

Pediatric Cancer in Wisconsin



Agenda

- Welcome
- Childhood Cancers in Wisconsin-Lena Swander, DHS
- Presentation by Dr. Christian Capitini, MD
- Panel presentations featuring:
 - Dr. Cathy Lee-Miller, MD UW Carbone Cancer Center
 - Christina Nielsen, Leukemia and Lymphoma Society
 - Julie Nichols, Children's Wisconsin
- Q&A
- WCC Updates



Who We Are

The Wisconsin Cancer Collaborative is a statewide coalition of 140

organizations working together to reduce the burden of cancer for everyone in Wisconsin.

Join Us! Membership is free!



www.wicancer.org/join/

Wisconsin Cancer Plan 2020-2030



www.wicancer.org

Wisconsin Cancer Plan 2020-2030

- Serves as a common framework and foundation for action for all working on cancer prevention and control in Wisconsin
- Designed to provide a vision of what needs to be done and the resources needed to reduce the burden of cancer in Wisconsin



Wisconsin Cancer Plan 2020-2030



Pediatric Cancer Care Locations

American Family Children's Hospital *Madison, WI*

Children's Wisconsin Milwaukee, WI

Gundersen Health System La Crosse, WI

HSHS St. Vincent Children's Hospital Green Bay, WI

Marshfield Clinic Marshfield, WI







Childhood Cancers in Wisconsin Lena Swander, MPH





WISCONSIN DEPARTMENT of HEALTH SERVICES



Outline

- Introduction
- Incidence
- Mortality



Outline

- Introduction
- Incidence
- Mortality



Wisconsin Cancer Reporting System (WCRS)

- Established in 1976 by <u>Wis. Stat. § 255.04, Cancer</u> <u>Reporting</u> to collect cancer incidence data on Wisconsin residents
- High-quality incidence data currently available for diagnosis years 1995–2020
- Cancer incidence data are dynamic
- Data used in public health surveillance and to support cancer prevention and control research



Childhood cancers are a collection of many diseases found in different places in the body.

- All newly diagnosed malignant invasive neoplasms occurring among all children living in Wisconsin under the age of 20
- The most common types of cancer in childhood are:
 - Leukemias.
 - Brain and other central nervous system (CNS) tumors.
 - Lymphomas.



Top 5 causes of death, 2020 (ages $1-19)^2$



Although childhood cancer is considered rare, it's a leading cause of death past infancy.

- 24% (1.4 million) of Wisconsin's population is under age 20.
- In 2020:
 - 251 Wisconsin children were diagnosed with cancer and reported to WCRS.¹
 - 36 Wisconsin children died of cancer, making it the fourth leading cause of death in Wisconsin for those over one-yearold.²



The outlook for children and adolescents with cancer has improved over the last five decades.

- In the 1970s, 58% of children and 68% of adolescents diagnosed with cancer survived at least 5 years.³
- The most recent 5-year survival rates are now estimated at 85%.⁴





0%

mid-1970s 2011-2017

Outline

- Introduction
- Incidence
- Mortality



Wisconsin childhood cancer incidence rates have increased since 2000 and mirror U.S. trends.^{5,6}



Males are more likely to be diagnosed with cancer before age 15. The female rate is nearly equal between ages 15 to 19.⁵



Total Cases (00–19 years), 2016–2020

Age at			
Diagnosis	Males	Females	Total
00-04	222	186	119
years	232	100	410
05-09	100	107	225
years	120	107	233
10-14	151	115	266
years	151	115	200
15-19	005	225	460
years	230		
Total	746	633	1,379

From 2016–2020, Leukemias, Brain and other CNS tumors, and Lymphomas were the most diagnosed cancers for Wisconsin children.⁵



Childhood cancer incidence trends by site in Wisconsin mirror U.S. rates.^{5,6}



From 2016–2020 in Wisconsin, Non-Hispanic (NH) American Indian/Alaskan Native (AI/AN) children had the highest incidence rates. NH Asian or Pacific Islander (API) had the lowest. Differences were not statistically significant.⁵

> Data on race and ethnicity should be interpreted with caution. Small counts are at play. Additionally, categories are derived from source materials (patient's self-declaration of identified race, medical record documentation, and/or death certificate) available to certified tumor registrars. Incorrect or missing information can impact rates.



*From 2016-2020, rural counties had higher childhood cancer rates than urban counties. Differences were not statistically significant.*⁵







Outline

- Introduction
- Incidence
- Mortality



Wisconsin childhood cancer mortality rates have declined on average since 2000. Rates rose slightly in 2019–2020, but are not statistically different from U.S. rates.⁷



Between 2016–2020, 158 Wisconsin children died of cancers.⁷

Total Deaths (00–19 years), 2016–2020

Age at Death	Males	Females	Total
00–04 years	14	18	32
05–09 years	20	11	31
10–14 years	22	25	47
15–19 years	22	26	48
Total	80	78	158



Wisconsin mortality rates from Leukemias, Brain and Other CNS tumors, and Lymphomas in Wisconsin children have declined.⁸

Childhood cancer mortality rates from 2001-2010 to 2011-2020 declined by:

- 12.1%: All malignant cancers
- 26.6%: Leukemias
- 11.3%: Brain and other CNS tumors
- 55.6%: Lymphomas



Age-adjusted mortality rates per 1,000,000





Conclusions

- Childhood cancer mortality rates are declining and survival is improving.
- Wisconsin childhood cancer rates are similar to national rates.



More data available from the Wisconsin Cancer Reporting System

- Explore online, public data platforms.
- Email <u>DHSWCRSDataRequests@dhs.wisconsin.gov</u> to request technical assistance if you can't find data you need.





