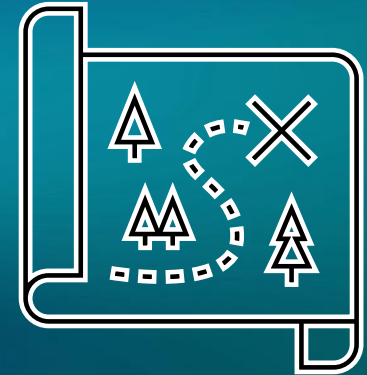


Cancer Survivorship: A Lifelong Journey

Jocelyn Morin, MPH & Rachel Phelan, MD, MPH
Next Steps Survivorship Program

October 8, 2026
Wisconsin Cancer Collaborative Summit



Children's
Wisconsin





Disclosures

- RP: Medexxus, advisory board; Sanofi, speaker's bureau



Objectives



Provide an overview of Childhood Cancer Survivorship in the Current Era



Review the Next Steps Survivorship Program at Children's Wisconsin and Ongoing Initiatives



Discuss Associated Programs (Onco-Fertility and Proton Radiation) and how they may Impact Ongoing Survivor Care



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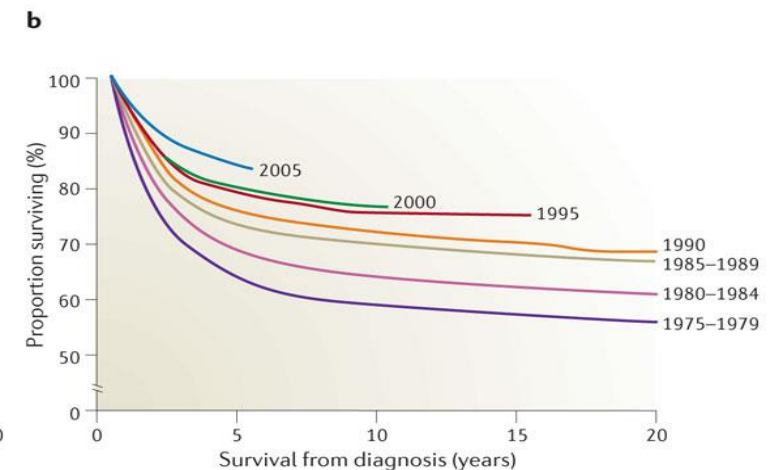
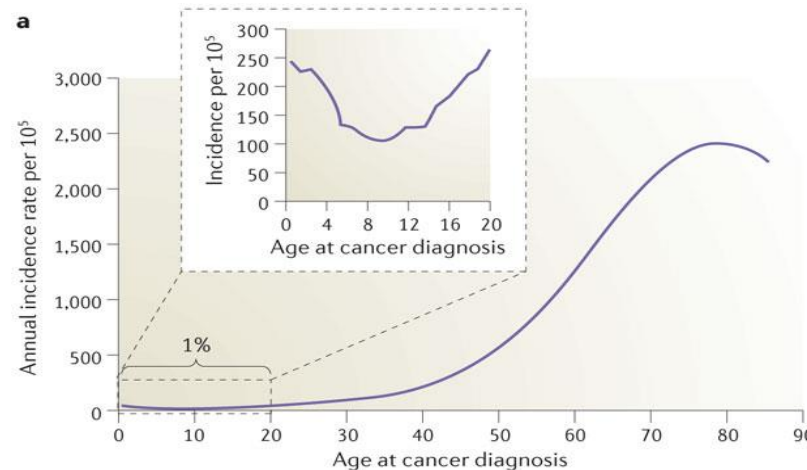


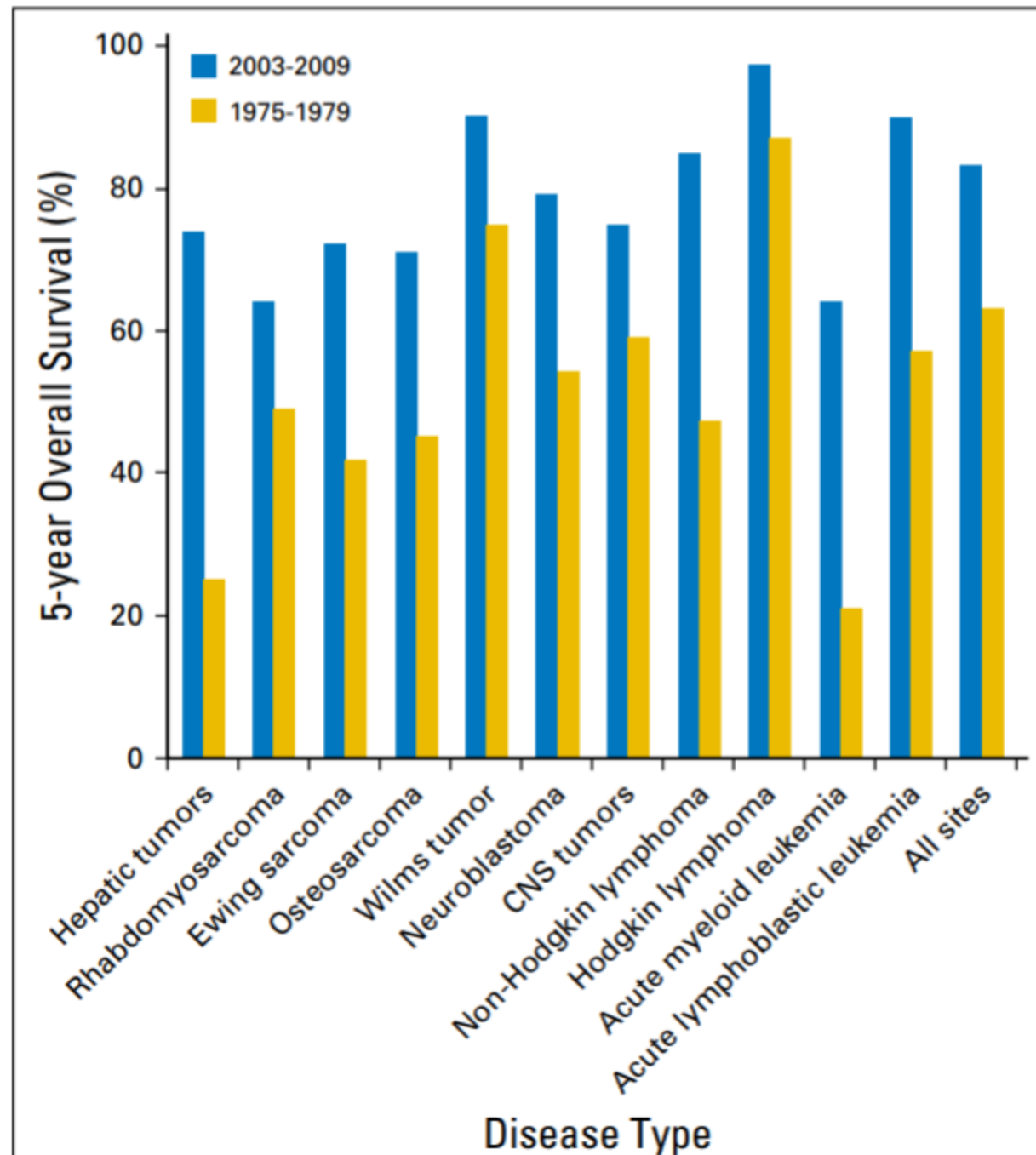
Childhood Cancer

- Leading cause of death in children in the US
- ~15,000 children/adolescents diagnosed with cancer each year
 - ~1700 estimated to die of the disease yearly
- Most common types: leukemia, brain tumors, lymphoma, soft tissue sarcoma
- The number of childhood cancer survivors continues to grow
 - ▶ We are getting much better at treating cancer...

1950-1954: 5yr survival of children diagnosed with cancer ages 0 to 14 years was 20%

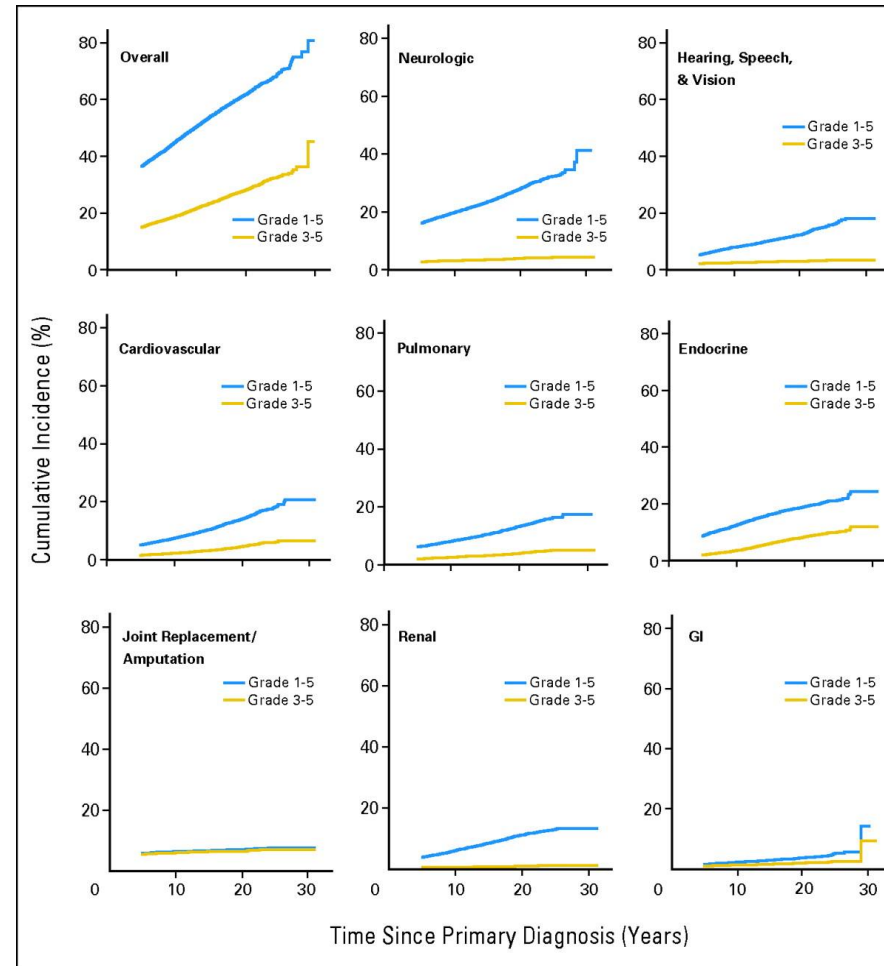
Now: >80%





Childhood Cancer Survivorship Study (CCSS)

