cancer Survivors,” and “Your Child in the Hospital.”

### 3. Why are we important?

With our books, we inspire a sense of community for children, families and loved ones affected by through childhood cancer. Also with our help, information is easy to understand and families can get the best care for their child.

### 4. How did we get started?

Childhood Cancer Guides was founded in 2003 by two parents of children who survived childhood cancer. Nancy Keene and Catherine Woodman had the vision to create a brighter future for anyone going through the fight of childhood cancer.

### 5. Where can I find your books?

You can purchase any of our books directly on our website or on Amazon, Barnes & Noble, Books-A-Million, Indigo and on the iBookstore.

### 6. How much do your books cost?

The average cost of our books is around \$25, but keep in mind, you can find our books in countless libraries. Also, our books are provided free-of-charge in over 100 hospitals nationwide.

### 7. How can I get connected?

You can subscribe to receive our email blasts by entering your email at the bottom of any of our pages on our website. You can also find us on Facebook:

[www.facebook.com/survivors.of.childhood.cancer/](http://www.facebook.com/survivors.of.childhood.cancer/)

### 8. Can I donate? If so, where?

Donations are always welcome! You can contribute through mail or online here:

[www.childhoodcancerguides.org/support-us/donate/](http://www.childhoodcancerguides.org/support-us/donate/)



9. Where are you located?

We are located in Bellingham, Washington, but we work with kids and families all over the world.

10. Where can I find other resources for childhood cancer?

You can find more resources for childhood cancer, including resources for medical treatment and community building, [here](#).

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## Logos and Tagline

Primary:



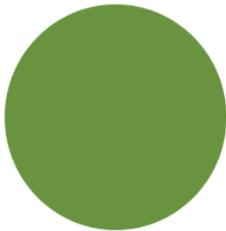
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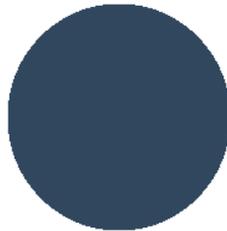
Alternate:



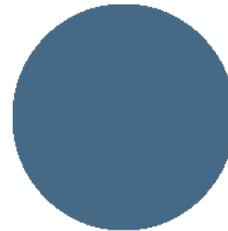
The three logos above can be used at any size, although the orientation should not be altered. The colors should not be changed, altered or manipulated in any way other than black & white representation. The pantones are as follows:



#69933e



#30475e



#466a86

Tagline: "Childhood Cancer Guides, Cope Together."



## Potential Feature Story Ideas

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### Director/president profile

Nancy Keene is the cofounder of Childhood Cancer Guide, along with Catherine Woodman, MD – both are parents of childhood cancer survivors. She is a writer and an advocate for those affected by childhood cancer. She would make a great feature story because her goal is to provide easy-to-understand information for those affected by childhood cancer. She is very passionate about her work and hopes to help others cope through literature, helpful resources and a community of people who understand. Her story could inspire others to get involved in raising money or awareness for childhood cancer. To reach Nancy Keene, contact Childhood Cancer Guides here:

<https://www.childhoodcancerguides.org/support-us/contact-us/>

### Member/customer/or beneficiary profile

If we were able to speak with someone that has shared their story with Childhood Cancer Guides, it would give another perspective to how a family copes with a child that has cancer. Contacting Nancy Keene through Childhood Cancer Guides' website <https://www.childhoodcancerguides.org/support-us/contact-us/> would be the best place to start. There is a great deal of inspiration that comes from reading how people thrive despite hardships and Childhood Cancer Guides takes pride in representing a diverse group of people with varying perspectives – they provide support to parents, children and teens around the world. Also, people find narrative storytelling compelling. There would be great response to the willingness to share a story that may be difficult.

### Mission/issue story

Childhood Cancer Guides is a nonprofit organization whose goal is to provide education and support to those affected by childhood cancer. Every day 43 children and teens are diagnosed with cancer in the United States and there are more than 420,000 survivors of childhood cancer living in the U.S. Your readership could benefit from knowing about Childhood Cancer Guides because more research, awareness and funding will lead to improved treatment and the finding of a cure. Three of the top issues surrounding childhood cancer are the lack of funding, the strong community of parents and families, and post-cancer treatment and care.



## Media Mentions and Recognition

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Guidestar

We hold a bronze level award with Guides.

Guidestar is internationally recognized for its non-profit reporting services.



Coalition Against Childhood Cancer

CCG is a proud founding member of the Coalition of Childhood Cancer.



## Sources

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Children's Cancer Research Fund. 2017. "Types of Childhood Cancer." Children's Cancer Research Fund. Accessed January 16, 2017.

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