

**Wisconsin
Cancer
Collaborative**

Breakout Session A | Pediatric Cancer Panel

10:15-11:15AM

Pediatric Cancer Panel



Amy Newman, PhD, RN, CPNP-PC

Assistant Professor
Marquette University



Autumn Gentry

Childhood Cancer Advocate
MACC Fund



Mariah Forster Olson, MBA

Board Secretary, Survivorship Interest Group Liaison
Coalition Against Childhood Cancer

Childhood Cancer



Amy R. Newman, PhD, RN, CPNP-PC

Assistant Professor, Marquette University

Pediatric Nurse Practitioner, MACC Fund Center for Cancer and Blood Disorders/Children's Wisconsin/Medical College of Wisconsin

2024 Wisconsin Cancer Summit

September 26, 2024

Learning Outcomes

- Describe the most common types of childhood cancer
- List some of the advances that have been made in pediatric cancer treatments
- Describe some of the key differences between adult and pediatric cancers
- Identify some of the ongoing challenges that pediatric cancer patients and their families face

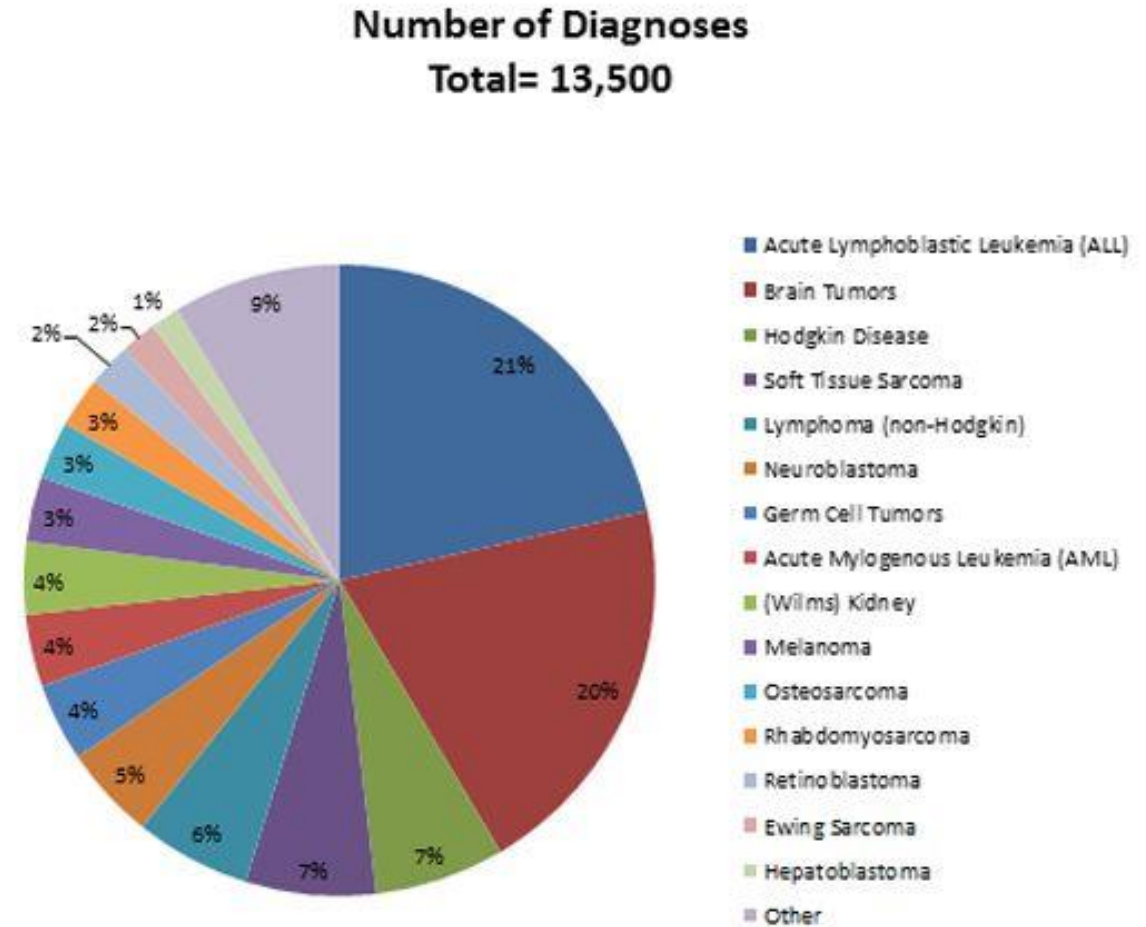


More than
15,000 children
are diagnosed
with cancer each
year in the US.



CURESEARCH
FOR CHILDREN'S CANCER

Different Types of Childhood Cancer



Source: Children's Oncology Group's Disease Committees

Childhood Cancers in Wisconsin: Data Brief

Lena Swander, MPH¹, Alexandria L. Cull Weatherer, MPH², Mary Cianciara, MPH²

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²Outreach Specialist, Wisconsin Cancer Collaborative

Figure 1. Age-Adjusted Childhood Cancer Incidence Rates per 1,000,000 by Age at Diagnosis and Sex in Wisconsin, 2016-2020.

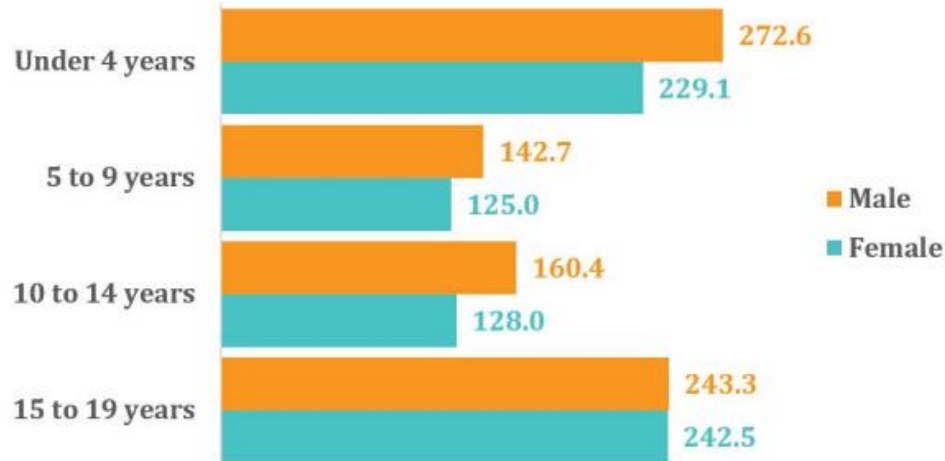
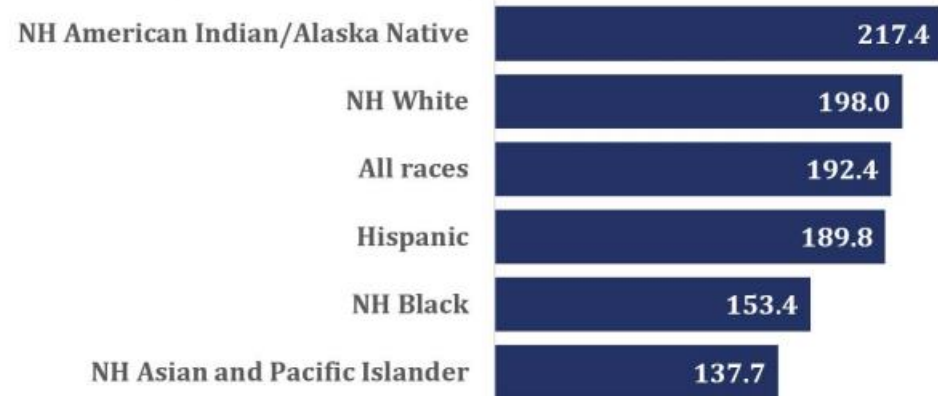