Cumulative incidence of chronic health conditions (grade 1 to 5 and grade 3 to 5)

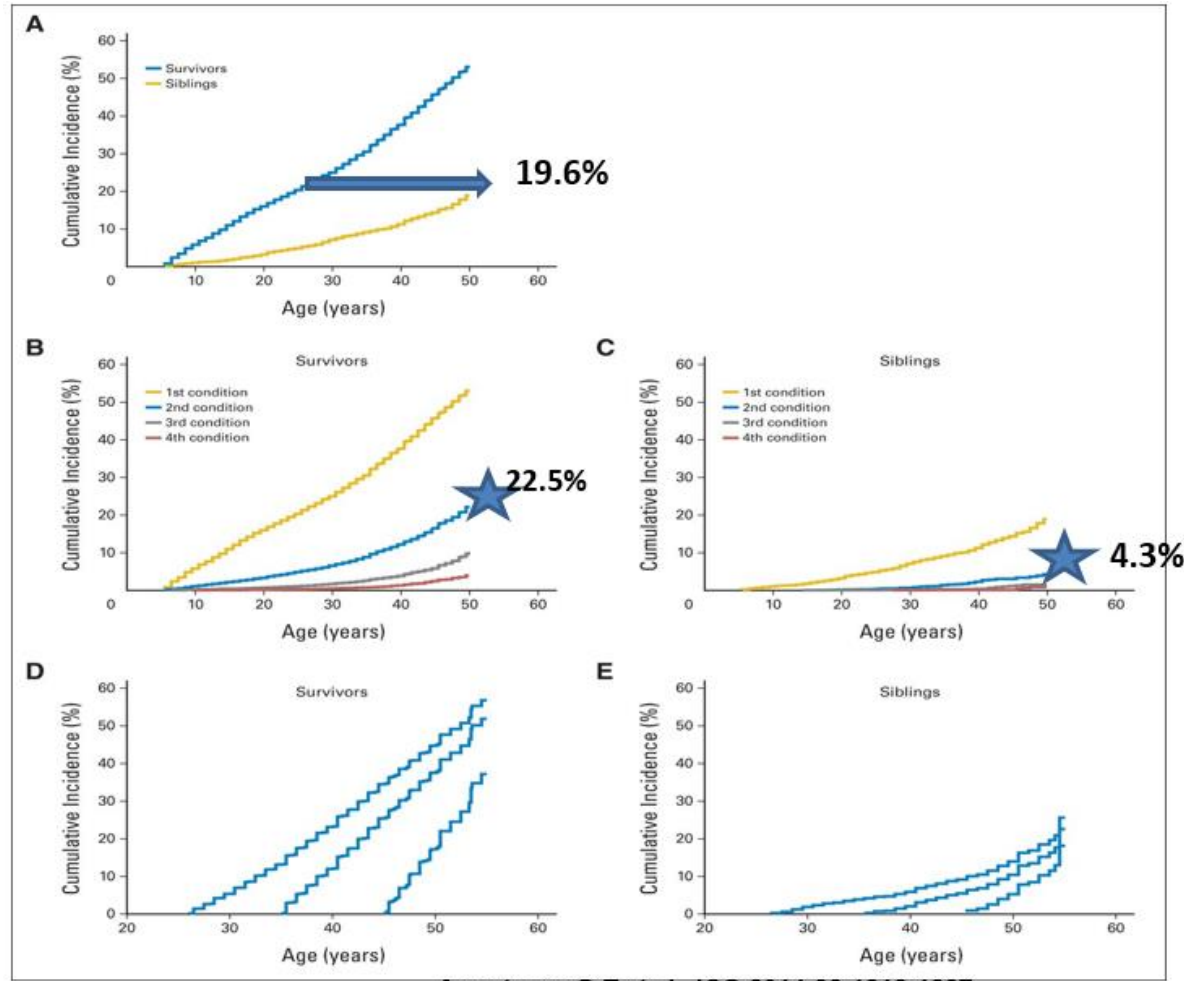


Diller, L. et al. J Clin Oncol; 27:2339-2355 2009

JOURNAL OF CLINICAL ONCOLOGY



Cumulative Incidence of Chronic Health Conditions in Childhood Cancer Survivors vs. Sibling Cohort



Armstrong G T et al. JCO 2014;32:1218-1227

24-year old survivors had the same (19.6%) cumulative incidence of grade 3 to 5 health conditions as the 50-year old siblings

By age 50 years, 22.5% of survivors vs. 4.3% of siblings (95% CI, 3.0 to 5.8) had ≥ 2 severe, disabling, life threatening, or fatal health conditions

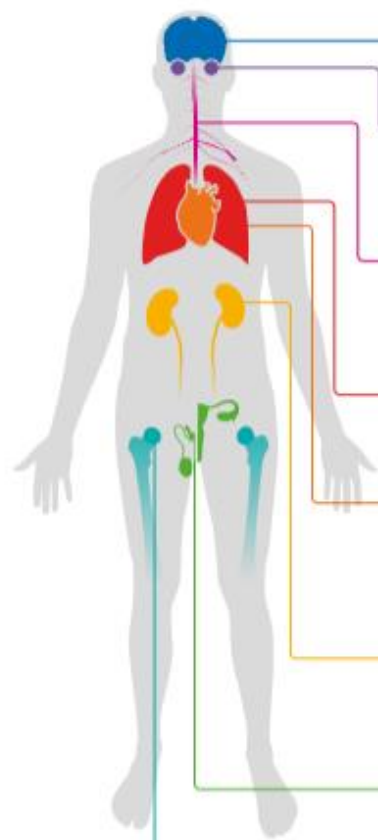


Late Effects can Encompass Basically Every Organ System

- Immune system
- Respiratory
- Cardiac
- Eye
- Liver
- Renal
- GU
- Musculoskeletal
- Nervous system
- Endocrine
- ENT
- Skin
- Ob/Gyn
- Mental health

Managing long term side effects of chemotherapy

Teenagers and young adults (TYA) who survive cancer treatment can have a range of side effects later in life. If it is known which chemotherapeutic agents were used, the "Principal causative drugs" column can guide monitoring and management. Factors that further increase the risk of complications from chemotherapy are listed in the "risk groups" section.



Psychosocial effects of chemotherapy include:

- Post-traumatic stress disorder
- Financial burden
- Depression
- Employment difficulties
- Social isolation
- Educational difficulties
- Strained relationships with partner, family, and peers

Effects of chemotherapy

er treatment can have a range
therapeutic agents were
uide monitoring and
of complications from
.1.

Principal causative drugs

thebmj Read the full article online

<http://bmj.com/chemfx>

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Loss of executive function

Memory loss

Cataract

Peripheral neuropathy

Tinnitus

Deafness

Raynaud's phenomenon

Pulmonary fibrosis

Ventricular failure

Coronary artery disease

Hypertension

Chronic kidney disease

Haemorrhagic cystitis

Renal tract malignancy

Infertility

Primary hypogonadism

Necrosis of femoral head

Second malignant neoplasm

Psychosocial problems

Fatigue

Osteoporosis

Risk groups

Managing those at risk

Concurrent cranial RT³

Baseline MMSE⁴

C

Repeat if symptoms

Consider: Neurorehabilitation Psychotropic drugs

Encourage communication with school/ university/ place of work

Consider referral to: Social worker Psychologist Occupational therapist

Concurrent RT³

Funduscopy

C

Every year

Refer to ophthalmology if symptoms

Neurological examination

C

Every year for first 3 years

After this, reassess if symptoms change

Baseline audiological assessment

C

Repeat if symptoms

Refer to ENT specialist if changes

Consider: Hearing aid Speech therapy Assessment of reversible causes

Offer advice Against smoking

Warm gloves in winter

Calcium channel blockers

Baseline tests

Chest radiograph Lung function

Respiratory examination

C

Every year

Vaccinations Influenza Pneumococcal

Smoking

Younger

HD¹

Exposure to high O₂ concentration

CVS risks

Smoking

Diabetes

High cholesterol

Mediastinal RT³

High dose

Time since chemo

Pregnancy

Encourage early presentation

C

Cardiac disease may occur at much younger ages in people who have had chemotherapy

MUGA/⁵echocardiogram

C

Consider ECG and blood pressure

Every year

Total anthracycline dose (mg/m²)

1-300 300-500 >500

Chest RT

Every 3 years

No chest RT

Every 5 years

Every 2 years

Every 1 year

Prior renal dysfunction

Diabetes

Blood pressure

C

Every year

Urinalysis

C

Every year

Baseline urea and electrolytes

C

Repeat if symptoms or signs of renal failure

Concurrent RT³ to urinary tract

Encourage self reporting

C

Advise patient to report potential symptoms

Refer to renal specialist if deterioration in symptoms or results

Older age at time of treatment

+RT³ to gonadal region

Higher cumulative doses

Fertility preservation

C

Refer as TYA⁷ undergoing chemotherapy to fertility preservation services

Baseline bloods

C

Men Testosterone

Women LH FSH Oestradiol

Hormone replacement

Mammogram Breast MRI

C

Every year

from 8 years after RT / age 25 (whichever is later)