- 1. Wisconsin Cancer Reporting System, Office of Health Informatics, Division of Public Health, Wisconsin Department of Health Services.
- 2. Wisconsin Dept. of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, https://www.dhs.wisconsin.gov/wish/index.htm, Mortality Module, accessed 7/31/2023.
- 3. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer Statistics, 2021. CA: A Cancer Journal for Clinicians 2021; 71(1): 7–33.
- 4. Howlader N, Noone AM, Krapcho M, et al. (eds). SEER Cancer Statistics Review, 1975–2018, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2018/, based on November 2020 SEER data submission, posted to the SEER web site, April 2021.
- 5. Software: Surveillance Research Program, National Cancer Institute SEER*Stat software version 8.4.1.2. (www.seer.cancer.gov/seerstat). SEER*Stat Database: 9520Incidence. Created 5/16/2023.
- 6. Software: Surveillance Research Program, National Cancer Institute SEER*Stat software (www.seer.cancer.gov/seerstat) version 8.4.1.2. Data: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence - SEER Research Plus DATA Database: Incidence - SEER Research Plus Limited-Field Data, 22 Registries, Nov 2022 Sub (2000-2020) - Linked To County Attributes - Total U.S.
- 7. Software: Surveillance Research Program, National Cancer Institute SEER*Stat software (www.seer.cancer.gov/seerstat) version 8.4.1.2. Data: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Aggregated With DATA Database: Mortality - All COD, Aggregated With State, Total U.S. (1990-2020) <Katrina/Rita Population Adjustment>.
- 8. Software: Surveillance Research Program, National Cancer Institute SEER*Stat software (www.seer.cancer.gov/seerstat) version 8.4.1.2. Data: SEER*Stat Database: 9520Mortality. Created on 4/24/2023.



Thank You



Dr. Christian Capitini, MD









American Family Children's Hospital

Research Update: Pediatric Cancer in Wisconsin

Christian Capitini, MD

Jean R. Finley Professor in Pediatric Hematology and Oncology

Associate Professor of Pediatrics

Chief, Pediatric Hematology, Oncology and Bone Marrow Transplant

University of Wisconsin School of Medicine and Public Health

Co-Leader, Developmental Therapeutics

UW Carbone Cancer Center

Wisconsin Cancer Collaborative September 14, 2023

@CapitiniMD





American Family Children's Hospital

Disclosures

- Bayer: Advisory Board/Honorarium
- Elephas Biosciences: Consulting
- Nektar Therapeutics: Advisory Board/Honorarium
- Novartis: Advisory Board/Honorarium
- No off-label use of FDA-approved drugs will be discussed

Objectives

• Understand the epidemiology of childhood cancer in the USA

Review background of advanced cell therapies including CAR T cells

• Discuss future outlook for immunotherapy for cancer

Epidemiology

- Estimated 12,400 American children <20 years of age diagnosed yearly
- Risk of developing cancer before the age of 20 is 1 in 300 children
- Estimated 2,300 children die from cancer yearly
- Second leading cause of death among children 1-14

Adapted from SEER data and American Cancer Society

@CapitiniMD

2022 New Patients by Diagnosis



We see 80-100 new cancer diagnoses per year

Survival: The Good News

• Overall survival from all childhood cancers is approaching 85%

• Survival has increased yearly since 1970

• 1 in 640 young adults age 20-39 is a childhood cancer survivor

• Estimated 483,000 persons are childhood cancer survivors

Adapted from US census data, SEER and Childhood Cancer Survival Study

@CapitiniMD

Acute lymphoblastic leukemia is now curable with risk-adapted combination chemotherapy




Survivor Morbidity/Mortality

Childhood cancer survivors have a 10.8 fold excess in overall mortality

• 21% due to treatment related consequences

• Two thirds of survivors have at least one long term complication

• One fourth have a severe or life threatening long term complication

We need treatments that have high efficacy and minimal toxicity

Immunotherapy - helping the immune system recognize and fight cancer

History of Pediatric Cancer and Blood Disorders at UW

- 1st unrelated bone marrow transplant
- Importance of T-cells in bone
 marrow transplant
- New immunotherapy treatment for neuroblastoma
- CAR-T cells for pediatric leukemia







Regional and National Reputation

- "Pediatric Cancer Dream Team"
- NCI Cancer Immunotherapy Trials Network
- Beau Biden Moonshot
- ¹³¹I-MIBG radiopharmaceutical therapy
- Most clinical trials at Carbone







Cellular immunotherapy is a rapidly growing field in oncology







The replicating ability of the virus is removed, but the ability to infect T cells (with new DNA coding for an antibody fragment against cancer) is retained















CAR T-cell Therapy





6 FDA approved CAR T cells

- Tisagenlecleucel (Kymriah)
- Axicabtagene clioleucel (Yescarta)
- Brexucabtagene autoleucel (Tecartus)
- Lisocabtagene maraleucel (Breyanzi)
- Idecabtagene vicleucel (Abecma)
- Ciltacabtagene autoleucel (Carvykti)

All treat blood cancers!







Multiple cytokines and chemokines peak 2-4 weeks after CAR T infusion





Event-free survival 73% at 6 months and 50% at 12 months Overall survival 90% at 6 months and 76% at 12 months



Maude et al. N Engl J Med. 2018 Feb 1;378(5):439-448.





Table 3. Adverse Events of Special Interest within 8 Weeks after Infusion, Regardless of Relationship to Tisagenlecleucel.*

Type of Event	Any Grade (N=75)	Grade 3 (N=75)	Grade 4 (N = 75)		
	number of patients (percent)				
Any adverse event of special interest	67 (89)	26 (35)	30 (40)		
Cytokine release syndrome	58 (77)	16 (21)	19 (25)		
Neurologic event	30 (40)	10 (13)	0		
Infection	32 (43)	16 (21)	2 (3)		
Febrile neutropenia	26 (35)	24 (32)	2 (3)		
Cytopenia not resolved by day 28	28 (37)	12 (16)	12 (16)		
Tumor lysis syndrome	3 (4)	3 (4)	0		





We are now treating children with high risk B cell leukemia upfront with CAR T cells in a multicenter trial

