Wisconsin Cancer Collaborative
REDUCING THE BURDEN TOGETHER

Childhood Cancer Resources

The Wisconsin Cancer Collaborative has compiled various childhood cancer resources aimed at health care providers and community partners looking to add or further incorporate childhood cancer topics into their work.

Wisconsin Cancer Collaborative Resources

- Wisconsin Childhood Cancer Action Plan 2024-2028 - This Childhood Cancer Action Plan aims to fill the gaps found within the awareness, education, and care given to those with cancer as children. The Action Plan also addresses the long-term physical, psychological, and psychosocial impacts cancer has on patients throughout their lifetime, and on their families, support systems, and care teams.
- Childhood Cancers in Wisconsin: Data Brief - Childhood cancers are relatively rare but extremely challenging for children and their families when diagnosed. This data brief summarizes childhood cancer incidence and mortality in Wisconsin with a focus on leukemias, brain and other central nervous system (CNS) tumors, and lymphomas.
- Pediatric Cancer in Wisconsin Webinar (September 2023) - In honor of Pediatric Cancer Awareness month, this webinar focused on the state of pediatric cancer in Wisconsin, featuring a panel of experts working on pediatric cancer including Dr. Christian Capitini of the UW Carbone Cancer Center, as well the Wisconsin Cancer Reporting System.
- WCC Childhood Cancer Action Hub - This online resource hub links to the various internal and external resources covered in this list, along with WCC partner spotlights to help connect local, statewide, and national organizations working in this space.

External Partner Resources

The following partner resources are organized into six subtopics matching the format of the WCC Childhood Cancer action hub.

1. Psychosocial Support for Children and their Families
2. Childhood Cancer Survivorship
3. Resources for Providers
4. Pediatric Palliative and Hospice Care
5. Childhood Cancer Statistics
6. Federal and State Policy

External Partner Resources

Psychosocial Support for Children and their Families

- Gilda's Club – Gilda's Club Madison offers support for children's, teen's, young adults, and caregivers through their Youth & Family programs and their Young Adult programs.
- Joshua's Camp - Joshua's Camp offers free services for families with a child 17 or younger being treated for cancer or out of treatment for less than three years. Joshua's Camp includes a four-day stay at a resort with food, play, their stay, other activities, and therapy provided for free.
- Sibling Support Toolkit (Pediatric Palliative Care Coalition and Courageous Parents Network) – This toolkit helps families better understand the experience of siblings of children with medical complexities and how they interact in the family.
- Hope Portal (CAC2's Childhood Cancer Hub) – The Hope Portal is a searchable website that offers resources for childhood cancer patients and their families during treatment.
- Care for Caregivers Support Network (MACC Fund) - With over 20 years of psychosocial oncology experience, Melissa Minkley, MSW, co-facilitates this gathering with former pediatric cancer parent, Nora Millies, to offer helpful resources, effective ways to navigate the journey, and a space to connect with other caregivers of children with pediatric cancer and related blood disorders who are going through a similar experience. This free group meets virtually over Zoom.
- A School's Guide for Children with Cancer (Leukemia and Lymphoma Society) - This guide helps the school and larger community to assist young people with cancer in maintaining continued involvement in school and other normal life activities.

Childhood Cancer Survivorship

- Beyond Treatment (LLS) – This chapter of the LLS Family Workbook specifically focuses on the post-treatment experience for children previously diagnosed with cancer.
- Better Together (CAC2's Childhood Cancer Hub) - Better Together is a searchable website focused on organizations that provide support for survivors of childhood and AYA cancer.
- CAC2 Survivorship Toolkit (CAC2) - The CAC2 Survivorship Toolkit provides education and resources for childhood cancer survivors and families, covering topics like transitioning to adulthood, insurance and financial health, and physical health and late effects.
- Children's Survivorship Programs Offered by Various Health Organizations:
  - Children's Wisconsin: Next Steps Survivorship Program
  - UW Health: Caring for Life Clinic
  - UW Health Carbone Cancer Center: AYA Telehealth Program
  - Marshfield Clinic: Childhood Cancer Survivorship Program
  - Medical College of Wisconsin: AYA Cancer Program
  - La Crosse Area YMCA: YOUTHSTRONG
  - Gundersen Health System: Pediatric Hematology Oncology Providers
  - HSHS St. Vincent Children's Hospital: Pediatric Hematology and Oncology Department