Clinical breast exam

C

Every year

from puberty to age 25

Every 6 months

after age 25

+

Breast self-exam

C

Every month

Concurrent RT³

Clinical examination

C

Every year

Refer for MRI if clinical suspicion

High dose

+RT³

t-AML survivors

Autologous stem cell transplant

Full blood count for t-AML survivors

C

Every year

After thoracic radiotherapy

C

Enhanced breast cancer surveillance

CNS tumour

Cranial RT³

Hearing loss

Female

Younger

Lower SEG⁶

Depression

Psychosocial assessment

C

Every year

Support groups

C

Psychology referral

C

Counselling

C

Antidepressants

C

Anxiolytics

C

Assess impact on family members and carers

Smoking

Bone density scan

C

Calcium and vitamin D according to results

C

Rule out hypogonadism

¹HD = High dose

²Topoisomerase II inhibitors

³RT = radiotherapy

⁴Mini Mental State Examination

⁵Multigated acquisition scan

⁶SEG = socio-economic grouping

⁷TYA = teenagers and young adults

thebmj

Read the full article online

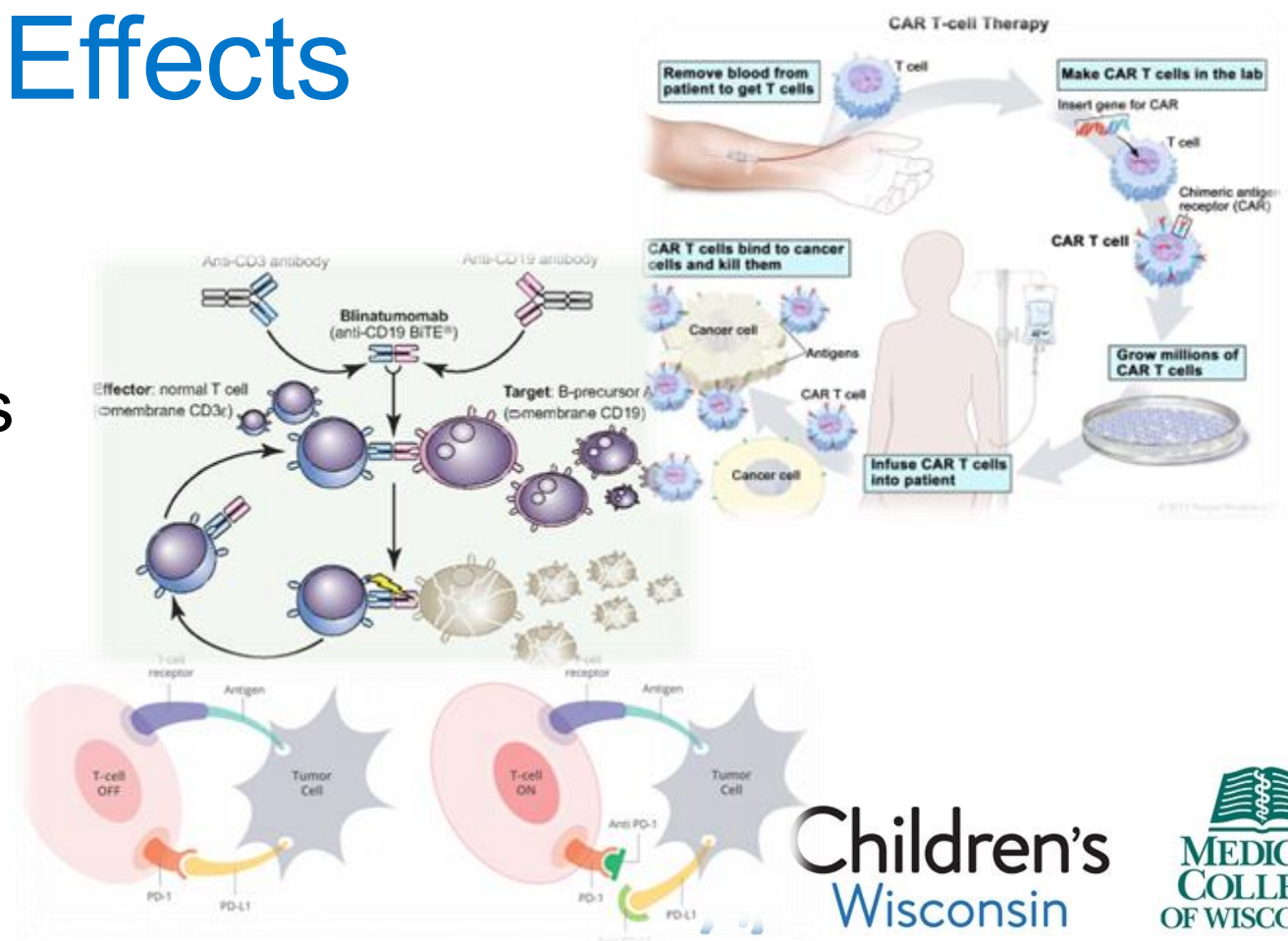
<http://bmj.co/chemfx>

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Emerging Therapies...Unknown Late Effects

- Chimeric antigen receptor (CAR)T cells
- Bi-specific T-cell engagers
- Checkpoint inhibitors
- Gene Therapy
- Other targeted molecular therapies...





Multiple Critical Transitions in Care

Active Therapy

Surveillance

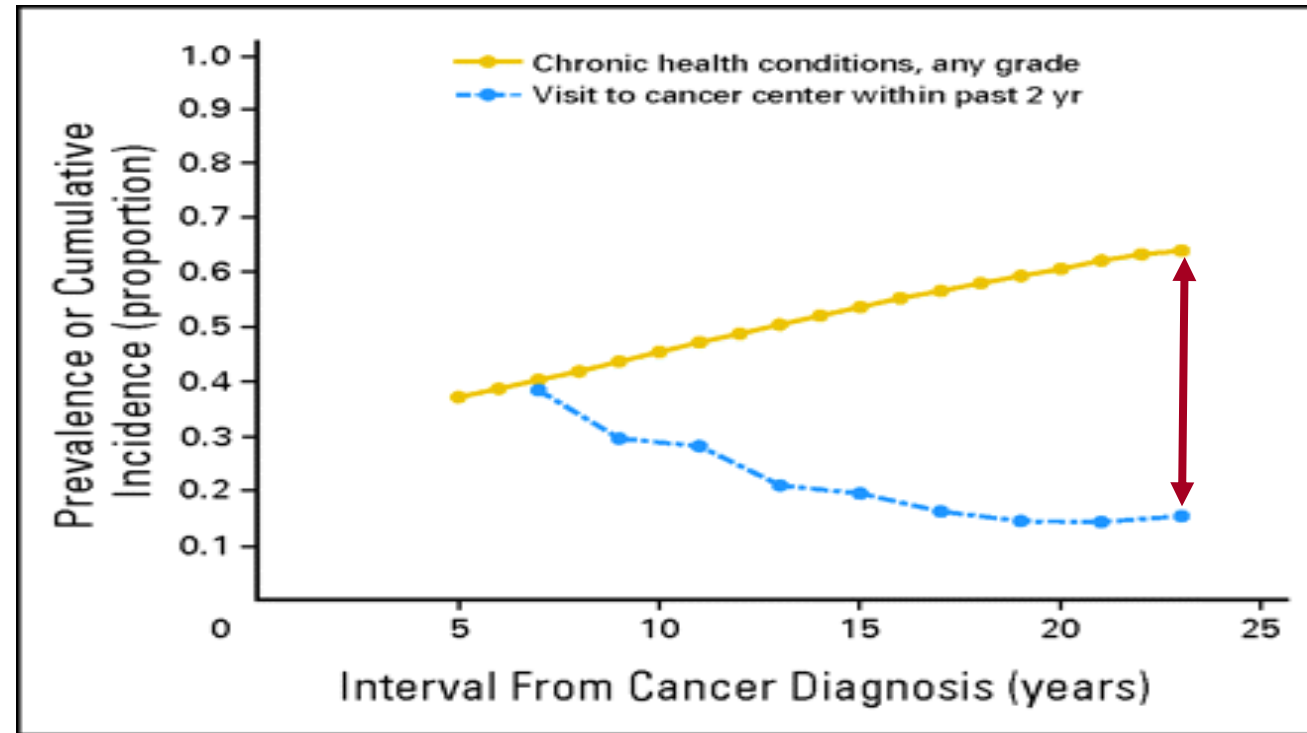
Surveillance

**End
of
Therapy**

**Survivor-
ship
Program**

**PCP/
Adult
Care**

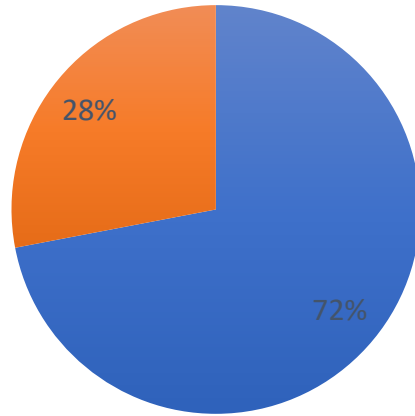
Follow-up of Childhood Cancer Survivors



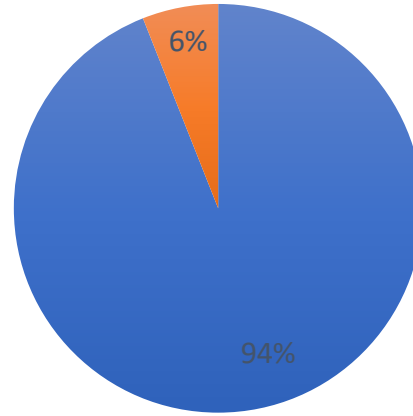
Nathan PC, et al. J Clin Oncol 27:2363-73, 2009

