



# Wisconsin Childhood Cancer Action Plan 2024-2028

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**Wisconsin  
Cancer  
Collaborative**

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*This plan is dedicated to our young cancer patients and survivors, their caregivers, our dedicated researchers and clinicians, and everyone in Wisconsin whose lives have been touched by pediatric cancer. Together, we honor the memory of those we have lost to childhood cancer.*



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# INTRODUCTION

This action plan was created with childhood cancer advocates, feedback from national and local organizations involved with childhood cancer work, and the Wisconsin Cancer Collaborative Steering Committee. We would like to especially thank Autumn Gentry and Mariah Forster Olson for their help.

The Wisconsin Cancer Collaborative's Childhood Cancer Action Plan 2024-2028 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 throughout their lifetime and on their families, support systems, and care teams.

We invite anyone in Wisconsin to engage in the action steps highlighted in this document. We also indicate action steps the Wisconsin Cancer Collaborative staff plan to lead. We invite you to keep us updated on your progress.

Note: A cancer diagnosis is upsetting at any age, but especially so when the patient is a child. In this Childhood Cancer Action Plan, we use the terms pediatric, childhood, and adolescent and young adult (AYA).

- Childhood cancers are defined as cancers diagnosed between the ages of 0-14 years.
- Adolescent and Young Adult (AYA) cancers are defined as cancers diagnosed between the ages of 15 to 39 years.
- The action steps in this plan focus on the children and adolescents 0-19 years.

# Goal #1

## IMPLEMENT ACTIVITIES TO PROMOTE THE OVERALL AWARENESS OF CHILDHOOD CANCER IN WISCONSIN.

*By raising awareness of childhood cancer, we can bring more attention and education to people in Wisconsin engaged in cancer control work.*

### RECOMMENDED

### ACTION STEPS FOR EVERYONE

- 1 Share Childhood Cancer Awareness Month materials every September. Include platforms that help to inform childhood cancer awareness with state policymakers.
- 2 Secure local proclamations regarding Childhood Cancer Awareness Month.
- 3 Promote childhood cancer events and resources from government, health systems, and community organizations.
- 4 Create a state-wide awareness campaign discussing prevalence and the need for an increase in funding for research.



# Goal #1

## IMPLEMENT ACTIVITIES TO PROMOTE THE OVERALL AWARENESS OF CHILDHOOD CANCER IN WISCONSIN.

### Steps the Wisconsin Cancer Collaborative program can take:

- Update the Wisconsin Cancer Plan 2020-2030 action steps to include childhood cancer needs (2024).
- Share the Wisconsin Cancer Collaborative *2023 Childhood Cancer in Wisconsin: Data Brief* and 2023 childhood cancer webinar recording. Publish updated data brief in 2025.
- Assess the number of Wisconsin Cancer Collaborative members that work on childhood and/or adolescent and young adult (AYA) cancer (2024, repeat in 2026 & 2028).



## Goal #2

# UTILIZE DATA SOURCES TO BETTER IDENTIFY EMERGING NEEDS FOR THE TREATMENT AND SUPPORT OF CHILDHOOD CANCER PATIENTS AND SURVIVORS.

*The collection and reporting of data within our state can help identify different needs of childhood cancer patients, along with allowing us to target those specific needs.*

### RECOMMENDED

## ACTION STEPS FOR EVERYONE

- 1 Collect and report on health inequities of childhood cancer (i.e.: distance needed to travel to care, access to fertility preservation services, survivorship focused clinics, clinical trials), including identifying sources of data on the loss of income by parents. Include the caregiver perspective through dedicated focus groups to identify actionable items.
- 2 Develop Policy, Systems, and Environmental (PSE) changes to improve the treatment and support of childhood cancer patients' needs.
- 3 Establish a better understanding of data available regarding genetic risk and childhood cancer, and make steps to improve data acquisition.



## Goal #2

# UTILIZE DATA SOURCES TO BETTER IDENTIFY EMERGING NEEDS FOR THE TREATMENT AND SUPPORT OF CHILDHOOD CANCER PATIENTS AND SURVIVORS.

### Steps the Wisconsin Cancer Collaborative program can take:

- Partner with the Wisconsin Cancer Reporting System to understand the opportunities to further analyze childhood cancer data.
  - Topics to explore include: survival data time period, availability of regional or county level data, and the age range for AYA cancer incidence and mortality.
  - Update the *Childhood Cancers in Wisconsin: Data Brief* in 2025.
  - Add childhood cancers to future Wisconsin relative survival report.
  - Explore the opportunity to publish a report on secondary cancer data in Wisconsin.
- Evaluate data that could be monitored and tracked through the Wisconsin Cancer Collaborative online metrics.