NIH) U.S. National Library of Medicine <i>ClinicalTrials.gov</i>	Find Studies 🔻	About Studies ▼	Submit Studies 🕶	Resources ▼	About Site 🔻		
Home > Search Results > Study Record Detail					Save this study		
Trial record	1 of 2 for: c	assiopeia					
Previous Study <u>Return to List</u> <u>Next Study</u> ► Study of Efficacy and Safety of Tisagenlecleucel in HR B-ALL EOC MRD Positive Patients (CASSIOPEIA) ClinicalTrials.gov Identifier: NCT03876769							
The safety and scientific validity of this study is the responsibility of the study sponsor and investigators. Listing a study does not mean it has been evaluated by the U.S. Federal Government. Know the risks and potential benefits of clinical studies and talk to your health care		Recruitment First Posted Last Update	Status (1): Recruiting (1): March 15, 2019 Posted (1): September	24, 2019			
provider before participating. Read our disclaimer for details.			s and Eocations				

Novartis Pharmaceuticals





CARs in development for solid tumors

- AFP (liver cancer)
- ALK (neuroblastoma)
- Carbonic anhydrase IX (kidney cancer)
- CD24 (ovarian cancer)
- **CD70** (kidney cancer)
- **CD133** (liver, brain, breast cancer)
- **CD171** (neuroblastoma)
- **CD276** (multiple histologies)
- CEA (lung, colorectal, gastric, pancreatic cancers and liver metastases)
- cMet (breast cancer)
- CSFR1 (tumor-associated macrophages)
- EGFR (lung, colorectal, ovary, pancreatic cancer)
- EGFRvIII (gliomas, glioblastoma)
- EpCAM (liver, stomach and colon cancer)
- EphA2 (glioma)

- Fibroblast activation protein (mesotheiloma)
- Folate receptor alpha (breast, ovarian cancer)
- **GD2** (neuroblastoma, DIPG, sarcomas and melanoma)
- Glypican-3 (liver, lung cancer)
- HER2 (breast cancer, glioblastoma, ovarian, lung, pancreatic, sarcoma and medulloblastoma)
- IL-13Rα (gliomas)
- Lewis-Y (breast cancer)
- Mesothelin (pancreatic, ovarian, mesothelioma, breast cancer)
- **MG7** (liver metastases)
- MUC-1 (breast, liver, lung, pancreatic, glioma, colorectal, gastric cancer)
- NKG2D (multiple histologies)
- PSCA (pancreatic cancer)
- **PSMA** (prostate cancer)
- TEM8/ANTRX1 (breast cancer)
- VEGFR2 (multiple histologies)







Neuroblastoma

- Most common extra-cranial solid tumor in children
- 700 cases per year in U.S.
- 90% are younger than 5 years at diagnosis, with a median age at diagnosis of 19 months
- Approximately 50% have "high risk" features
- Overall survival for high-risk neuroblastoma < 50%

IH NATIONAL CANCER INSTITUTE

Spine Paraspinal nerve tissue Adrenal glands Left kidney Right kidnes

2

<u>Standard high-risk treatment</u> Chemotherapy Surgery Autologous stem cell transplant Radiation therapy

The glycolipid GD2 is overexpressed on pediatric and adult cancers





@CapitiniMD

Berois and Osinaga, 2014 Front Oncol

Antibodies have been developed to target GD2



Anti-GD2 Dinutuximab (Unituxin) was FDA approved in 2015



1/3 high risk patients still not cured



@CapitiniMD

Yu et al. N Engl J Med. 2010;363(14):1324-34.

Why not genetically engineer T cells to target GD2 using CAR T?



GD2 CAR T cell trials have had isolated reports of activity, but overall low response rates (<21%)

NCT00085930	Phase I: N = 19	Active, not recruiting	GD2	14g2a	CD3; only	CR in 3/19 patients, PR in 1/19 patients, response correlated with CAR T cell persistence, no DLT	Baylor College of Medicine/Texas Children's Hospital (Texas, USA)	(27); (28)
NCT01822652	Phase I: N = 11	Completed	GD2	14g2a	CD28.OX40.CD3;	No objective responses, no DLT	Baylor College of Medicine/Texas Children's Hospital (Texas, USA)	(43)
NCT02761915	Phase I: N = 12	Recruiting	GD2	KM8138	CD28.CD3g	Mixed response in 1/12 patients, no DLT	University College London (London, United Kingdom)	(30)
NCT02765243	Phase II: N = 34	Recruiting	GD2	Unknown	CD28.4- 1BB.CD27.CD3;	PR in 15% of patients, no DLT	Zhujiang Hospital (Guangzhou, Guangdong, China	(31)
NCT03294954*	Phase I	Recruiting	GD2	14g2a	CD28.CD3; in invariant NKT cells	N/A	Baylor College of Medicine/Texas Children's Hospital (Texas, USA)	Unpublished
NCT02107963	Phase I	Completed	GD2	14g2a	OX40.CD28.CD3ţ	N/A	National Cancer Institute (Washington, D.C., USA)	Unpublished
NCT01460901	Phase I	Completed	GD2	14g2a	CD3; only	N/A	Children's Mercy Hospital Kansas City (Kansas, USA)	Unpublished
NCT03373097	Phase I/II	Recruiting	GD2	14g2a	CD28.4-1BB.CD3ţ	N/A	Bambino Gesu Hospital and Research Institute	Unpublished
NCT02919046	Phase I	Recruiting	GD2	14g2a	CD28.OX40.CD3ţ	N/A	Nanjing Children's Hospital (Nanjing, China)	Unpublished

Trials are failing bc:

- 1. Lack of CAR persistence
- 2. Exhaustion/lack of memory
- 3. Possibly loss of antigen

Intracerebroventricular GD2 CAR T cells can induce transient responses in diffuse midline gliomas (DIPG)



@CapitiniMD

Majzner et al. 2022 Nature

How can we generate a GD2 CAR T product that will:

(1) have activity(2) persist(3) preserve memory phenotype

Can we do this completely virus-free?

Current methods for CAR generation



.

- Most CAR products are made using retrovirus or lentivirus for CAR delivery
- Nonviral editing methods include TALENs, ZFNs, transposons, CRISPR





Why use CRISPR to insert CARs?

Limitations of viral approaches

- Viral vectors involve random insertion of DNA
- Require monitoring plan for insertional oncogenesis
- Require monitoring for replication competency
- Highly expensive to produce (Adds tens of millions \$ to biomanufacturing costs)
- 2-3 year queue at manufacturing facilities (e.g., for AAVs)
- Potential immune response to viral proteins
- Difficult to control expression level of transgenes precisely

Tailored <u>nonviral</u> (NV) gene editors could be produced as off-the-shelf reagents for rapid and cost effective manufacture of safer, more potent CARs.