What our Patients Remember

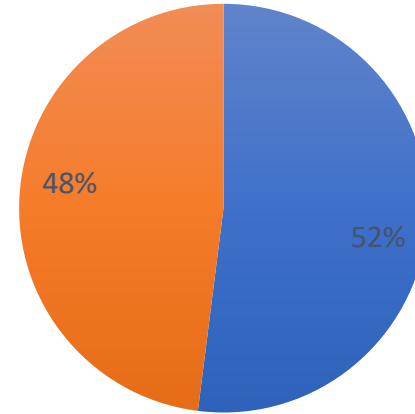
Diagnosis



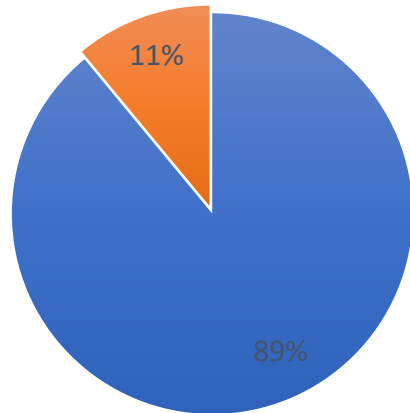
Chemo



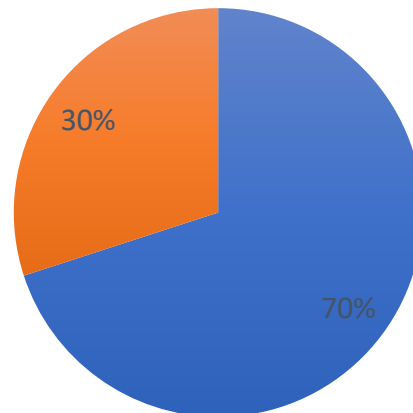
Doxorubicin



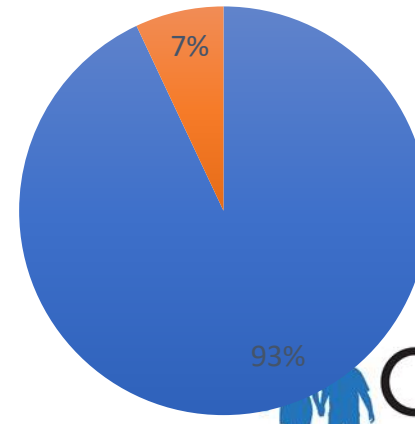
Radiation



Radiation Site

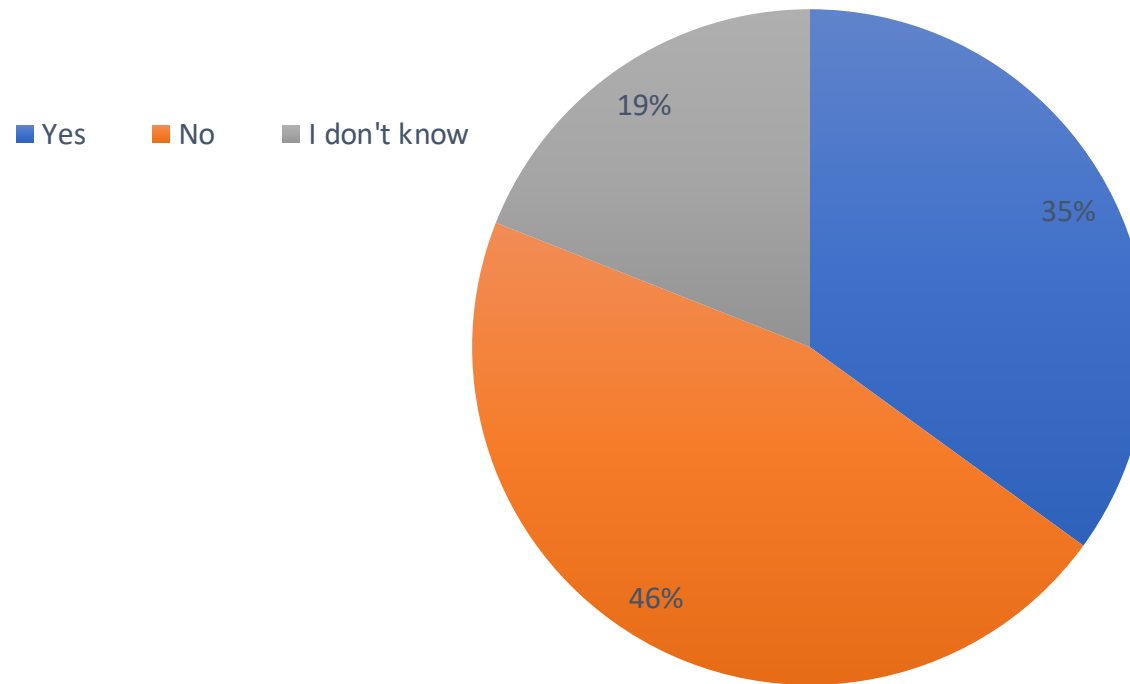


Splenectomy



What our Patients Understand

Can Past Therapies Cause Serious Health Issues Over Time?



Kadan-Lottick NS. JAMA 2002 Apr 10;287(14):1832-9.



Objectives



Provide an overview of Childhood Cancer Survivorship in the Current Era



Review the Next Steps Survivorship Program at Children's Wisconsin and Ongoing Initiatives



Discuss Associated Programs (Onco-Fertility and Proton Radiation) and how they may Impact Ongoing Survivor Care



Multiple Critical Transitions in Care



Next Steps Survivorship Program

- Ped Onc/BMT Specialists (MD + NP team)
- Endocrinology
- Psychology
- Social Work
- Dietician
- School teachers/advocates
- Nurse Clinician
- Community Navigator
- Physical Therapy
- Fertility Navigator
- Dental
- Cardiology





Next Steps Survivorship Program

- Patients transition to the program based on diagnosis and time since end of treatment (i.e. 2 years post end of treatment for leukemia diagnosis)
- First visit is a “full” visit where patients have a comprehensive clinic experience meeting different services
- Subsequent “mini” visits are generally with APP/MD + any ancillary services still needed
- No strict age cut-off, but ongoing discussions regarding transition of care

Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation	Health Counseling/ Further Considerations																						
34	Anthracycline Antibiotics Daunorubicin Doxorubicin Epirubicin Idarubicin Mitoxantrone Dose Conversion Use the following formulas to convert to doxorubicin isotonic equivalents prior to calculating total cumulative anthracycline dose. To estimate cumulative anthracycline dose in doxorubicin isotonic equivalents $1.0 \times (\text{doxorubicin total dose}) + 0.5 \times (\text{daunorubicin total dose}) + 0.67 \times (\text{epirubicin total dose}) + 5.0 \times (\text{idarubicin total dose}) + 10.0 \times (\text{mitoxantrone total dose})$	Cardiac toxicity Cardiomyopathy Subclinical left ventricular dysfunction Congestive heart failure Arrhythmia	HISTORY Shortness of breath Dyspnea on exertion Orthopnea Chest pain Palpitations If under 25 yrs: nausea, vomiting Yearly PHYSICAL Blood pressure Cardiac exam Yearly SCREENING Echo (or comparable imaging to evaluate cardiac function) <table border="1"> <thead> <tr> <th colspan="3">RECOMMENDED FREQUENCY OF ECHOCARDIOGRAM</th> </tr> <tr> <th>Anthracycline Dose*</th> <th>Radiation Dose**</th> <th>Recommended Frequency</th> </tr> </thead> <tbody> <tr> <td>None to <100mg/m²</td> <td>None to <15Gy</td> <td>No screening</td> </tr> <tr> <td>None to <100mg/m²</td> <td>15Gy to <30Gy</td> <td rowspan="2">Every 5 years</td> </tr> <tr> <td>≥100 to <250mg/m²</td> <td>None to <15Gy</td> </tr> <tr> <td>≥100 to <250mg/m²</td> <td>≥15Gy</td> <td rowspan="2">Every 2 years</td> </tr> <tr> <td>None to Any</td> <td>≥30Gy</td> </tr> <tr> <td colspan="3"> *Based on doxorubicin isotonic equivalent dose. **Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole], TBI). See section 77. </td> </tr> </tbody> </table> EKG (include evaluation of QTc interval) Baseline at entry into long-term follow-up, repeat as clinically indicated	RECOMMENDED FREQUENCY OF ECHOCARDIOGRAM			Anthracycline Dose*	Radiation Dose**	Recommended Frequency	None to <100mg/m ²	None to <15Gy	No screening	None to <100mg/m ²	15Gy to <30Gy	Every 5 years	≥100 to <250mg/m ²	None to <15Gy	≥100 to <250mg/m ²	≥15Gy	Every 2 years	None to Any	≥30Gy	*Based on doxorubicin isotonic equivalent dose. **Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole], TBI). See section 77.			HEALTH LINKS Heart Health Cardiovascular Risk Factors Nutrition and Physical Activity COUNSELING Traditional CVRFs significantly increase survivors' risk of death regarding the importance of maintaining blood pressure within goal ranges per general population guidelines. Regarding exercise: - Exercise is generally safe and encouraged for patients - Consult cardiology for survivors with asymptomatic cardiac activity limits and precautions. - Consider cardiology consultation to define physical activity high risk survivors (i.e., those requiring an echo every 2 years in intensive exercise). If QTc interval is prolonged: Caution use of QTc prolonging anti-depressants, antifungals, macrolide antibiotics, metoprolol. POTENTIAL CONSIDERATIONS FOR FURTHER TESTING Cardiac MRI as an adjunct imaging modality when echo is inconclusive. Cardiology consultation in patients with subclinical abnormalities, LV dysfunction, dysrhythmia, or prolonged QTc interval. For patients who are pregnant or planning to become pregnant, evaluation is indicated in patients who received: ≥250 mg/m² anthracyclines ≥30 Gy chest radiation, or - Anthracycline (any dose) combined with chest radiation Evaluation should include a baseline echo (pre- or early post-treatment) and with normal pre- or early-pregnancy echos may be obtained at the provider's discretion. The presence of LV dysfunction or with pre- or early-pregnancy systolic dysfunction, pregnancy-associated cardiomyopathy, and should be monitored periodically during pregnancy, labor and delivery due to increased risk for heart failure.
RECOMMENDED FREQUENCY OF ECHOCARDIOGRAM																										
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ASTCT
American Society for
Transplantation and Cellular Therapy

ELSEVIER

International Recommendations for Screening and Preventative Practices for Long-Term Survivors of Transplantation and Cellular Therapy: A 2023 Update

Seth J. Rotz^{1,2,*}, Neel S. Bhatt^{3,*}, Betty K. Hamilton², Christine Duncan⁴,
Mahmoud Aljurf⁵, Yoshiko Atsuta⁶, Kristen Beebe⁷, David Buchbinder⁸,
Peggy Burkhard⁹, Paul A. Carpenter³, Naeem Chaudhri¹⁰, Mohamed Elemuay¹¹,
Mahmoud Elsayy¹², Greg MT Guilcher¹³, Nada Hamad¹⁴, Amado Karduss¹⁵,
Zinaida Peric¹⁶, Duncan Purtill¹⁷, Douglas Rizzo^{18,19}, Morgani Rodrigues²⁰,
Maria Belén Rosales Ostriz²¹, Nina Salooja²², Helene Schoemans²³, Adriana Seber²⁴,
Akshay Sharma²⁵, Alok Srivastava²⁶, Susan K Stewart²⁷, K. Scott Baker³,
Navneet S. Maihail²⁸, Rachel Phelan^{19,29}

Although mitoxantrone is an anthraquinone, it is related to the anthracycline family and is included in this section because of its cardiotoxic potential. Childhood cancer survivors exhibit clinical and subclinical toxicity at lower levels than adults. In patients with abnormal LV systolic function, certain conditions (such as isometric exercise and viral infections) have been anecdotally reported to precipitate cardiac decompensation. Prospective studies are needed to better define the contribution of these factors to cardiac disease risk. Abdominal symptoms (nausea, emesis) may be seen more frequently than exertional dyspnea or chest pain in younger patients.