Figure 3. Age-Adjusted Childhood Cancer Incidence Rates per 1,000,000 by Race and Ethnicity in Wisconsin, 2016-2020.



Differences were not statistically significant between groups.

Software: Surveillance Research Program, National Cancer Institute SEER*Stat software (www.seer.cancer.gov/seerstat) version 8.4.1.2. Data: SEER*Stat Database: 9520IncidencePatched. Created on 8/8/2023.

Causes of Childhood Cancer



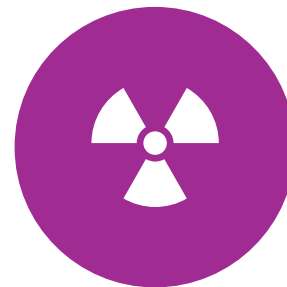
Largely unknown



Inherited genetic changes

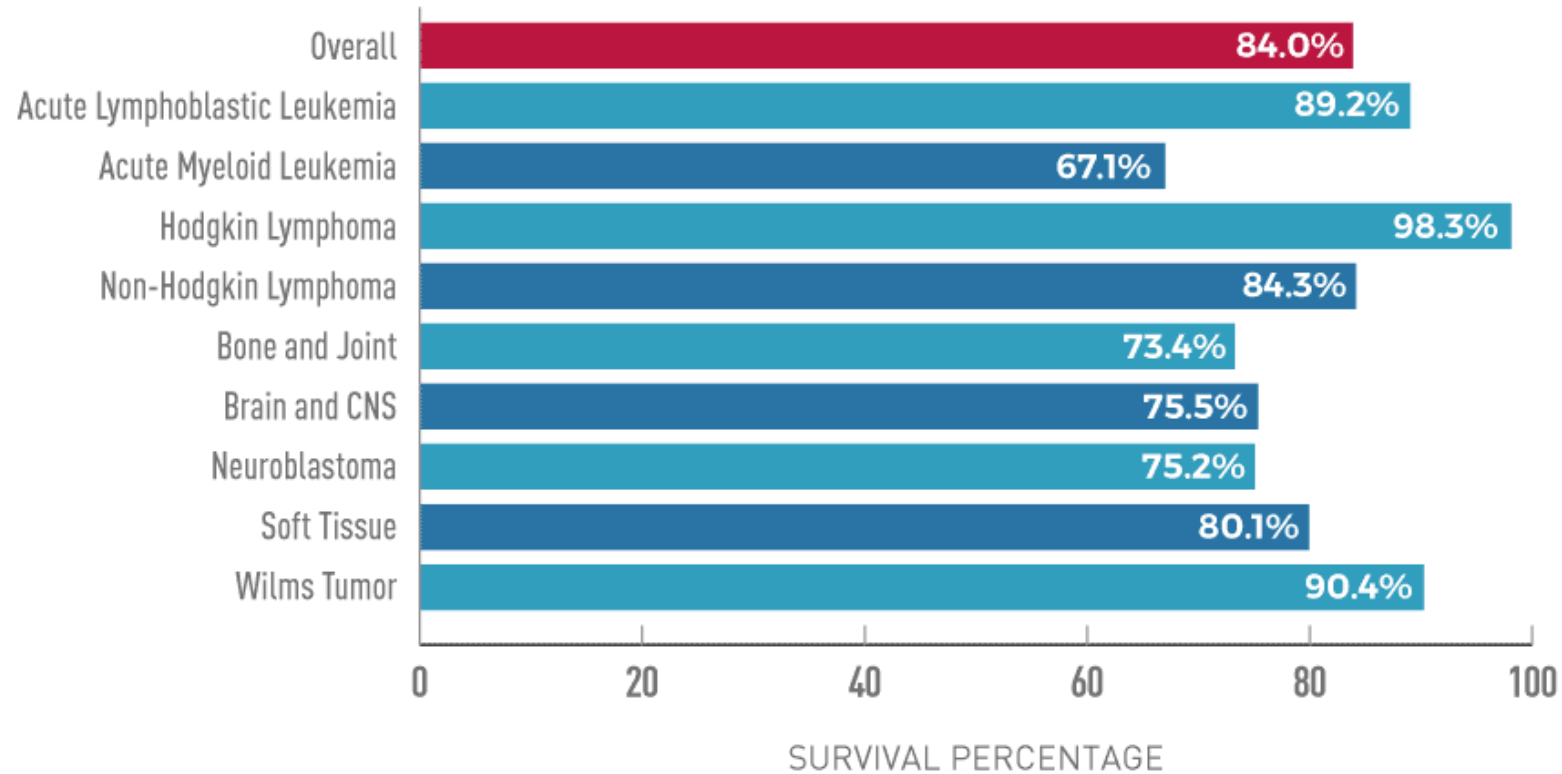


Environmental exposures



Exposure to ionizing radiation

Five-Year Survival Rate for Selected Cancers Among Children Ages 0–19



Racial & Ethnic Disparities

- Incidence rate of leukemia twice as high in Hispanic and American Indian/Alaska Native (AI/AN) children and adolescents as Black children and adolescents
- Rates of brain and other central nervous system tumors higher in White and AI/AN children and adolescents than in all other racial and ethnic groups

Children from racial and ethnicity minority groups and/or of lower socioeconomic status experience higher rates of relapse, decreased overall survival, and inferior psychosocial outcomes compared with their Non-Hispanic White or wealthier counterparts

Approach to Treatment

Chemotherapy

Surgery

Radiation

Immunotherapy

Hematopoietic
stem cell
transplant

Advances in Childhood Cancer Treatment

- CAR T-cell therapy
- Targeted therapies
- Registries and biorepositories



PROJECT:EVERYCHILD



<https://childrensoncologygroup.org/cog-registry-project-everychild>

NATIONAL CANCER INSTITUTE

WHAT IS THE CCDI Molecular Characterization Initiative?