Open access

Original research

Journal for ImmunoTherapy of Cancer Production and characterization of virus-free, CRISPR-CAR T cells capable of inducing solid tumor regression

Katherine P Mueller,^{1,2} Nicole J Piscopo,^{1,2} Matthew H Forsberg,³ Louise A Saraspe,² Amritava Das,² Brittany Russell,² Madeline Smerchansky,^{1,2} Dan Cappabianca,^{1,2} Lei Shi,³ Keerthana Shankar,^{1,2} Lauren Sarko,^{1,2} Namita Khajanchi,^{1,2} Nina La Vonne Denne,^{1,2} Apoorva Ramamurthy,^{1,2} Adeela Ali,³ Cicera R Lazzarotto,⁴ Shengdar Q Tsai,⁴ Christian M Capitini ^{(B},³) Krishanu Saha ^(O),^{1,2}

Virus-free, CRISPR (VFC) CAR T Cells



- Double-stranded PCR CAR donor repair template avoids viral vector manufacturing
- Critical parameters: DNA quality, quantity, and postnucleofection culture conditions

Retroviral GD2 CAR T cells show high cytokine production pre-antigen exposure and are "burned out" pre-infusion



@CapitiniMD

Mueller et al. 2022 J ImmunoTher Cancer

Virus-free CRISPR GD2 CAR T cells show enrichment of stem cell memory genes



Despite lower % CAR surface expression, CRISPR GD2 CAR T cells are noninferior to Retroviral GD2 CAR T cells in vivo



CRISPR GD2 CAR T cells show less exhaustion than retroviral CAR T cells



Establish a Cell and Gene Therapy Program at UW for treating cancer and beyond

- Increase support of laboratory and clinical research in cancer immunotherapy
- Develop "homegrown" cell and gene therapies
 - CAR T for solid tumors
 - Novel bone marrow transplants for nonmalignant blood disorders
 - Potential for expansion into nononcology indications

Perspective



Malignant diseases

- Blood cancers
- Solid cancers

Autoimmune diseases

- SLE
- Pemphigus vulgaris
- Multiple sclerosis
- Type 1 diabetes
- Asthma

Fibrosis diseases

- Cardiac disease
- Liver disease
- · Pulmonary fibrosis
- Kidney disease

Senescence diseases

- Liver fibrosis
- Solid cancers
- Atherosclerosis
- Natural ageing

Infectious diseases

- HIV
- Hepatitis C or B
- Tuberculosis





Conclusions

- Key points
 - CAR T cells are genetically engineered to precisely recognize and eliminate cancer cells, with high potency, but also at high regulatory oversight
- Potential impact
 - Virtually all tumors that are not curable by surgery alone are (or soon will be) targets for immunotherapy
 - This will change the nature of oncology care (and training)
- Lessons learned
 - Advanced cell therapy products, particularly if genetically modified like CAR T cells, have the potential to generate personalized medicine for children with advanced cancer

Acknowledgements Kris Saha Lab

Christian Capitini Lab

- Adeela Ali
- Paul Bates
- Monica Cho
- Matt Forsberg, PhD
- Nick Hess, PhD
- Aicha Quamine
- Sean Rinella
- Ankita Shahi, PhD
- Lei Shi, PhD
- Fernanda Szewc
- Katie Voelz, MD

Paul Sondel Lab

• Amy Erbe-Gurel, PhD

Ken DeSantes, MD

Melissa Skala Lab

- Rebecca Schmitz
- Dan Pham

Igor Slukvin Lab

• Jue Zhang

Kat Mueller, PhD Nicole Piscopo, PhD Amritava Das, PhD Louise Saraspe Brittany Russell Madeline Smerchansky Dan Cappabianca Keerthana Shankar Lauren Sarko Namita Khajanchi Nina La Vonne Denne Apoorva Ramamurthy

St Jude Hospital

- Shengdar Q. Tsai, PhD
 - Cicera Lazzarotto

Baylor College of Medicine

- Malcolm Brenner, MD, PhD
- Cliona Rooney, PhD

University of Georgia

- Lohitash Karumbaiah, PhD
 - Megan Logun







Questions?

ccapitini@pediatrics.wisc.edu Phone (608) 262-2415



Panel Presentations
How do we define 'Cancer Survivorship?

- According to the National Cancer Institute (NCI), "an individual is considered a cancer survivor from the time of diagnosis, through the balance of their life."⁴ Survivors include those with a current diagnosis and those now free from cancer. Caregivers (often called "cosurvivors"), family members, and friends are an important part of the survivor experience.
- Cancer survivorship refers to "the health and life of a person with a cancer, post-treatment until the end of life."





Survivorship Care Plan

• "A *survivorship care plan* is a record of your cancer and treatment history, as well as any checkups or follow-up tests you need in the future. It may also list possible long-term effects of your treatments, and ideas for staying healthy."

https://www.cdc.gov/cancer/survivors/life-after-cancer/survivorship-care-plans.htm#:~:text=A%20survivorship%20care%20plan%20is,and%20ideas%20for%20staying%20healthy.