Survivor Healthcare Passport

Next Steps Clinic
Survivor Healthcare Passport
Recommended Follow-Up

CureSearch
 Children's Oncology Group

Children's
 Hospital of Wisconsin
 Kids deserve the best.

Patient: DOB: Updated: September, 2017
 Providers: Dr. /, APNP 414-266-2420

System	Exam	Time Frame
<i>All Survivors: History and Physical Exam Yearly, Dental Exam Every 6 Months</i>		
Secondary Cancer	Routine cancer screening for secondary malignancies CBC with manual differential	Ongoing As clinically indicated
Cardiology	Echocardiogram	Every 5 years
Endocrine	Bone mineral density test (dexa scan) Monitor growth and pubertal development	Baseline, then as clinically indicated Ongoing
Neuro-Cognitive	Neuro-psychologic testing	As clinically indicated and if school problems develop

Abbreviated Treatment History
 Diagnosis: Acute Promyelocytic Leukemia in (date) on Protocol:
 Relapse in (date)
 Bone marrow transplant on (date)
 Donor Information:

Cumulative Chemotherapy Doses

Anthracycline Total = mg/m², age at first dose.

Cyclophosphamide = gm/m²

Cytarabine = gm/m²

Etoposide = mg/m²

Pre-Transplant Therapy

Daunomycin, Retinoic Acid and Cytarabine

Cytarabine, Retinoic Acid, Clofarabine and Etoposide

BMT Conditioning Regimen

Cytarabine, Cyclophosphamide and total body irradiation

Radiation Treatment	Date	Dose
Total body irradiation		14 Gy

For detailed Long-Term Follow-Up Guidelines (V4.0): www.survivorshipguidelines.org
 ©2006 UCSF All Rights Reserved. Used With Permission



Navigating "Scanxiety" in Pediatric & AYA Cancer Survivorship

- **Root Drivers:** Driven by Fear of Cancer Recurrence (FCR), somatic hypervigilance, and conditioned post-traumatic stress responses to medical environments.
- **Peak Vulnerability:** Distress peaks during the "waiting window" (days leading up to the scan through result delivery).
- **Dyadic Effect:** In pediatric cases, parental and patient scanxiety reinforce each other; supporting the family unit is essential to mitigating child distress.

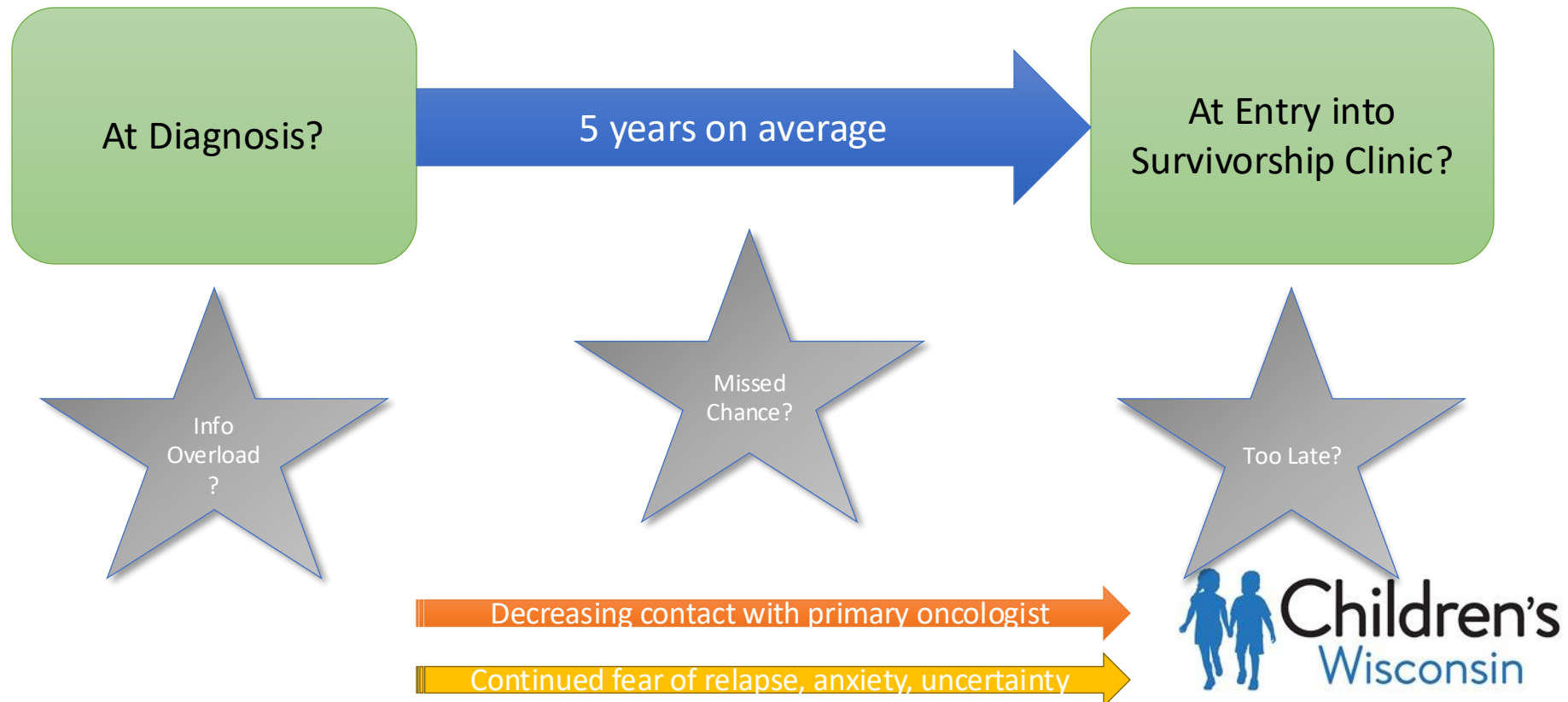
Heathcote, L.C., et.al. (2023), Peikert, M. et.al. (2020); Webster, S. N., et.al. (2025)



Actionable Interventions for Scanxiety

- **Operational & Scheduling Optimizations**
 - **Morning Appointments:** Schedule surveillance imaging as early in the day as possible (and early in the week) to minimize anticipation hours and avoid weekend result gaps.
 - **Rapid Result Protocols:** Establish clear, predictable timelines for result delivery. Deliver same-day results whenever clinically feasible.
 - **"Portal Protection" Counseling:** Advise patients/families in advance regarding automated online portal releases to prevent misinterpretation of technical radiology findings before clinical review.
- **In-Clinic & Procedural Support**
 - **Child Life & Sensory Accommodations:** Utilize Child Life specialists for mock preparation, medical play, sensory modifications (headphones, VR, weighted blankets), and distraction.
 - **Transparent Communication:** Acknowledge scanxiety to normalize the emotional response and remove stigma around seeking help.
 - **Screen for Maladaptive Coping:** Identify those using "bracing for the worst" strategies or exhibiting severe distress prior to scans.
 - **Targeted Interventions:** Refer to psycho-oncology for grounding techniques and cognitive restructuring.

When is the Optimal Time to Receive Information/Education re: Survivorship Care?

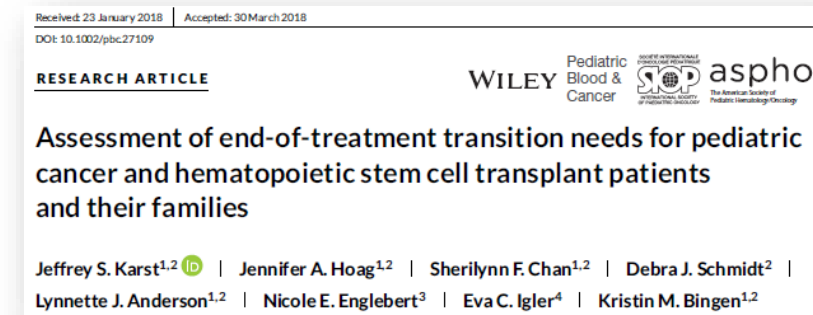




A Study led by our Team

Study Aims

- To better understand the needs and preferences of pediatric & AYA cancer patients transitioning off of active treatment
- To inform development of a formal transition program for pediatric & AYA cancer patients and families



- 
- 49 caregiver/child dyads
 - Interviews/surveys 1-2 months before treatment ended (Time 1), and then again 3-7 months after (Time 2)
 - Perceptions of knowledge of follow-up care/late effects
 - Perceptions of preparation for transition off treatment
 - Perceptions of PCP's cancer treatment knowledge
 - Info they felt would be helpful /who provided it
 - Preference for when to receive this info