## Goal #3

# SUPPORT THE ONGOING EDUCATIONAL NEEDS OF MEDICAL PROFESSIONALS IN WISCONSIN TO LEARN MORE ABOUT CHILDHOOD CANCER.

***Improving the knowledge and skills of the health professionals within Wisconsin can help improve the care they give to those with childhood cancer, helping establish a higher standard for childhood cancer care.***

### RECOMMENDED

## ACTION STEPS FOR EVERYONE

- 1 Support learning needs around childhood cancer, particularly on early symptoms, for medical professionals including, but not limited to: pediatricians, emergency medicine, family practice, internal medicine, and obstetrics.
- 2 Establish roundtable meeting involving healthcare professionals and people impacted by pediatric cancer to learn about pediatric cancer, and solve/discuss barriers to accessing specialized care.
  - Include a variety of medical institutions spanning the spectrum of childhood cancer care to learn from one another, bridge gaps, and reduce disparities.
  - Determine if there is the need to develop a screening tool, including the warning signs and symptoms of childhood cancer for children with potential symptoms of cancer.
- 3 Hold an annual Wisconsin childhood cancer conference or webinar to share data, collaborative opportunities, research, and supportive resources.
- 4 Promote cancer prevention among childhood cancer survivors (such as HPV vaccination, smoking prevention and cessation, limited alcohol use, sunscreen usage, and appropriate subsequent cancer screenings).
- 5 Increase awareness among families and primary care professionals about the surveillance for chronic health conditions secondary to cancer treatments.



## Goal #3

**SUPPORT THE ONGOING EDUCATIONAL NEEDS OF MEDICAL PROFESSIONALS IN WISCONSIN TO LEARN MORE ABOUT CHILDHOOD CANCER.**

### **Steps the Wisconsin Cancer Collaborative program can take:**

- Assess what continuing education requirements and opportunities exist for primary care professionals regarding childhood cancer.
- Promote learning opportunities to membership of the Wisconsin Cancer Collaborative as well as other local or regional cancer-focused organizations and programs.



## Goal #4

# SUPPORT THE ONGOING TRAINING AND DEVELOPMENT FOR PALLIATIVE AND HOSPICE CARE PROFESSIONALS PROVIDING CARE TO CHILDHOOD CANCER PATIENTS AND THEIR FAMILIES.

*A part of caring for those with childhood cancer may include providing high quality end of life or palliative care, and proper training on how to care for children and their families is crucial.*

### RECOMMENDED

## ACTION STEPS FOR EVERYONE

- 1 Assess the quantity of hospice care professionals for childhood cancer needs.
- 2 Offer trainings to hospice care professionals to better understand the needs of childhood patients and families.

### Steps the Wisconsin Cancer Collaborative program can take:

- Recruit additional palliative care provider organizations to join Wisconsin Cancer Collaborative.
- Conduct an environmental scan of childhood palliative care and hospice resources, attitudes, and practices.
- Promote existing resources regarding childhood palliative and hospice care.
- Create a childhood hospice infographic and tip sheet regarding ways to uniquely support the family of a dying child for hospice workers and a “What to Expect” end-of-life resource for parents.

## Goal #5

# SUPPORT ACCESS TO QUALITY CARE FOR THOSE IMPACTED BY CHILDHOOD CANCER AND RESEARCH ON CHILDHOOD CANCER.

***Comprehensive access to quality cancer care for children in Wisconsin includes continued research on prevention, treatment, survivorship, and secondary cancers.***

### RECOMMENDED

## ACTION STEPS FOR EVERYONE

- 1 Assess the needs of health care systems around childhood cancer treatment and survivorship.
- 2 Promote awareness of existing program opportunities for childhood cancer (for example, the Carbone AYA telehealth program).
- 3 Develop Policy, Systems, and Environmental (PSE) changes, such as programs and resources that better address unmet needs around childhood cancer treatment and survivorship.
- 4 Educate primary care teams on screening recommendations and risk reductions behaviors for cancer survivors to help prevent and identify additional and secondary cancers.
- 5 Continue support for telemedicine platforms and insurance reimbursement when caring for cancer survivors.

### Steps the Wisconsin Cancer Collaborative program can take:

- Share funding opportunities for childhood cancer research in Wisconsin Cancer Collaborative materials.
- Connect researchers and the childhood cancer community on how they both can support, fund, and contribute to research in ways that focus on the needs of the child.
- Facilitate connections between community organizations and medical professionals working to reduce childhood cancer and its impact.