External Partner Resources

Resources for Providers

- The Leukemia and Lymphoma Society offers several Continuing Medical Education opportunities (with continuing education credits) on a variety of topics. These are intended for hematologist/oncologists, nurses, social workers, and other healthcare professionals. Three particularly relevant programs include:
    - Evolving Treatment Strategies in Pediatric Leukemia
    - Treating Adolescents and Young Adults (AYA) with Blood Cancer
    - Clinician Strategies and Resources: Caring for AYAs as they Transition to Cancer Survivorship
- Additionally, LLS offers podcast episodes for health care professionals to provide relevant and current information on blood cancer. (Please note these do not provide CE credits.) The podcasts are:
    - Pediatric and AYA episodes
    - General Treatment and Support episodes
- This Palliative Care Network of Wisconsin fast facts post entitled Grief and Bereavement in Pediatric Palliative Care discusses culturally informed care in pediatric grief, as well as caregiver grief and the dual process model of coping.
- The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (COG LTFU Guidelines) is a resource for healthcare professionals who provide ongoing care to survivors of pediatric malignancies. The screening recommendations in these guidelines are appropriate for asymptomatic survivors of childhood, adolescent, or young adult cancer presenting for routine exposure-based medical follow-up.
- The Courageous Parents Network complements the important work of physicians, nurse practitioners and nurses, social workers, chaplains and allied health professionals as they support families whose child faces serious illness. The CPN clinician portal provides resources for self-education, educating colleagues, and introducing patient families to key concepts and the wealth of CPN content.

Pediatric Palliative and Hospice Care

- Pediatric Facts and Figures 2023 Edition (National Alliance for Care at Home) – This report provides an overview of pediatric hospice and palliative care in the United States, including information on pediatric patient characteristics, barriers and facilitators to care, and gaps in services.
- Improving the Pediatric Cancer Care Experience with Palliative Support (CPN) – This Guide provides an overview of the benefits of palliative care in pediatric oncology, helping you understand how it can make a meaningful difference. Also available in Spanish.
- Pediatric Care Plan Book (PPCC) - This Care Plan Book was created with the hope that it will make the job of a caregiver a little bit easier. This reference guide can be used by families, caregivers and medical professionals, and covers topics like medical history, appointments, medications, and legal topics.
- Pediatric Cancer (CPN) – This pediatric cancer palliative care hub includes blog posts from parents, videos from physicians, and podcasts hosted by families covering their experiences.
- Tips for Caring for a Child When You are an Adult Provider (NACH) – This fact sheet, geared towards providers familiar with adult palliative and hospice care, covers the differences in pediatric palliative care practices.

External Partner Resources

Pediatric Palliative and Hospice Care (continued)

- Caring Conversations Toolkit (PPCC) - The information in this toolkit will help families and caregivers ask questions to learn if it is time to start a conversation about palliative care or hospice. The information has also been modified so that medical professionals and health care providers can ask similar questions of families to begin a conversation about if and when it is time to talk about palliative care or hospice for their child.

- Self-Advocacy Toolkit (PPCC) - A child or adolescent with medical complexity and their families often face challenges where self-advocacy becomes important. Young people may not be able to advocate for themselves if they do not understand their illness or know how to express their wants and needs. This toolkit is designed to help parents, caregivers, children, adolescents and teens on the advocacy journey.

- Caring for Kids and Adolescents with Blood Cancer Workbook (LLS) - This workbook, Caring for Kids and Adolescents with Blood Cancer, was created by The Leukemia & Lymphoma Society. The workbook is written for the parent/guardian of a minor child (up to age 18), and includes information about caring for your child, treatment options, school, nutrition, financial and legal issues, and more. This Family Workbook includes a set of worksheets and activities and includes a tote, journal, pen and pill organizer.
    - Treatment Options – This chapter focuses specifically on treatment options, which includes palliative (supportive) care.
    - Side Effects and Supportive Care – This chapter focuses specifically on palliative (supportive) care and side effect management.
    - End-of-Life Care – This chapter focuses specifically on end-of-life decisions, conversations, and resources available for children and their families.

Childhood Cancer Statistics

- US Childhood Cancer Statistics (American Childhood Cancer Organization) – This page organizes various sources of national statistics on child and adolescent cancer incidence, survival, and research funding.
    - Also available in childhood cancer fast facts.

- Facts About Childhood Cancer (MACC Fund) – This factsheet highlights key childhood cancer statistics to raise awareness about childhood cancer incidence, survivorship, and challenges faced by patients and their families.
    - Also available for sharing on social media.

- Childhood Cancer Fact Library (CAC2) – This fact library serves as a comprehensive, well-documented and trusted source of information for anyone seeking data and statistics related to pediatric cancers.

- International Childhood Cancer Statistics (World Health Organization) - This WHO fact sheet covers key statistics about the international childhood cancer burden, along with an overview of some causes and ways to improve childhood cancer outcomes.

External Partner Resources

Federal and State Policy

Please note: WCC doesn't lobby or advocate for any specific policies. These resources are provided for educational purposes.