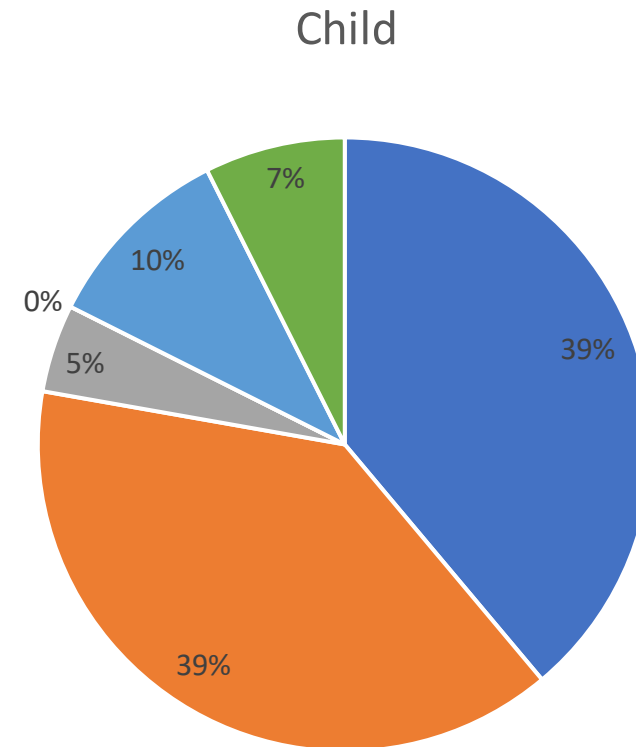
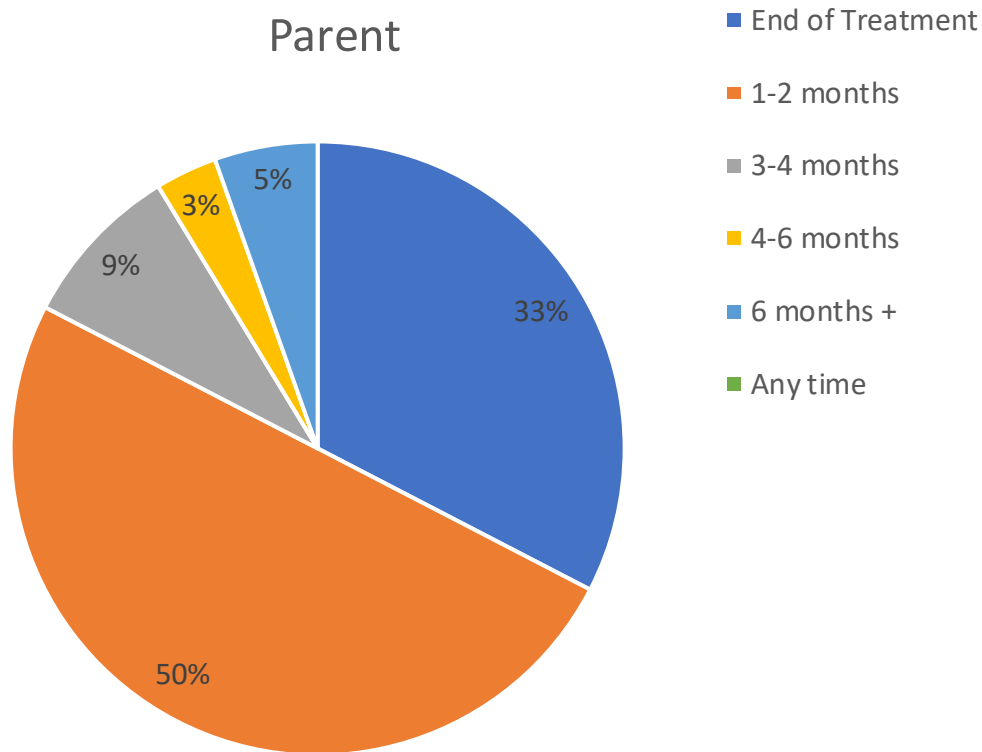
Children's
Wisconsin



Information Identified as Most Helpful

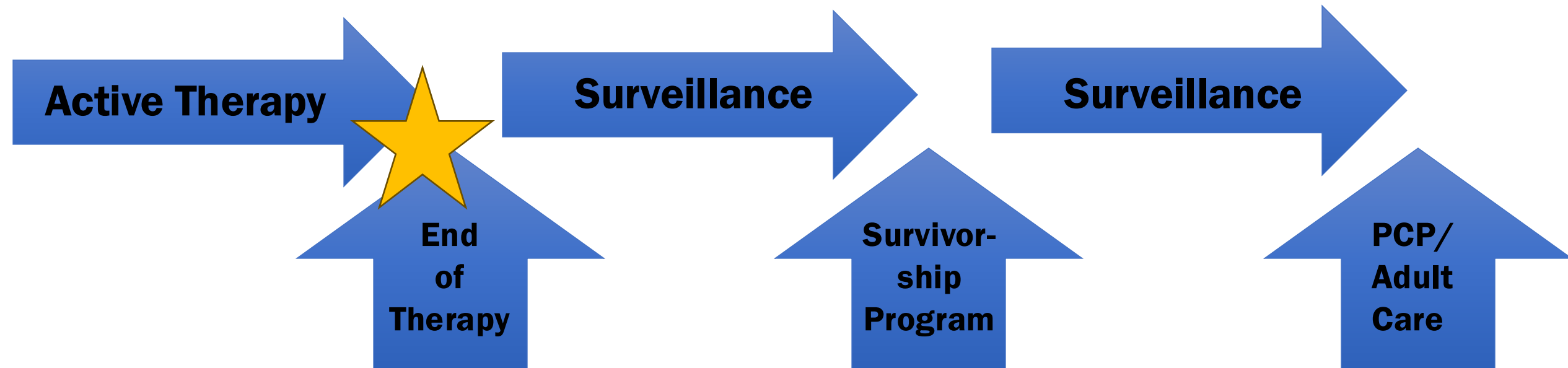
	Parent	Child
Time 1	1) Review of Late Effects 2) Schedule of Follow-up Appointments 3) Health/Physical Restrictions 4) Communication with PCP 5) Treatment Summary	1) Review of Late Effects 2) Schedule of Follow-up Appointments 3) Health/Physical Restrictions 4) Communication with PCP 5) Treatment Summary
Time 2	1) Review of Late Effects 2) Schedule of follow-up Appointments 3) Health/Physical Restrictions 4) Communication with PCP Emotional/Adjustment Issues	1) Review of Late Effects 2) Review of Follow-up Tests 3) Communication with School Staff 4) Communication with PCP 5) Treatment Summary

How long before the end of treatment should transition preparation begin?





Multiple Critical Transitions in Care



Bridge to Next Steps

- 2 visits (one pre and one post end of treatment)
- 1st Visit: Healthcare Provider
- 2nd Visit: Provider & Psychologist

Active Treatment

Next Steps Clinic

- Multidisciplinary Team Visits
- First visit minimum of 2-5 years post treatment
- Ongoing follow-up thereafter

BRIDGE TO NEXT STEPS

**Visit 1 (30 min)
(1-2 mos prior to EOT,
Survivorship Provider)**

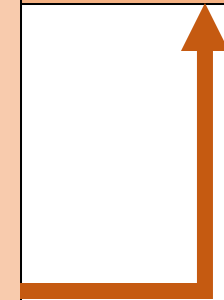
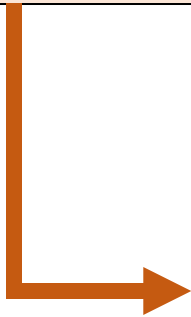
- Discuss transitional process
- Discuss & Distribute Healthy Living Resources
 1. Intro to LTFU
 2. Diet & Physical Activity
 3. Reducing Risk of Secondary Cancers
 4. Emotional Issues
- Verify that patient has PCP

**2-3 Years Post Treatment
Transition to Next Steps Clinic**

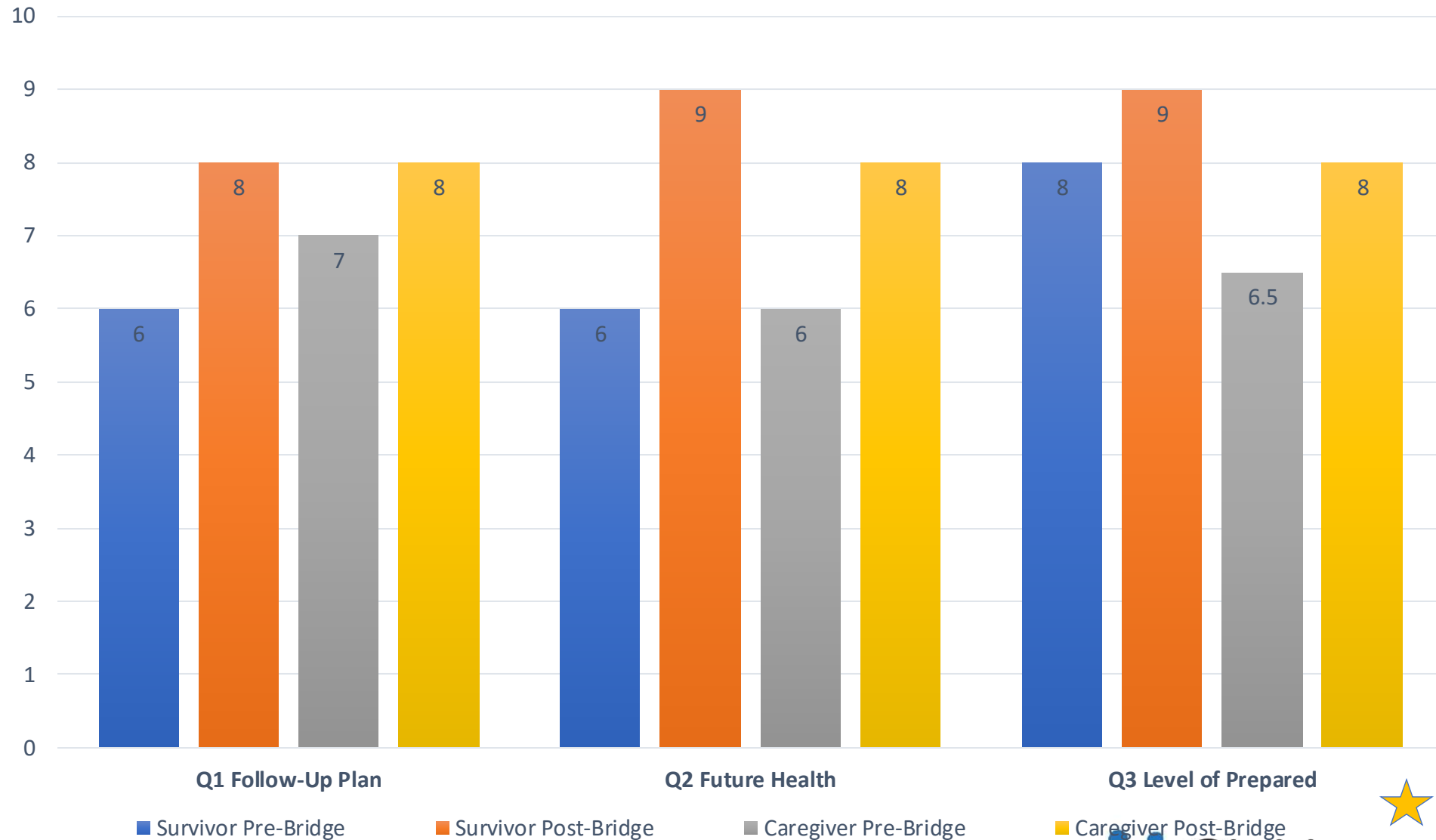
- Multidisciplinary Team Approach
- Discuss & Distribute Health Links & Education/Supportive Care Materials
- Late Effect Clinical Evaluation
- Follow-Up Care Plan
- Connection to Survivor Resources