Dr. Cathy Lee-Miller, MD





Adolescent and Young Adult (AYA) Oncology

CATHY LEE-MILLER 14 SEPTEMBER 2023 WISCONSIN CANCER COLLABORATIVE



Burden of Oncologic Diagnoses in AYAs

•NCI Definition of AYA Oncology:

Diagnosed with cancer between 15 and 39 years of age

- 1 million cancer diagnoses/year worldwide; global population of 3 billion AYAs
- •Estimated 87,000 AYAs diagnosed with cancer in the United States each year
- •Cancer incidence among AYAs increasing on average 0.3% per year 2010-2019 (faster than other age groups)
- •Over 2 million AYA cancer survivors in US

Wisconsin Interactive Statistics on Health (2016 Data)							
Age Group	# of Cancer Cases						
15-19	102						
20-24	152						
25-29	259						
30-34	375						
35-39	530						
Total	1418						

Increasing incidence of cancer in AYAs



Bleyer et al PB&C 2017

Oncologic Diagnoses in AYAs



Figure 4. Types of Cancer in Older Adolescents and Young Adults (% cases/disease)

5-YEAR RELATIVE SURVIVAL

	Total	85.5
	Males	82.3
	Females	87.5
	NH White	88.7
	NH Black	75.4
,	NH Asian or Pacific Islander	83.8
	NH American Indian/Alaska Native	82.3
	Hispanic	81.7

Relative survival

1.2



FIGURE 5 APC from 1990 to 2010 in the 5-year relative survival of all invasive cancer except KS and NHL in males, by 5-year age intervals, and proportion of all invasive cancer in AYAs and younger and older age groups, United States SEER 9–18 regions. Updated from Bleyer study²⁰

Bleyer et al PB&C 2017

https://seer.cancer.gov/statfacts/html/aya.html

Differential survival rates in AYAs: causes

- •Age-specific sense of invulnerability that leads to delay in diagnosis
- •AYAs are least insured group in US
- •Age limits at Children's Hospitals
- •AYA cancers have unique biological traits, leading to more resistance to treatment
- Lower rates of clinical trial enrollment
- Lack of psychosocial support
- Therapeutic adherence

Unique Needs of AYA Cancer Patients

•AYAs are diagnosed with cancer during a complex psychosocial time

- •Often meeting developmental milestones
 - Completing formal education
 - Entering the workforce
 - Getting married/entering into lifelong relationships
 - Starting a family

•This "normal" developmental trajectory is often derailed by a cancer diagnosis

•Disruptions lead to psychological distress, seen in up to 41% of AYA cancer patients

•Negatively affects both cancer care and quality of life

 January 2021: Initiation of a telemedicine consultative program that offers AYAfocused individualized needs assessments by a dedicated team of providers that address four key focus areas:

- Psychosocial and supportive care
- Fertility
- Genetic predisposition
- Survivorship care



• Patient Population:

- All AYA patients (15-39 years) with active cancer, targeting initial consultation, if possible, at time of new or recurrent cancer diagnosis
- All patients currently in the AYA age range (15-39 years) who are transitioning to survivorship as determined by the treating physician (including cancer survivors transitioning out of pediatric care models)
- AYA patients (15-39 years) with a current or prior diagnosis of cancer felt to have needs that could be better addressed by the AYA care team

- Clinic model
 - 3-4 times monthly half-day clinic (Monday afternoons)
 - One-hour long appointments via telemedicine
 - Patients seen one-on-one by oncologist
 - Patients presented 2 days later at AYA Interdisciplinary Team (IDT) meeting
 - Discuss patients
 - Determine appropriate referrals
 - Oncologist calls patient back after IDT meeting to discuss recommendations
 - AYA patients post-treatment will have survivorship care plan developed and sent to patient, oncology providers, and primary care provider
 - Notes sent to primary oncologist and primary care physician

Multi-Disciplinary Care Team					
Social Work					
Contraception/Fertility/Sexual Health					
Physical Therapy/Occupational Therapy					
Rehabilitation Medicine/Pain Management					
Genetic Counseling/Cancer Predisposition Syndromes					
Health Psychology/Psychiatry					
Peer support					
Nutrition					
Behavioral Health					
Integrative Medicine					
Pharmacy					

References

National Cancer Institute Surveillance, Epidemiology, and End Results Program, Cancer Stat Facts: Cancer Among Adolescents and Young Adults (AYAs) (Ages 15-39). <u>https://seer.cancer.gov/statfacts/html/aya.html</u>.

Bleyer A, Ferrari A, Whelan J, Barr RD. Global assessment of cancer incidence and survival in adolescents and young adults. Pediatr Blood Cancer. 2017; <u>https://doi.org/10.1002/pbc.26497</u>

Tricoli JV, Blair DG, Anders CK, et al. Biologic and clinical characteristics of adolescent and young adult cancers: Acute lymphoblastic leukemia, colorectal cancer, breast cancer, melanoma, and sarcoma. Cancer. 2016; <u>https://doi.org/10.1002/cncr.29871</u>

Christina Nielsen







ADVANCING CANCER CURES

The mission of The Leukemia & Lymphoma Society® (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

We fund **RESEARCH** to advance lifesaving treatments

We drive **ADVOCACY** for policies that protect patient access to lifesaving treatment

We provide patients and families with hope, guidance, education and **SUPPORT**



WE NEED SAFER, LESS TOXIC, MORE EFFECTIVE



Approximately

Of Childhood Cancer Survivors Develop Chronic Health Issues From Treatment Only

Of Oncology Drugs Have

Been Approved For First

Time Use In Children

PROJEĆ

ATTACKING PEDIATRIC BLOOD

LLS PedAL MASTER CLINICAL TRIAL

Test new, safer therapies on kids with acute leukemia who are matched to treatments based on their unique tumor biology in this, the first integrated, global, pediatric AML master clinical trial.

RESEARCH

Focus on global collaboration, uniting doctors, pharmaceuticals, and scientists to expedite pediatric blood cancer cures and care.



POLICY & ADVOCACY

Drive policy to advance research for childhood cancers, break down barriers to care.

PATIENT EDUCATION & SUPPORT

Expand free education, 1:1 support, and financial services for children and their families.



WE'RE ADVANCING GROUNDBREAKING GLOBAL RESEARC

- Drastically increasing our pediatric-focused multi-year research grants since The Children's Initiative's inception, from \$11M in 2018 to \$30.5M in 2022, with a goal of reaching \$52M by 2027.
- Funding over 32 pediatric-specific grants, researching longterm treatment side-effects and improving detection of relapse.







ADVANCING THE LLS PEDAL MASTER CLINICAL

LLS PedAL has already achieved so much:

- Launched the **first integrated**, **global**, **pediatric leukemia master clinical trial** to test new, safer therapies on young patients to match a specific treatment to a specific type of cancer.
- Partnered with UChicago to create the **first pediatric Data Commons**, a platform that ensures consistency in global data collection and reporting.
- Collaborated with UChicago to fund **GEARBOx**, a unique search tool to help physicians quickly match patients' cancers to available clinical trials, based on their unique tumor biology.