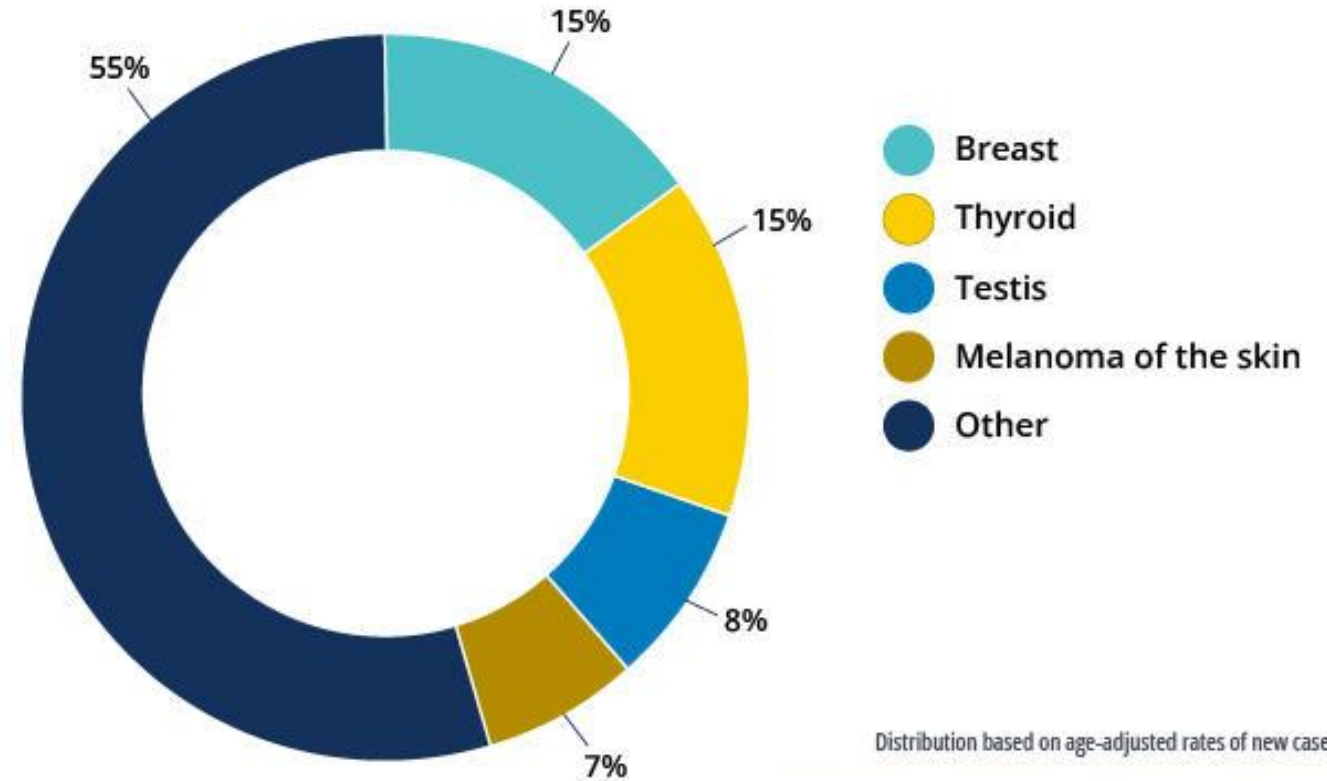
cancer.gov/CCDI-molecular

Adolescents and Young Adults (AYAs) with Cancer

- Ages 15 to 39
- Unique concerns
 - Development
 - Presentation & access to care
 - Cancer biology

Janardan & Wechsler, 2023

Common types of new cancers among AYAs



Distribution based on age-adjusted rates of new cases.

NCI's Surveillance, Epidemiology, and End Results (SEER) Program
SEER 22, 2017-2021

Survivorship



Sadly, more than 95% of childhood cancer survivors will have a significant health related issue by the time they are 45 years of age.



Learn More at [CAC2.org](https://www.cac2.org)