- Concurrent Care for Children Implementation Toolkit (NAHC) – This toolkit is intended to educate about the impact of the CCCR on state Medicaid programs and outline how to develop a coordinated, collaborative state-wide approach for advocating for children living with serious illness through a comprehensive array of services.
    - Pediatric Concurrent Care (NAHC) – This website covers an overview defining pediatric concurrent care and providing additional resources to better understand the impact of this policy for people under 21 years of age receiving active care.
- Wisconsin State-Specific Palliative Care Resources (Center to Advance Palliative Care) – This 2025 state report covers Wisconsin organizations, licensing boards and registries, and state laws and regulations that impact palliative care in Wisconsin. *Note: some resources and data represent all palliative and hospice care populations, not just pediatric.
- Pending Federal Legislation Regarding Childhood Cancer (MACC Fund) – This page discusses current legislation affecting children with cancer and their families, in addition to providing resources for reaching out to relevant members of Congress.

Community Partners

Local Partners

- MACC Fund - The MACC Fund is a non-profit that provides critical funding for childhood cancer and related blood disorders research at The Medical College of Wisconsin, Children’s Wisconsin, UW Carbone Cancer Center and Marshfield Clinic. Their mission is to find a cure for childhood cancer and related blood disorders by providing funding for research.
- Children’s Wisconsin - The Children's Wisconsin team cares for every aspect of a child's health. This includes their physical, social and mental well-being. In order to provide highly specialized cancer therapies, Children's Wisconsin offers a range of clinical trials through our own research programs as well as through participation in Children's Oncology Group (COG), an organization comprised of the world’s experts dedicated to studying childhood cancer.
- Gilda’s Club Madison - Gilda’s Club Madison uplifts and strengthens people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care. The Gilda's Club Madison team works toward that mission by providing free emotional support, cancer education, and hope to children and adults living with any kind of cancer, and those who care for them.
- Badger Childhood Cancer Network - The Badger Childhood Cancer Network serves families from all over Wisconsin and several northern Illinois counties whose child has been diagnosed with cancer or a life-threatening blood disorder. Their mission is to educate, support, serve and advocate for children with cancer and blood disorders, their families, survivors of childhood cancer and the professionals who care for them.
- UW Health Kids - The UW Health Kids Carbone Cancer Center team provides the latest and best treatment options so children with cancer or a blood or bone marrow disorder can heal quickly and grow up healthy. Their doctors are national leaders in treatment and research, and their research improves the care of children with cancer and blood and bone marrow disorders around the world.

Community Partners

Local Partners (continued)

- Camp One Step - Camp One Step by Children's Oncology Services is a leader in providing empowering, supportive, educational and fun experiences for children (ages birth -19) who have been diagnosed with cancer and their families. Camp One Step provides free year-round camp experiences for kids with cancer and their families that foster joy, belonging, confidence, and lifelong friendships.
- Brave Like Mackenzie - Brave Like Mackenzie is an all-volunteer childhood cancer organization that provides support to patients and their families as they battle pediatric cancer. In addition, they help support the MACC Fund Center through gifting books, art supplies, and toys for patients who are receiving treatment.

National Partners

- Coalition Against Childhood Cancer - Coalition Against Childhood Cancer (CAC2) is a collaborative network of nonprofits, corporations, and individuals from 41 states and nine countries, supporting and serving the childhood cancer community. CAC2 members effectively advance a variety of childhood cancer causes by unifying their efforts.
- The Leukemia & Lymphoma Society - Dedicated to curing leukemia, lymphoma, myeloma, and other blood cancers, we are now The Leukemia & Lymphoma Society (LLS), the world's largest voluntary (nonprofit) health organization dedicated to funding blood cancer research and providing education and patient services.
- Courageous Parents Network - For more than a decade Courageous Parents Network (CPN), a nonprofit organization, has oriented, equipped and empowered those caring for children with a serious medical condition. We celebrate This Shared Journey: parents sharing their perspectives to support others and build community; clinicians sharing their expertise and commitment while learning from the insight and experience of families.
- American Childhood Cancer Organization - The American Childhood Cancer Organization (ACCO) was founded in 1970 by parents of children diagnosed with cancer. Formerly known as Candlelighters, ACCO is the nation's oldest and largest grassroots organization dedicated to childhood cancer.
- Pediatric Palliative Care Coalition - Pediatric Palliative Care Coalition (PPCC) provides information, education and resources for families of children with life-limiting conditions, and for the medical providers and professionals who support them. PPCC's website holds practical toolkits, educational webinars, extensive external resources, advocacy information, and more — all designed to Light the Way in pediatric palliative and hospice care.

Do you have any suggestions for an additional resource or featured partner?

*Let us know at **info@wicancer.org**.*