PROVIDING A WIDE ARRAY OF



Learning & Living with Cancer

Advocating for your child's educational needs



PRIORITIES read paperwork pacedure Return liturary loooks!

NOTES

LEUKEMA & For Int

18

9 Soc



COMMUNITY BASED EDUCATION AND SUPPORT

National Virtual Blood Cancer Conference - REGISTRATION IS NOW OPEN! Saturday, September 9, 2023 10:30 AM – 2:30 PM (Central)

Upper Midwest Blood Cancer Conference

Saturday, November 4, 2023 InterContinental Riverfront St. Paul, MN

Virtual Pediatric Education Program Spring 2024

New Pediatric Support Launching in Collaboration with MAAC Fund in MKE

*more details available soon



INFORMATION RESOURCE CENTER (800) 955-4572



REACH OUT TO OUR LLS INFORMATION SPECIALISTS

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individual clinical-trial searches



Contact us at 800-955-4572 or IIs.org/informationspecialists Monday - Friday 9am to 9pm ET Callers may request the services of a language interpreter. We can speak to you in 170 languages.

Information Resource Center (IRC) (800) 955-4572 Infocenter@LLS.org Monday – Friday, 9am to 9pm ET



CLINICAL TRIAL SUPPORT CENTER

The Clinical Trial Support Center at LLS is comprised of Nurse Navigators who work one-on-one with patients and their families to explore the clinical trial landscape, learn about clinical trials and treatment options, provide personalized clinical trial searches, help identify and overcome barriers to clinical trial participation, and support patients on their journey through the entire clinical trial process.

CTSC PROCESS FOR SUPPORTING PATIENTS





SUPPORT RESOURCES





PATIENT PODCASTS The Bloodline with LLS www.LLS.org/Podcast







PROJECT





LEUKEMIA & LYMPHOMA SOCIETY'

Google play

. .

0

LLS HEALTH

MANAGER"

Track Your Daily Health

App Store

A free service of LLS that matches patients and their loved ones with trained peer volunteers who have shared similar experiences.



Personalized Nutrition Consultations

Talk to a registered dietitian about nutrition and cancer.



FINANCIAL SUPPORT (877) 557-2672

- Patient Aid Program
 - www.lls.org/patientaid
 - \$100 grants that can be used for any cost
- **Co-pay Assistance Program**
 - www.lls.org/copay
 - Helps to cover treatment co-payments & insurance premiums
- Susan Lang Pay-It-Forward Travel Assistance Program •
 - www.LLS.org/travel •
 - \$500 grants to help cover travel and lodging costs
- Local Financial Assistance Programs •
 - www.lls.org/localfinancialassistance
 - \$500 grants to help cover non-medical related expenses
- **Urgent Need Financial Assistance Program** ٠
 - www.lls.org/urgentneed

PROJEC

- \$500 grants to cover non-medical costs
- Application must be submitted by a healthcare provider
- Susan Lang Pre CAR T-cell Therapy Travel Assistance Program
 - www.lls.org/PreCARTTravel
 - \$2500 grant to assist with treatment-related transportation and lodging expenses for patients being evaluated to receive CAR T-cell therapy



 \mathbb{R}



SCHOLARSHIP

The Leukemia & Lymphoma Society (LLS) knows the challenges you face when planning for your future as a blood cancer patient or survivor. As you navigate life after diagnosis or treatment, we want to support your next step.

Announcing the LLS Scholarship for Blood Cancer Survivors!

This scholarship provides up to **\$7,500** to cover the cost of tuition for virtual or in-person vocational, two-year, or four-year higher education, so you can pursue your dreams.

ELIGIBILITY REQUIREMENTS

- Be diagnosed with a blood cancer at age 25 or younger
- · Be a United States citizen or permanent resident of the U.S. or a U.S. territory
- Submit an LLS Diagnosis Verification Form (available on our website) that verifies your blood cancer diagnosis and date of diagnosis
- Currently attending or planning to attend virtual or in-person vocational, two-year, or four-year post-secondary education in the U.S.

HOW TO APPLY

Visit www.LLS.org/Scholarship for program guidelines and application steps.

Applicants must submit their completed application by **October 31, 2023**.

Capped at first 300 applications submitted

Contact us Email Scholarship@LLS.org with any questions









THANK YOU

66





Next Steps Survivor Program

Julie Nichols, RN, BSN





The Next Steps Survivor Clinic

- Transition Program bridging patients from active treatment to off-therapy treatment
- Open to any patient of any age with a history of pediatric cancer or Bone Marrow Transplant (BMT)
- Variety of resources
- Multidisciplinary team



Multidisciplinary Team

- Nurse Practitioners
 Dietitian
- Physicians
 School Teachers
 - Social Workers
- Fertility Nurse Navigator
- Psychologists

- Community Navigator
- Research Coordinators



• RN

Dear Families,

The end of treatment can be a time of mixed feelings. Families can feel happy to be ending therapy but may be worried about the future. The *Bridge to Next Steps* is a new program to help patients and families feel more ready and less stressed as treatment ends.

You will be seen by our team on the same day as your regular follow-up appointments. These visits will give you time to talk about end of treatment needs.

- Visit 1: This visit will discuss healthy living, the Next Steps Clinic, and your follow-up plan of care.
- Visit 2: At this visit you will get your therapy summary, treatment passport, and other information. We will also discuss watching for possible long term side effects of treatment and emotional health.