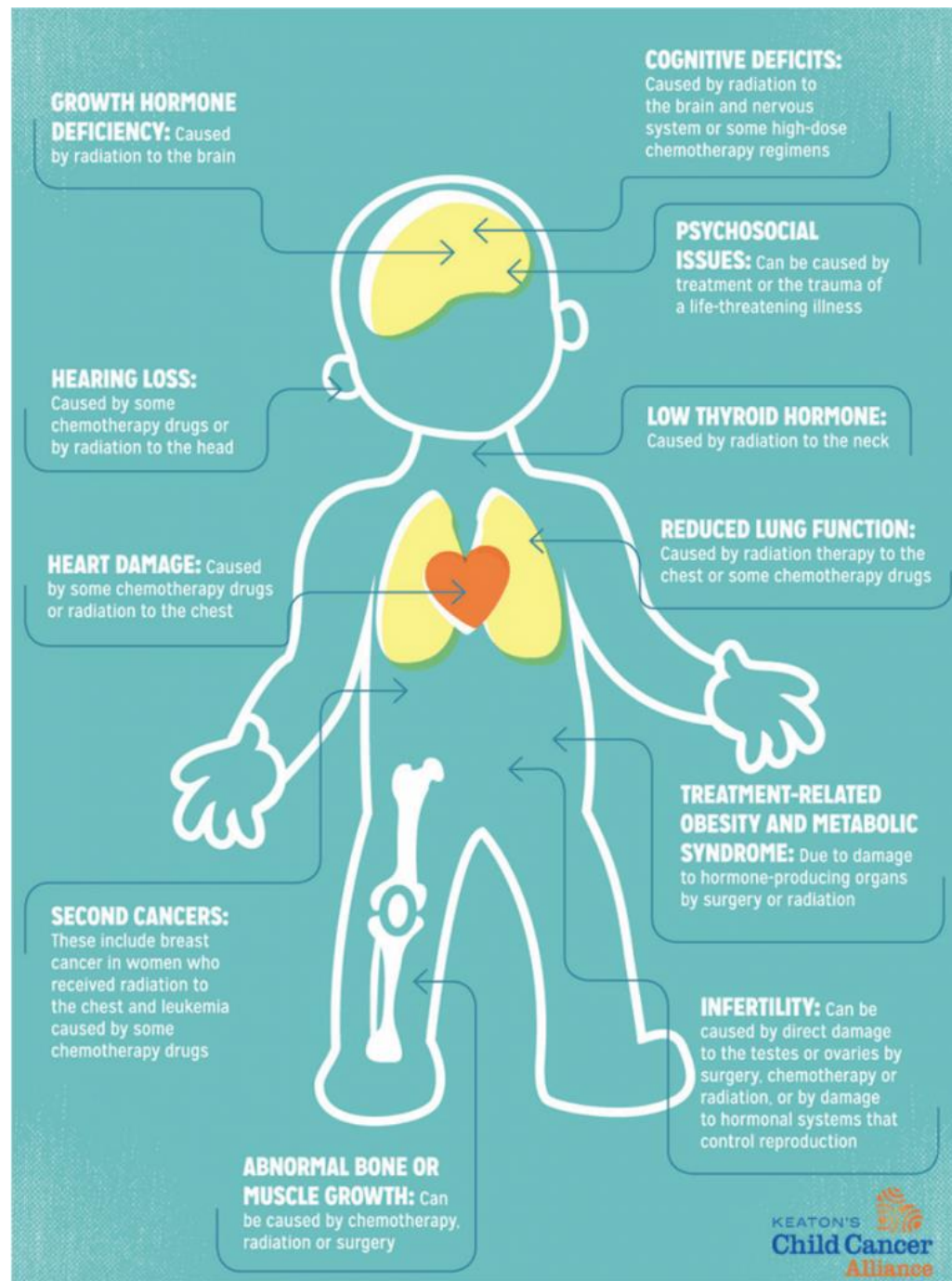


Image source: Keaton's Child Cancer Alliance

**CHILDREN'S
ONCOLOGY
GROUP**

Late Effects Directory of Services

<https://cogmembers.org/public/lateeffects/default.aspx>

Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers, Version 6 (October 2023)

<https://www.survivorshipguidelines.org>



Key Differences Between Pediatric and Adult Cancers

Different types of cancers

Treatment more intense and more successful

Children with cancer are treated at pediatric cancer centers

Long-term side effects are more of a concern

Unique Needs of Pediatric Patients

- Developmentally appropriate care
- Expanded team members including child life and schoolteachers
- Adherence
- Impact on parents and siblings
- Academic continuity & school re-entry
- Death and bereavement

Christiansen et al. 2015; Kearney et al., 2015

Ongoing Challenges in Treating Childhood Cancer



LACK OF IDENTIFIABLE
TARGETS



LOWER INCIDENCE PRESENTS
RESEARCH OBSTACLES



LIMITED AMOUNT OF
FUNDING AVAILABLE



Wisconsin Childhood Cancer Action Plan 2024-2028

AUGUST 2024

Suggested citation: Childhood Cancer Action Plan.
Wisconsin Cancer Collaborative, Madison, Wis.
Available online at: www.wiscancer.org.



<https://wiscancer.org/resource/childhood-cancer-action-plan-2024-2028/>

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MACC FUND[®]

Hope for Kids

Connecting with Childhood Cancer

Autumn Gentry
agentry@maccfund.org



**MACC
FUND**

Hope for Kids



- MACC Fund's Mission: To find a cure for childhood cancer and related blood disorders by providing funding for research.

- MACC Fund has contributed over \$85 million to research.

- MACC Fund supports research at Children's Wisconsin, Medical College of Wisconsin, University of Wisconsin Carbone Cancer Center, and Marshfield Clinic.



Carbone Cancer Center
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



**Marshfield Clinic
Health System**

Building Connections with Childhood Cancer

The topic of childhood cancer is relatively new in the Wisconsin Cancer Collaborative.

Stories are powerful in connecting us with the human side of a problem.

Here is one of thousands of stories.



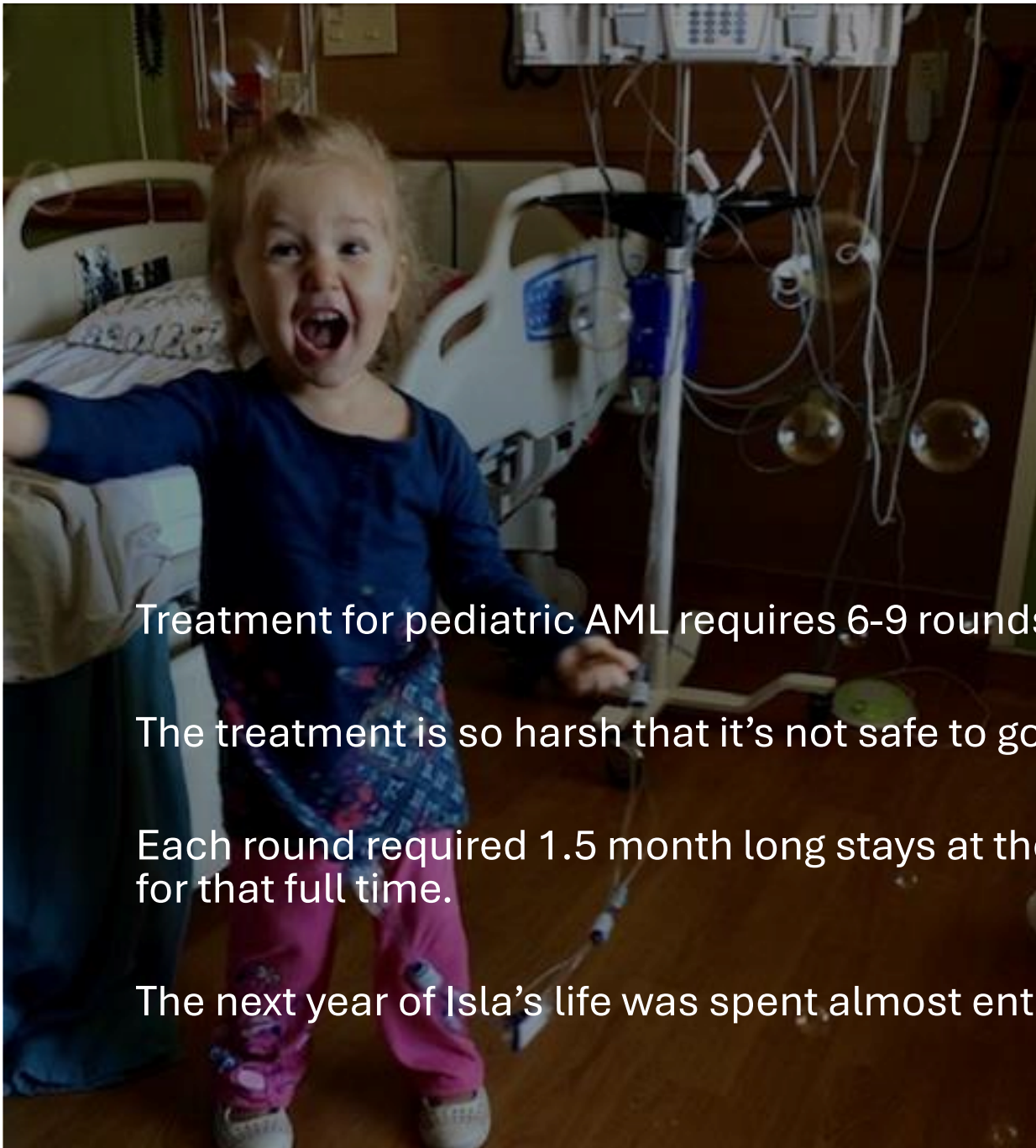


In a day, our lives turned upside down

I noticed a strange rash and bruising on Isla's legs and stomach.