**Visit 2 (60 min)
(Within 7 mos after EOT, Provider & Psychology)**

- Discuss therapy summary
- Distribute passport
- Distribute Health Links
- Discuss potential late effects
- Provide follow-up schedule
- Psychological consultation: adjustment; school/work/social reintegration
- Survivorship plan of care to PCP



Preparedness Outcomes





Multiple Critical Transitions in Care

Active Therapy

Surveillance

Surveillance

**End
of
Therapy**

**Survivor-
ship
Program**

**PCP/
Adult
Care**



Children's
Wisconsin



Transition Preparation: What Helps

- **Provide Anticipatory Guidance/Education**
 - Important of follow-up care
 - Review of health risks/late effects
 - Emotional adjustment
 - Developing a new normal
 - Schedule of follow-up appointments, labs, and scans
 - Healthy lifestyle behaviors
 - Fertility/family planning
 - Sexual health
 - Transition to Adult Health Care
- **Survivorship Care Plan (Share with PCP)**
 - Treatment Summary
 - Follow-up Care Plan
- **Ask your patient how he/she is adjusting to life after cancer at each visit**
 - Normalize feelings/concerns
- **Psychosocial assessment/distress screening**
- **Provide supportive care resources and referrals to reintegrate**
 - College/employment reintegration
 - Social reintegration
 - Psychological support
 - Financial counseling

Transition Support: What Helps

- **Anxiety/Stress Management Strategies**
 - Meditation/Relaxation
 - Mindfulness
 - Exercise
 - Behavioral Activation
- **Professional Psychological Support**
 - Counseling
 - Neuropsychological Testing
- **College/Job Reintegration**
 - Department of Vocational Rehabilitation (DVR)
 - Career Counseling
 - Vocational Support
- **Financial Counseling/Planning**
- **Social Support/Social Reintegration**
 - Connect with friends, family
 - Connect with other cancer survivors/support groups
 - Social Media



University of
Wisconsin





Closing the Communication Gap: Improving Survivorship Care Through Treatment Summary Communication

- *Quality Improvement Initiative
Children's Wisconsin Survivorship Program*

The Problem & Opportunity

Why This Project Matters

- Childhood cancer and BMT survivors require lifelong follow-up care
- As survivors move further from treatment, primary care providers assume a larger role in care
- Treatment summaries contain critical information about risks, surveillance, and follow-up recommendations
- Communication between survivorship teams and PCPs is not always consistent, creating potential gaps during transitions

Standardized Survivorship-to-PCP Handoff

Communication Touchpoint #1

Two weeks after a survivorship clinic visit

- Confirm treatment summary was received
- Verify PCP knows where to access it
- Review key recommendations and answer questions

Communication Touchpoint #2

At the final survivorship clinic visit

- Confirm transition of care
- Provide final support and clarification
- Gather PCP feedback on the communication process



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Expected Outcomes & Impact

We Will Measure:

- Treatment summary receipt
- PCP understanding of survivorship information
- Provider satisfaction with communication
- Preferred communication methods
- Feasibility of the workflow

Expected Benefits:

- Stronger collaboration between survivorship and primary care
- Reduced burden on patients and families
- More confident PCP management of survivors
- Safer, more coordinated transitions of care
- Sustainable communication process for future survivors

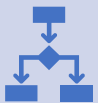




Objectives



Provide an overview of Childhood Cancer Survivorship in the Current Era



Review the Next Steps Survivorship Program at Children's Wisconsin and Ongoing Initiatives



Discuss Associated Programs (Onco-Fertility and Proton Radiation) and how they may Impact Ongoing Survivor Care



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adolescent + young adult cancer program

- 
- AYAs are at risk for psychosocial problems due to the impact of cancer:
 - Lower Quality of Life
 - Lower self-image
 - Poor body-image
 - Medical adherence problems
 - Depression & anxiety
 - High levels of distress
 - Post-traumatic stress symptoms
 - Risky behaviors
 - Social functioning problems

• Barnett et al., 2016; Butow et al., *J Clin Oncol* 2010; Kondryn et al., *Lancet Oncol* 2011;
Kwak et al., *J Clin Oncol* 2013; Salsman et al., *Pediatr Cancer* 2019; Smite et al., *J Clin Oncol* 2013;
JNNCN, 2023



Results from CDC's 2009 Behavioral Risk Factor Surveillance System

Characteristic	% AYA Survivors (N = 4,054)	% Comparison Group (N = 345,592)
Unemployed/unable to work	24 (%)	14(%)
Currently smoking	26	18
No leisure-time physical activity in past month	31	24
≥ 2 weeks of poor mental health in past month	20	10
≥ 2 weeks of poor physical health in past month	24	10
Unable to visit a physician d/t cost	24	15

Tai et al., Cancer 2012

Financial Toxicity for AYA Patients

VULNERABILITY & SCALE

\$259,324

Avg. lifetime economic burden per patient

- **Life Stage Disruption:** Hits during career start, education, and early asset building.
- **Older AYA Severity:** Ages 26–39 face 77.8% high toxicity vs 37.5% in ages 15–25 ($p=0.005$).
- **Long-Term Peril:** Economic hardship persists deep into post-treatment survivorship.

KEY DRIVERS

Primary Cost Burden

- **Income Reduction:** Major loss in earnings, most acute in the first 5 years post-diagnosis.
- **Insurance Barriers:** High deductibles, underinsurance, and complex claims processing.
- **Debt Accumulation:** Substantial increases in medical debt sent to collection agencies.
- **Practical Gaps:** Unmet needs for childcare, transport, housing, and legal aid.

IMPACT & MITIGATION

Clinical Outcomes

- **Care Non-Adherence:** Skipping meds, delaying care, or missing visits to manage costs.
- **Psychosocial Distress:** Severe mental health toll, anxiety, and delayed life milestones.
- **Routine Screening:** Integrating proactive toxicity screening into clinical pathways.
- **Support Navigation:** Providing dedicated financial navigation and policy-level protections.



National AYA Resources

• Camps/Adventure Programs

- Camp-Mak-A-Dream
- First Descents
- True North Treks
- Epic

• Peer/Online Support

- Imerman Angels
- Stupid Cancer
- CancerCare
- Cactus Cancer Society
- Dear Jack Foundation
- Elephants and Tea

• Financial Assistance

- Allyson Whitney Foundation
- Patient Advocate Foundation
- PAN Foundation
- The SamFund (Expect Miracles Foundation)
- Ulman Cancer Fund
- United Blood Cancer

Vocational Assistance

- Cancer and Careers

Fertility Resources

- Oncofertility Consortium
- LIVESTRONG

AYA Advocacy/Education

- 15 to 40 Connection
- Seventy K
- Triage Cancer
- Teen Cancer America
- Young Adult Survivors United



Collaboration between Sports Medicine & MACC Fund Center



Background

- Differences in physical activity between children with cancer and healthy peers begin during treatment and are maintained for decades after treatment completion.
- The side effects of treatment paired with a sedentary lifestyle contribute to chronic disease in survivorship.
- Survivors have reported that they are more likely to exercise if someone asks them to or provides a structure for the activity.



Cancer Awareness





Team Survivors for Everyone



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Wisconsin



Triathlon Race Day



10/7/2026



TEAM SURVIVORS: MOVEMENT MATTERS



Program

Physical activity and nutrition program for survivors who are deconditioned, need extra therapies, or not ready for other programming.



Timeline

12 week program, meeting once a week starting in Fall (September - December)



Eligibility

Open to MACC Fund Center Patients who are between the ages 9 - 17 & one sibling in same age range.



Physical Activity

60% of practices will be in a gym space and 40% of practices are field trips.



Nutrition Education

Two nutrition classes lead by dietician for participants and caregiver(s).