Treatment Summary

- Detailed summary of a patient's diagnosis through end of treatment
- Template from COG, revised into our own, lives in epic (EHR)
- Treatment summary content
- Shared electronically with PCP initially, then annually to enhance communication and collaborative care
- Same information is shared with the patient via MyChart or mailed letter



Treatment Summary as or (0) TODATDAT

ONAMEO DOD: ODODO

@NAME@ DOB. @DOB@					Post treatment follow up plan (appointment and test frequency)				
Chemotherapy: – All agents of treatment including ster					t including stero	(Post Follow up:36328)			
General Information			Total Isotoxic Anthra	cycline Dose: {Dose::	29077}				
Patient language			Cyclophosphamide E	Cyclophosphamide Equivalent Dose (CED) Total: *** gm/m			Immunizations as of Date: ***		
Soy / Pronounc			Drug	Route Cumulative Dos Up to date? {Yes No:36576}					
Sex / Pronouns (@CAPSEX(@; (@PRONOUNS(@			{Drug(s):27979}	{Drug(s):27979} {Route:27980} Were immunization titers checked post oncology treatment? {Tx Sum Imm Titers Asses				1 Imm Titers Assessed:36553}	
Diagnosis Informatio	n		{Drug(s):27979}	{Route:27980}		Revaccination status post-BMT: {Revaccination status post BMT:36554}			
Diagnosis		{Drug(s):27979}	{Route:27980}						
Diagnosis date and age Letter of the second address of the second		{Drug(s):27979}	{Route:27980}		Potential Late Effects of	Recommendation	Etiology		
End of Treatment Da	ago , al years olu		{Drug(s):27979}	{Route:27980}		Treatment	Neconimendation	Luology	
	116 ***		{Drug(s):27979}	{Route:27980}		Preventive Health	 Physical exam yearly 	All survivors	
Sites involved/				{Route:27980}		i lovenave rieditir	Dental exam every 6 months		
(i.e. Cytogenetics P	iek		{Drug(s):27979}	{Route:27980}			 Dental exam every o monutes Vision ovam voadv 		
Group Tumor Marke	215		{Drug(s):27979}	{Route:27980}			 Immunizations up to date 		
etc.)	@ONCSTAGE@		{Drug(s):27979}	{Route:27980}			Decommond flu obst success		
Relapse Diagnosis a	ind	his an a straight		{Route:27980}			in fall		
Date	***						 Drimany care physician yearly 		
Relapse End of						Secondary malignancy	 Filling care physicial yearly (Pecommondation(c):27706) 	 (cocondary malignary) 	
Treatment Date	***					Secondary manghancy	 {Recommendation(s).27700} 	etiology: 32433	
Treatment Center	Treatment Center:2	3796}	Owner, this set, for an association, line placement, line		Ophthalmology	{ophthalmology	{ophthalmology		
Treating MD/APP		DD D4-0000	Surgery (biopsy, tumor resection, line placement, line of diagnosis)			ophalamology	recommendations:32434}	etiology:32436}	
Contact Information {Provider:29079}7 {APP or PA:2908		Date Proce	dure		Hearing	{Hearing recommendations:32438}	{hearing etiology:32439}		
			*** ***	June		Endocrine	 {Recommendation(s):27703} 	 {endocrine etiology:32441} 	
Treatment Summary (Pertinent treatment protocols only)								All surviors	
Protocols						Cardiac	 {Recommendation(s):27705} 	 {cardiac etiology:32443} 	
Acronym/Number	Title/Description	Initiated	Complications During Therapy			Pulmonary	Pulmonary function test (PFT's) at	 {pulmonary etiology:32444} 	
***			0.00				baseline, then as clinically indicated		
						Kidney	 {Recommendation(s):27704} 	 {kidney etiology:32446} 	
			Lata Effecta From T	Thorapy		Musculoskeletal	 {Recommendations:31018} 	 {musculoskeletal 	
			***	петару				etiology:32447}	
						Neuro-cognitive	 {neuro-psychology 	 {neuro-cognitive 	
Radiation Treatmen	nt at *** Froedtert Hospital					Description	recommendations:32448}	etiology:32453}	
Radiation Site Start Date End Date						Reproductive	 {reproductive recommendations:32450} 	 {reproductive etiology:32454} 	
*** *** *** Boost site and dose						Gastroenterology	 {gastrointestinal recommendations:32451} 	 {gastrointestinal etiology;32455} 	
		Other Current Status or Issues			Other	{other recommendations:32452}	Due to history of ***		
Fertility			***				,	,	
Risk {	desc: fertility risk:36579}								
Preservation {YES/NO Fertility Preservation Attempted:34									


- Wallet size, double-sided individualized card
- Abbreviated treatment summary on one side
- Screening recommendations on the other side per COG Guidelines
- Card printer



lext Steps Clinic Survi	vor Healthcare Passport Recommended Fol Patient: DOB: Updated: Provider: 414-266-2420	low-Up Children's Hospital of Wisconsin Kids deserve the best.						
System	Exam	Time Frame						
All Survivors:	History, Physical, Vision Exam Yearly, Den	tal Exam Every 6 Months						
Secondary Cancer	Routine cancer screening for secondary malignancies	Ongoing Yearly and ongoing	Abbreviated Treatment History					
	soft tissues in irradiated fields	Yearly dermatology follow-up		U	Diagnosis and Date.			
	Self-skin exam/Self-breast exam	recommended Monthly	Pre-Transplant Therapy: COG					
	Clinical breast exam	Yearly	Total anthracycline dose =					
	CBC	Yearly starting in X						
	CDC	As clinically indicated						
Ophthalmology	Eye exam, screen for cataracts	Yearly	Alle nemeie Dans Manner Transmissio					
Hearing	Audiogram, hearing evaluation	Yearly	Allogeneic Bone Marrow Transplant:					
Cardiology	Echocardiogram	Every 2 years 5 years Per	Donor Information:					
	EKG	Cardiology	Conditioning Pagimon and Desage:					
	Doppler Ultrasound of Neck	As clinically indicated	Conduoning Regimen and Dosage.					
	Fasting lipid panel, fasting blood	As clinically indicated	Significant Surgery and Date					
	glucose, HbA1c	fearly						
Pulmonary	Pulmonary Function Testing (PFT's)	Baseline, then as clinically indicated	Radiation Trea	atment	Start	End	Fractions	Dose
Renal	Blood pressure and Urinalysis	Yearly	Total Body Irra	adiation				
Endocrine	Monitor growth and pubertal development Bone mineral density (dexa-scan) TSH, Free T4 FSH, LH, Testosterone, Inhibin B	Ongoing Baseline, then as clinically indicated Yearly Baseline at age 14 , then as clinically indicated	For detailed Long-Term Follow-Up Guidelines (V5.0): www.survivorshipguidelines.o 2006 UC SF All Rights Reserved. Used with Permission.					
	FSH, LH, Estradiol, AMH 8 AM Cortisol	Baseline at age 13, then as clinically indicated Yearly						
Reproductive	Referral to Reproductive Endocrinology Specialist	As clinically indicated						
Neuro-cognitive	Neuro-psychologic testing	As clinically indicated for learning concerns						
Gastrointestinal	Multi-target stool DNA test or colonoscopy	Beginning at age 30, then as clinically indicated				2	Ch:L	المحم
Musculoskeletal	Orthopedic surgery follow-up	As clinically indicated						Jren
		· · · · · · · · · · · · · · · · · · ·	ļ				Wisc	onsin