Isla was diagnosed with Acute Myeloid Leukemia, a cancer with a 50% 5-year survival rate. Many children relapse or develop a secondary cancer after those five years.





Treatment for pediatric AML requires 6-9 rounds of intense chemotherapy.

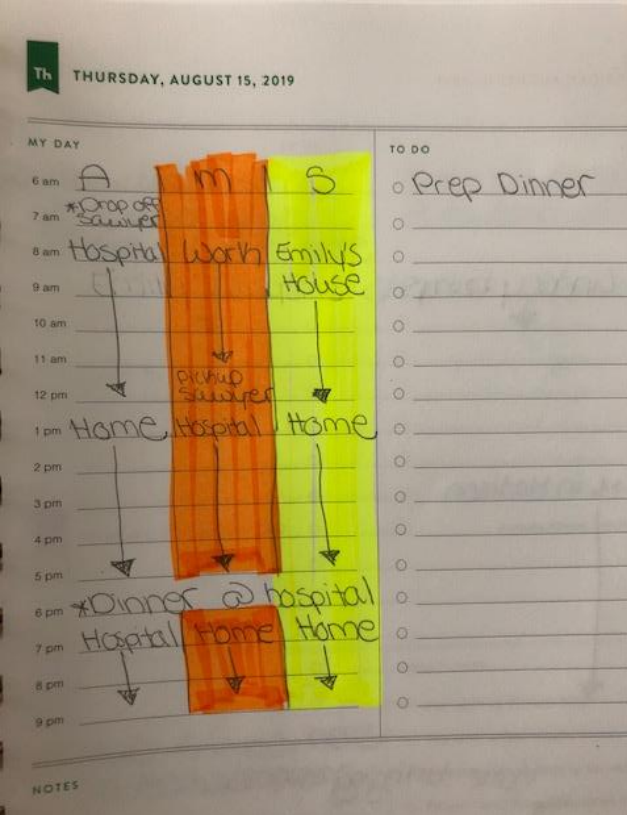
The treatment is so harsh that it's not safe to go home after the infusions.

Each round required 1.5 month long stays at the hospital as she was dangerously neutropenic for that full time.

The next year of Isla's life was spent almost entirely in the hospital.







Childhood cancer impacts the whole family

Ellis quickly became a part of our hospital routine. I stayed with Isla and the baby at the hospital while my husband worked, and our oldest son, Sawyer, was at kindergarten. We'd switch at the hospital every evening and morning. Michael was never home and rarely saw our newborn.

I had to work with therapists to help my 5-year-old through the emotional complexities of such a drastic change in our family life.





No One Fights Cancer Like a Kid

Though Michael and I were barely hanging on, Isla was incredible.

She'd ride the halls on a toy giraffe, chasing nurses with her "evil villain" laugh, while attached to the IV pole she affectionately named "Bobo".

Her energy was boundless, giving hugs, painting snowmen on windows, and creating endless games to pass the endless days.



Just before Christmas, we learned Isla relapsed while still in treatment.

She would now need a bone marrow transplant, and her big brother, Sawyer, was a match.





Delays

Bacterial infections, high fevers, ICU stays, and a disease that was increasingly resistant with each passing cycle delayed the transplant.

As the months dragged on, the pandemic hit along with fresh fears.

The desperate doctors began to experiment with new cocktails of chemotherapy drugs that were never tested on children with the hope that something- anything- would knock down her disease enough to receive the transplant.



Transplant

By spring, Isla's body was strong enough for transplant and her disease had reduced enough to move forward.

Sawyer's marrow was harvested and frozen, ready for transplant.

Just as we were preparing for transplant, results came back that Isla's leukemia had grown again- too aggressively this time.

Clinical Trial

We turned to a Stage 1 immunotherapy trial at Lurie Children's Hospital in Chicago.

Isla would be one of only six children in the world to test this new drug.

For two months she stayed hooked up to a continuous drip, her little body covered in wires and monitors.

It was jarring to see her actually *look* like the science experiment that she was.



Center for Cancer
and Blood Disorders



ROBERT H. LURIE
COMPREHENSIVE CANCER CENTER
OF NORTHWESTERN UNIVERSITY





Success

Though those two months were grueling, it was thrilling to see the immunotherapy work.

Her leukemia was down to 2%, and the team wanted to give it two more weeks to further reduce the disease.

Two weeks later, after her final spinal tap and bone aspiration, we were released from the hospital so Isla could fulfill her dream of riding a horse before the transplant.



We quickly realized something was very wrong. Isla wasn't recovering as usual.

Her pain was extreme, and she could no longer walk. She had to crawl, dragging her legs behind her, pulling on them by thrusting her upper body forward.

We rushed to the hospital for an MRI.

The MRI revealed a hematoma at the base of her spinal cord, caused by the spinal tap.

Surgery was necessary to avoid paralysis; but even with it, she would face permanent weakness.



While discussing options, another doctor came in with the aspiration results.

Isla's leukemia had grown to over 30% in those two weeks.

There was nothing more to be done.

Isla was given three weeks to live.

Watching your child rapidly decline in uncontrolled pain, becoming paralyzed, confused, and losing their mental abilities, personality, and desire to be near you is impossible.

The death happens before the death itself.



Isla died on
August 11, 2020





The Problem

As difficult as it is, I share Isla's heartbreaking story to illustrate what childhood cancer can look like and the great need for progress in its treatment and family supports.

Wisconsin ranks 19th in the nation for incidence of childhood cancer.

Wisconsin also ranks 8th for pediatric leukemia, 13th for brain and central nervous system tumors, and 13th for sarcomas.

This is a state problem. We need state solutions.



**MACC
FUND[®]**

Hope for Kids

Since joining the MACC Fund last year, I've allowed my personal experience and the connections I make with other organizations and pediatric cancer families to guide my efforts:

- State Legislation in Partnership with the American Childhood Cancer Organization
- Community Resources for Families
- Care for Caregivers Support Group
- New Diagnosis Care Bags
- Featured Fighter Stories
- Awareness Events

-
- Successfully advocated for the addition of children to the Wisconsin Cancer Plan
 - Contributed to the development of the newly published Wisconsin Childhood Cancer Action Plan 2024-2028





Wisconsin Childhood Cancer Action Plan 2024-2028

AUGUST 2024

Suggested citation: Childhood Cancer Action Plan.
Wisconsin Cancer Collaborative, Madison, Wis.
Available online at: www.wiscancer.org.



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.

This plan aims to fill the gaps found within the awareness, education, and care given to those with cancer as children.

It 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.



Wisconsin Childhood Cancer Action Plan 2024-2028

AUGUST 2024

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Wisconsin Cancer Collaborative, Madison, Wis.
Available online at: www.wiscancer.org.



Goal #1: Implement activities to promote the overall awareness of childhood cancer in Wisconsin.

Goal #2: Utilize data sources to better identify emerging needs for the treatment and support of childhood cancer patients and survivors.

Goal #3: Support the ongoing educational needs of medical professionals in Wisconsin to learn more about childhood cancer.

Goal #4: Support the ongoing training and development for palliative and hospice care professionals providing care to childhood cancer patients and their families.

Goal #5: Support access to quality care for those impacted by childhood cancer and research on childhood cancer.



Invitation for Action

There is truly something in this plan for everyone.

Where do *you* see yourself in this plan?

What can *you* do to ease the burden of childhood cancer for families in Wisconsin?

The Wisconsin Cancer Collaborative invites anyone in Wisconsin to engage in the action steps highlighted in this document. They invite you to keep them updated on your progress.

We can do more for our kids!


Contact Us:
maccfund.org
(414) 955-5835

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Hope for Kids



Building Childhood Cancer Connections through Nonprofits and Storytelling

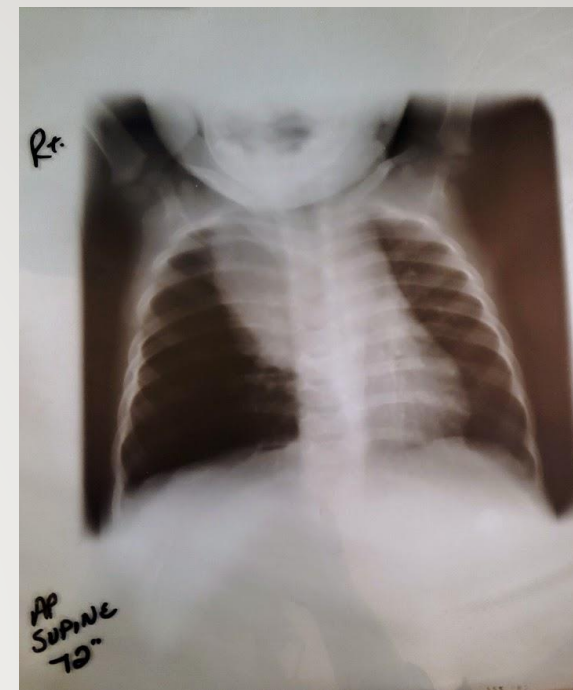
MARIAH FORSTER OLSON, MBA



Diagnosis and Treatment

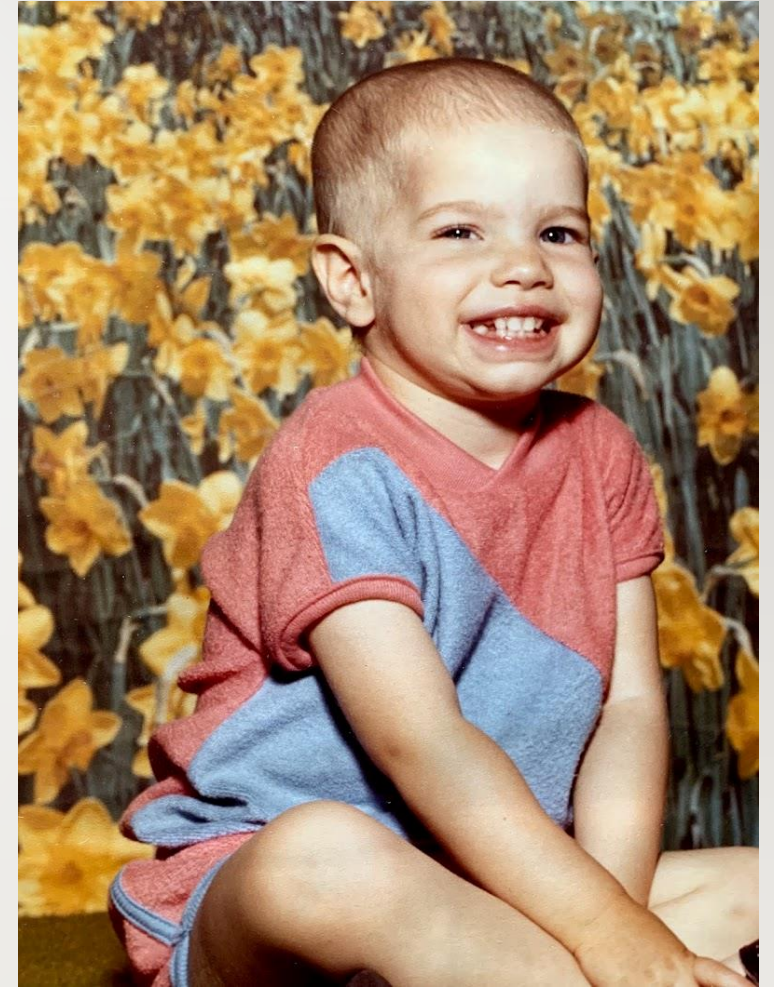


- Diagnosed with neuroblastoma at the age of one on June 6, 1980
- Tumor grew out of spine, wrapped around heart, pushed against lungs and trachea.
- Treatment:
 - 2 surgeries to remove the tumor
 - 18 rounds of radiation treatments
 - 2 years of a new, “experimental” chemotherapy protocol



Survivorship


- Final chemotherapy treatment on my 3rd birthday
- Not pronounced cancer-free or cured until my 8th birthday, which was 5 years after my last cancer treatment.
- 52 Surgeries
- Higher risk for 9 different secondary cancers
- Around 100 different medical conditions and late effects



Late Effects

- Severe Scoliosis and Multiple Fusion Surgeries
- Chronic and Excruciating Bone, Muscle, and Nerve Pain in my back, neck, and cancer scar
- Adrenal Insufficiency Disease
- Preventive Mastectomies, Reconstructive Surgeries
- Infertility and Childlessness
- Horner's Syndrome and Harlequin Syndrome
- Migraines
- Peripheral Neuropathy
- Stage 3 Kidney Disease
 - Hypomagnesemia, Hypokalemia, Hypophosphatemia
 - Vitamin D Deficiency
 - Osteopenia
 - Chronic Anemia
 - Hypertension
 - Fluid Retention
- Multiple Gastrointestinal/GI Issues
- Hypothyroidism
- Asthma and Restrictive Lung Disease





THE POWER OF
POSITIVE
THINKING


NORMAN
VINCENT PEALE



Change your thoughts and
you change your world.