Health Link



The world's childhood cancer experts

Healthy living after treatment of childhood, adolescent, and young adult cancer

Introduction to Long-Term Follow-Up after Cancer Treatment

Congratulations! You have "graduated" to long-term follow-up. *You can now think of yourself as a cancer survivor, not as a cancer patient!* In long-term follow-up, the goal is to help you stay as healthy as possible—to stay well and to do well in school or at work.

Even though you are a cancer survivor, it is still important that you continue to have regular medical care. In some cases, your care may continue at the same hospital or clinic where you received your treatment, but you may be seen by different doctors and nurses in a special Long-Term Follow-Up Program. In other cases, you may receive care from a healthcare provider working in partnership with your treatment center, or from a provider who is closer to your home. No matter where you receive your care, it is important that you learn what you need to know about your treatment and the follow-up care that you need so that you can stay in the very best health possible.

Your cancer treatment summary

When you graduate to long-term follow-up, it is important that you get a record of the cancer treatment that you received. This record, known as a *Summary of Cancer Treatment*, should contain the following information:

- Name of the disease that you had, the date when you were diagnosed, and the site/stage of the disease
 - Date(s) and description(s) of any relapses
 - Name, address, and phone number of hospital(s) or clinic(s) where you received your care
 - Name, address, and phone numbers of your cancer doctor (oncologist) and other health team members responsible for your care
 - Date that your cancer treatment was completed
- Names of all the chemotherapy medicines that you received and specific information about certain chemotherapy drugs as follows:
 - Total doses of anthracycline chemotherapy (such as doxorubicin or daunorubicin)
 - For cytarabine and methotrexate: How they were given (such as by mouth or into the vein), and if into the vein, whether you received "high dose" (1000 mg/m² or more in any single dose) or "standard dose"

therapy

- For carboplatin: Whether or not the dose was myeloablative (given during preparation for a bone marrow, cord blood, or stem cell transplant)
- Total doses of other chemotherapy agents and how they were given should be included, if available





- Janichols@childrenswi.org (Julie Nichols)
- <u>Children's Oncology Group</u>
- Next Steps survivorship program | Children's Wisconsin
- Save the Date: November, 2024!





Kids deserve the best.

Q & A Session



Become a Wisconsin Cancer Collaborative Member!

- Online networking directory
- Monthly and quarterly members-only newsletters
- Email alerts with new resources
- Free access to events
- Leadership opportunities
- Tools and resources to support your organization's efforts to implement the Wisconsin Cancer Plan 2020-2030
- Opportunities to collaborate with other Wisconsin Cancer Collaborative Members



Join Us!

Membership is free! Scan the QR code to join us today.



Register Today for the 2023 Wisconsin Cancer Summit

Save the Date

2023 Wisconsin Cancer Summit

Nov. 1 & 2, 2023 | Wilderness Resort, Wisconsin Dells, WI

Save the date for our 2023 Wisconsin Cancer Summit.

The Power of Action – Be inspired by the work and stories of people in your community – learn about your role in the cancer plan and how to improve health outcomes in Wisconsin.

2023 Wisconsin Cancer Summit



The Power of Action Nov. 1 & 2 Wisconsin Dells

Be inspired by the work and stories of people in your community – learn about your role in the cancer plan and how to improve health outcomes in Wisconsin.





Survivorship Mini-Grant Opportunity

- We are currently accepting applications **up to \$1,000** to support organizations and activities that offer psychosocial support so cancer survivors (such as support groups).
- The deadline to apply is **September 21st.**





Cancer Experience Registry



include the social support you needed?



Participate in Important Research

The Cancer Experience Registry (CER) survey from Cancer Support Community (CSC) uncovers the emotional, physical, practical, and financial impact of cancer to help patients and caregivers get the support they need. Through the CER survey, we reach those impacted by cancer so their voices can be part of this important research and so that together, we can:







Influence healthcare policies



Wisconsin

Collaborative

Cancer

services

www.cancerexperienceregistry.org/join/WI

Improve support

How It Works



The survey takes 35 minutes to complete.

Frequently Asked Questions

What is the Cancer Experience Registry?

by cancer.

The Cancer Experience Registry (CER) is an online

research survey that helps enhance cancer care,

Who can take the survey? The CER is open to

any adult who has been diagnosed with cancer

at any point in their life or has been a family

Participants must live in the United States, a U.S. territory, or Canada and be able to read

What about my privacy? The survey is an

Is there a cost to take part? No, there is no cost to take part in this research.

Institutional Review Board (IRB) approved research

study, which means that the confidentiality, rights and welfare of participants are protected.

and understand English.

or informal caregiver to someone with cancer.

improve health care policies, and ensure support

services better reflect the needs of people affected



Start and stop when you Be invited to take part in like by using the unique follow-up surveys or other link emailed to you research and programs



applicable to you



Use the QR code to take the survey!

What is the benefit to taking part? By generously giving your time for this important research, your contributions help deliver better outcomes for those impacted by cancer, now and in the future.

What happens when I've finished the survey? Once you complete the survey, you become part of a registry of patients and caregivers with the opportunity to complete follow-up surveys that track changes over time, or additional surveys that ask about emerging topics in cancer care.

Help change the future of cancer support by taking the CER survey

CANCER SUPPORT COMMUNITY







Thank You