Norman Vincent Peale

 quote fancy



“The most important things in life are the connections you make with others.”

— TOM FORD

HAPPIERHUMAN.COM

To build authentic relationships you need to lead with generosity & serve them first

— *Keith Ferrazzi* —



The Neuroblastoma Children's Cancer Society

HOPE for more tomorrows for children with neuroblastoma

- “Neuroblastoma Family Support Group” Facebook Group
 - Discussion Topic
 - Co-Administrator
- Board of Directors as the Survivor, Family, and Resource Director (2018)
- Representative in the Coalition Against Childhood Cancer (CAC2) (2018)
- Childhood C.A.N.C.E.R.S. Grant
 - Website Re-Do
 - Neuroblastoma and NCCS Awareness Cards
- Research for NCCS and our members
- Mariah Forster Olson Neuroblastoma Survivorship Grant (\$5,000 yearly grant)

”

”


**WHEN ENOUGH PEOPLE COME
TOGETHER, THEN CHANGE WILL COME
AND WE CAN ACHIEVE ALMOST
ANYTHING. SO INSTEAD OF LOOKING
FOR HOPE — START CREATING IT.**

– GRETA THUNBERG



MY ACS CAN EXPERIENCES

- Sent pre-written emails about cancer-based legislation to both state and federal legislators
- Delivered multiple speeches, and interviewed by multiple members of the press
- Attended and participated in the 2019 Medicare Part D and the Six Protected Classes of Medications Lobby Day
- Presented at a congressional briefing at the U.S. Capitol Building in Washington, D.C.
- Participated in making a professional commercial for Medicare Part D's national campaign
- Participated in the national Barriers to Care Project, and made a video for this campaign
- Attended and participated in the 2019 and 2021 Alliance for Childhood Cancer Action Days, and 2021 One Voice Against Cancer (OVAC)
- 2019 Wisconsin Volunteer of the Year Award
- Attended and participated in ACS CAN's 2018 Leadership Summit and Lobby Day.
- Authored multiple Letters to the Editor
- Interviewed and photographed by the New York Times for an article on Medicare Part D coverage
- Attend regular meetings



Human connections are
deeply nurtured in the
field of shared story.

Jean Houston

WHAT IS YOUR STORY?



American Cancer Society
Cancer Action Network™
fightcancer.org

Jamil
Metastatic Breast Cancer
Thrivor, Mother, Wife

**Share your story.
Make an impact.**

Your story is what distinguishes you from a statistic or a policy. It also puts a human face on a disease that impacts millions of Americans every year.

Your lawmakers are overwhelmed with numbers and studies. They need to hear stories about people – real people in their community or district. People like you.

To share your story, please
scan the QR code or visit us at
act.fightcancer.org/a/yourcancerstory



- **Who you are:** name, title, where you work
 - **Where you are from:** Are you a constituent? If not, why are you here?
 - **What you want:** the issue
 - **Why it's important:** your story
 - **The ask:** Will they support/oppose?
- **Remember: You are the expert on your story. You do not need to be an expert on public policy to join ACS CAN!**

*Information adapted from ACS CAN's "Your Voice and the Policy Process"

We must establish a personal
connection with each other.
Connection before content. Without
relatedness, no work can occur.

— *Peter Block* —



- As the American Cancer Society's childhood cancer initiative, Gold Together empowers individuals to raise funds that directly support research, advocacy, and patient support dedicated to childhood cancer.
- National Advisory Council - Advocacy Co-Lead
 - teach and support high school and college students about the basics of childhood cancer advocacy to help them become confident, effective advocates.
- Contribute ideas, resources, and information, and create and edit new documents for advocacy, survivorship, bereavement, family support, and other Gold Together Campaigns
- Attend virtual monthly meetings
- Attend and work at CureFest in Washington, D.C. from September 2022-Present.

Advocacy – Telling Your Story

Step 1) What is your “why”? (explain this) Are you a survivor, advocate, parent, sibling, etc.?

Step 2) Who is your audience, and what is best going to connect them?

- For legislators, we are asking for certain legislation.
- For businesses, we are asking for sponsorship or money
- For peers, we are educating people about childhood cancer.
- For the cancer community, it's helping people feel less alone and relating to them.

Step 3) Outline your story and identify the key points.

Step 4) Impact of Cancer: How has cancer changed your life? What do you want people to take away from your story?

Advocacy – Telling Your Story Continued...

Step 5) Know a couple of updated, reliable childhood cancer statistics

Step 6) Tailor the entire story down to 2-5 minutes to keep people engaged. Have a catchy beginning and an end. Craft a signature quote that you can use at the end of your speeches.

Step 7) Practice your speech. Record yourself saying it in front of a mirror.

Step 8) Be confident and passionate!

Step 9) After your speech, thank the person or organization that had you speak.

”

”

**IF YOU WANT TO BECOME AN INSTRUMENT
OF CHANGE, GATHER PEOPLE IN YOUR
COMMUNITY AND HOST A REGULAR
CONVERSATION. THE ONLY WAY TO SUCCEED
IS TO CONNECT PEOPLE, SHARE INSPIRATION
AND SUPPORT ONE ANOTHER.**

– DEEPAK CHOPRA



CAC2
COALITION AGAINST
CHILDHOOD CANCER

****The Coalition Against Childhood Cancer (CAC2) unites individuals, nonprofits, and corporations, and amplifies their efforts in pediatric cancer to enhance action and collaboration, minimize waste of resources and expertise, and improve outcomes for patients, survivors, and families.**

- “Survivorship Interest Group” Lead/Liaison since 2018
- Member of the Board of Directors since June 2019
- Secretary of the Board and Executive Committee since September 2020.
- Recipient of the 2022 Bob Piniewski Volunteer-of-the-Year Award.
- Co-Lead of the Succession Planning Committee (2020-2021), where we hired CAC2’s first professional, full-time employee
- Lead and Co-Lead of the CAC2 Survivorship Toolkit resource
 - Accepted for an oral presentation at the 2024 SIOP conference
 - Recorded multiple podcasts
 - The CAC2 Survivorship Toolkit working group won the 2024 Bob Piniewski Volunteer of the Year award.
- Co-Lead of the Better Together program, which connects childhood cancer survivors, parents, caregivers, family members, nonprofit organizations, professionals, and other stakeholders to a database of organizations that provide programs, services, and other types of assistance to childhood and adolescent cancer survivors.



GUIDANCE ALONG THE SURVIVORSHIP JOURNEY

- Educational Guidance and Planning
- Insurance and Financial Health
- Physical Health and Late Effects
 - Psychosocial and Emotional Health
 - Transitioning to Adulthood
 - Wellness and Healthy Behaviors





**Regardless of where
you are on your journey,
You are not alone.**

INTRODUCING THE CHILDHOOD CANCER HUB HOME TO THE HOPE PORTAL AND BETTER TOGETHER.

The Childhood Cancer Hub supports childhood cancer patients and survivors with searchable, curated, community-driven directories of organizations that support children and teens with cancer, survivors, and their families.



SUPPORT DURING TREATMENT

The Hope Portal directory offers patient support resources for:

- ✓ Patients
- ✓ Siblings/Families
- ✓ Parents/Caregivers
- ✓ Bereaved Families
- ✓ Professionals



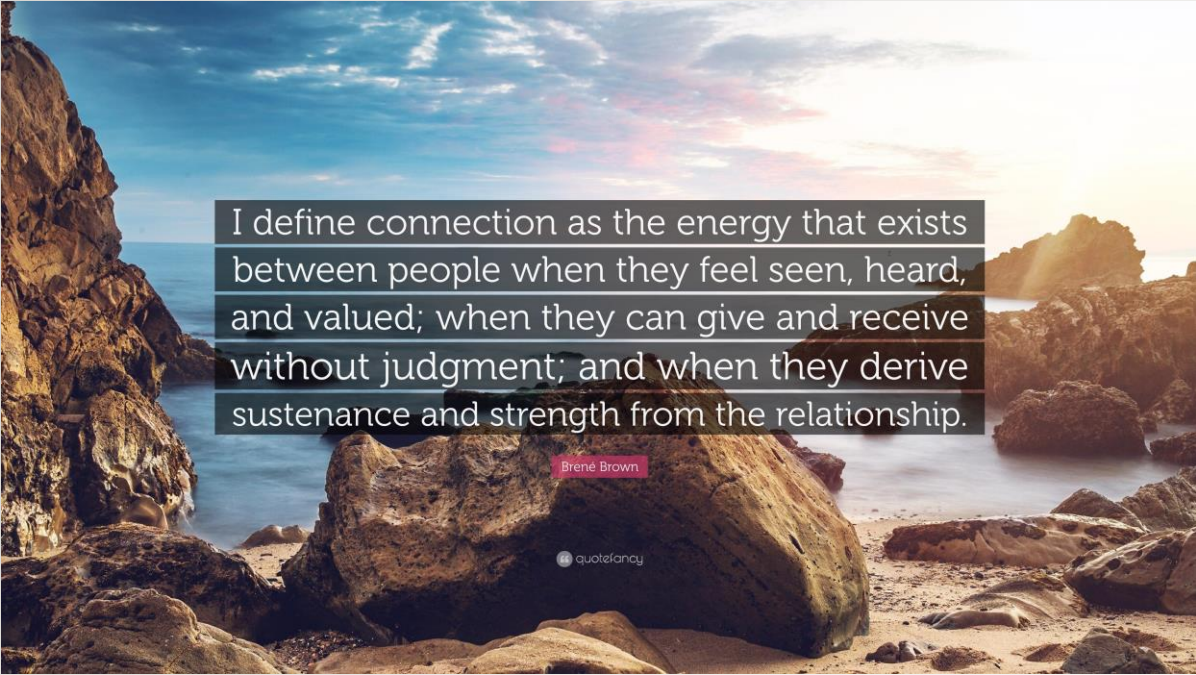
SURVIVORSHIP SUPPORT

The Better Together directory offers survivorship support resources for:

- ✓ Survivors
- ✓ Siblings/Families
- ✓ Parents/Caregivers
- ✓ Professionals

LEARN MORE AT [CHILDHOODCANCERHUB.ORG](https://childhoodcancerhub.org)





I define connection as the energy that exists between people when they feel seen, heard, and valued; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.

Brené Brown

quotefancy



Communication is merely an exchange of information, but connection is an exchange of our humanity.

Sean Stephenson

quotefancy



Wisconsin Childhood Cancer Action Plan 2024-2028

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CONTENTS

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.



Introduction..... Page 3

Goal #1: Page 4
Implement activities to promote the overall awareness of childhood cancer in Wisconsin.

Goal #2: Page 6
Utilize data sources to better identify emerging needs for the treatment and support of childhood cancer patients and survivors.

Goal #3: Page 8
Support the ongoing educational needs of medical professionals in Wisconsin to learn more about childhood cancer.

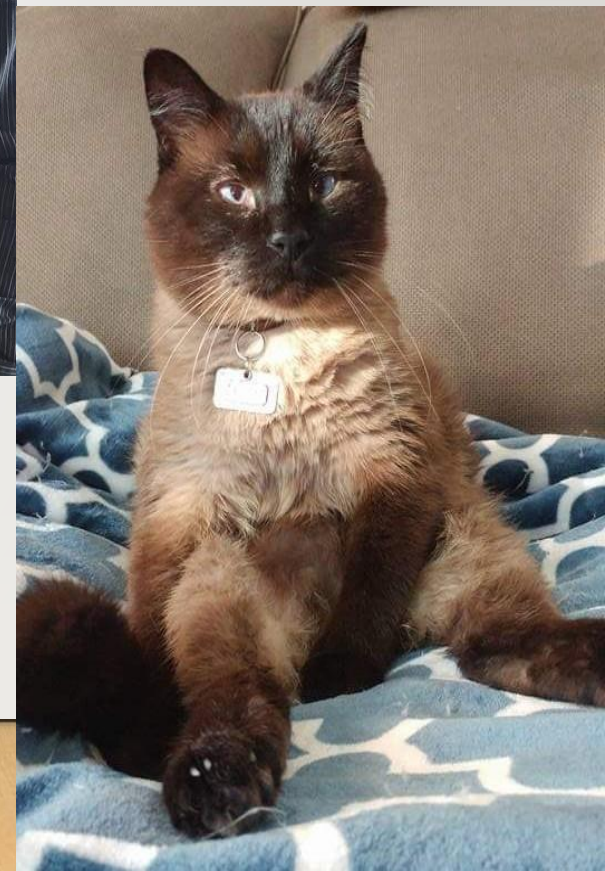
Goal #4: Page 10
Support the ongoing training and development for palliative and hospice care professionals providing care to childhood cancer patients and their families.

Goal #5: Page 11
Support access to quality care for those impacted by childhood cancer and research on childhood cancer.

Cherish your human
connections - your
relationships with
friends and family.

Barbara Bush

BrainyQuote®





THANK YOU!
QUESTIONS?

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Questions?