10/7/2026



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Children's Wisconsin Onco-Fertility Program

Data Driven / Guideline Supported



Supports:

- Counseling patients on fertility preservation
- Providing timely referrals
- Reducing distress, improving quality of life

Fertility Consult



Fertility Preservation Intervention

Fertility Consult



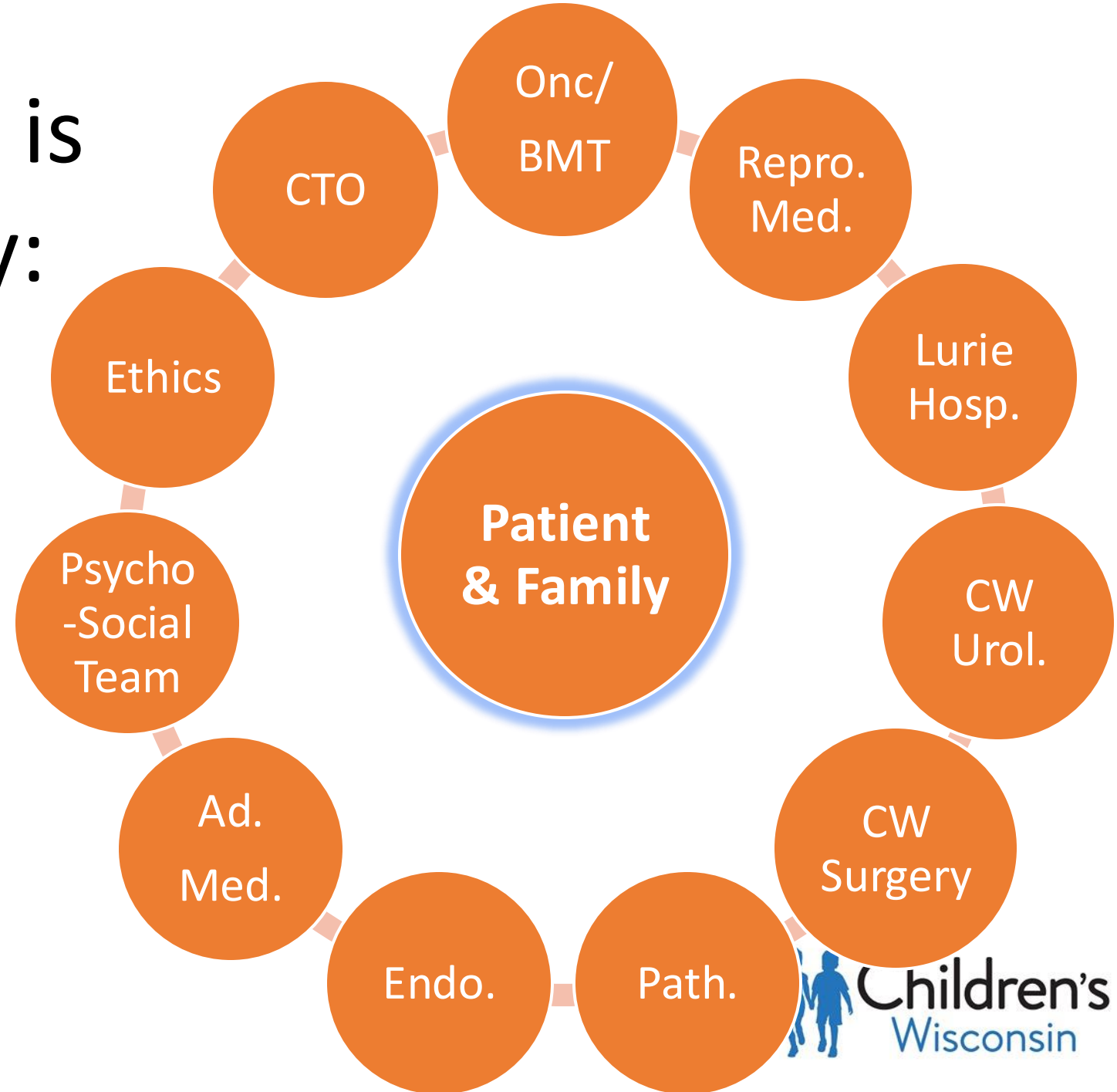
Informed decision making

Improved quality of life

Options for future family planning

Empowered patients and families

Collaboration is KEY in Fertility:



Standardized Risk Assessment Tables

FIG. 1. Female level of risk for gonadal failure/infertility above that for the general population. *CED.⁶ CED, cyclophosphamide equivalent dose.

			Minimally Increased Risk	Significantly Increased risk	High level of Increased risk
Alkylators CED* gm/m2	Prepubertal		CED < 8	8-12	> 12
	Pubertal		CED < 4	4-8	>8
Heavy Metal			Cisplatin Carboplatin		
Hematopoietic Stem Cell Transplant					Alkylator +/-Total body irradiation Myeloablative and Reduced intensity regimens
Radiation exposure	Ovary	Prepubertal		< 15 Gy	≥ 15 Gy
		Pubertal		< 10 Gy	≥ 10 Gy
	Hypothalamus		22-29.9	> 30-39.9 Gy	> 40 Gy

		Minimally Increased Risk	Significantly Increased risk	High level of Increased risk
Alkylators CED* gm/m2		CED < 4		CED ≥ 4
Hematopoietic Stem Cell Transplant				Alkylator +/-Total body irradiation Myeloablative and Reduced intensity regimens
Heavy Metal mg/m2		Cisplatin Carboplatin	Cisplatin > 500	
Radiation Exposure	Testicular	0.2-0.6Gy	0.7-3.9 Gy	≥ 4.0 Gy
	Hypothalamus	26-29.99	> 30-39.9 Gy	> 40 Gy
Surgery			RPLND [^]	

FIG. 2. Male level of risk for gonadal failure/infertility above that for the general population. *CED.⁶ CED, cyclophosphamide equivalent dose; [^]RPLND, retroperitoneal lymph node dissection..

PRE-pubertal female

Ovarian Tissue Cryopreservation
Ovarian Shielding & Transposition

PRE-pubertal male

Testicular Tissue Cryopreservation
Testicular Shielding & Transposition

Fertility Preservation Interventions

POST-pubertal female

Egg/Embryo cryopreservation
Ovarian Tissue Cryopreservation
Lupron (protective)
Ovarian Shielding & Transposition

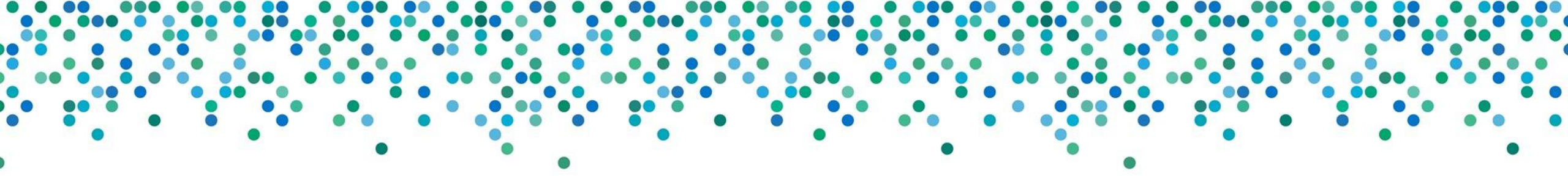
POST-pubertal male

Sperm cryopreservation
Testicular Tissue Cryopreservation
Surgical retrieval of sperm
Testicular Shielding & Transposition



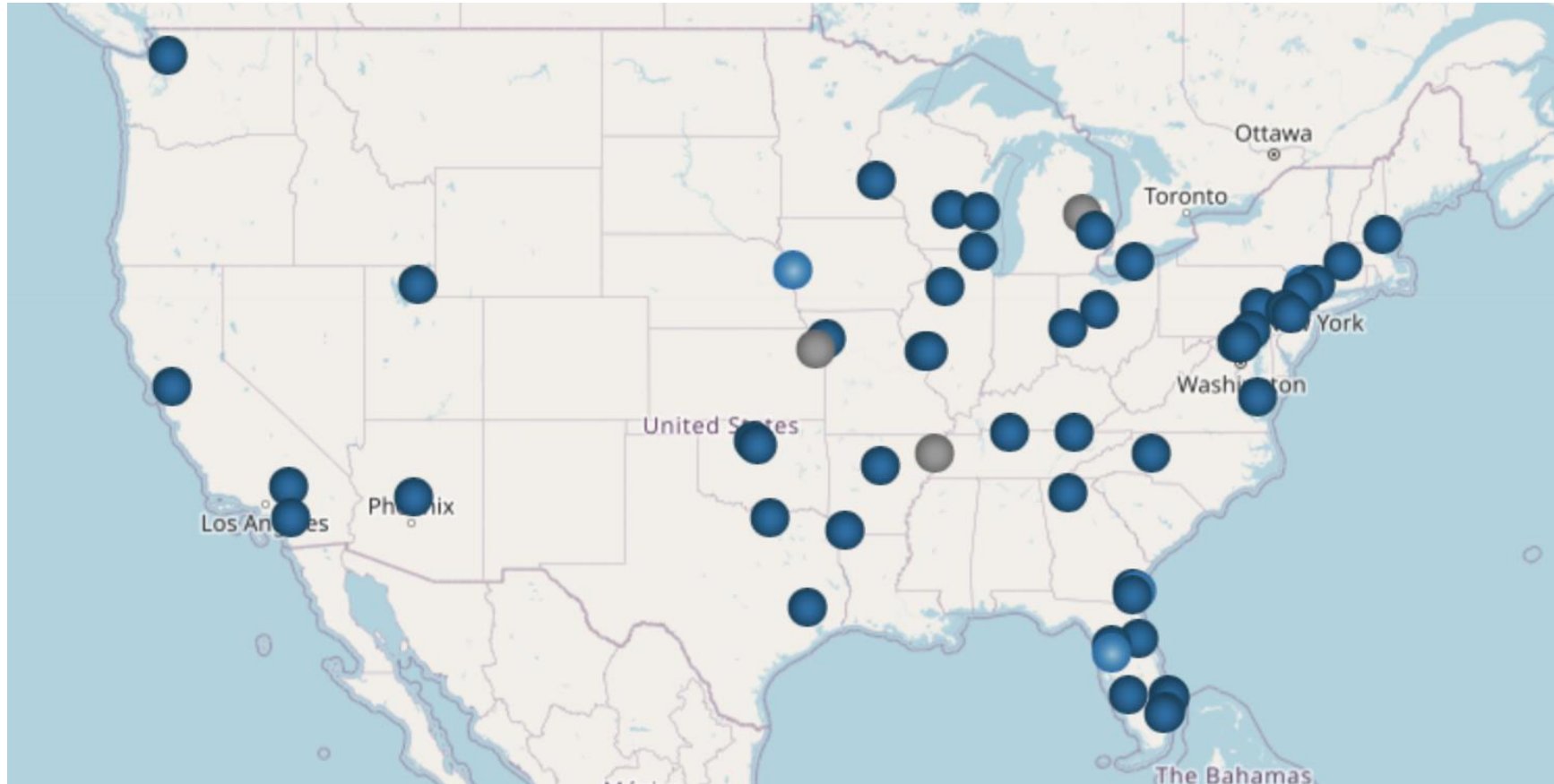
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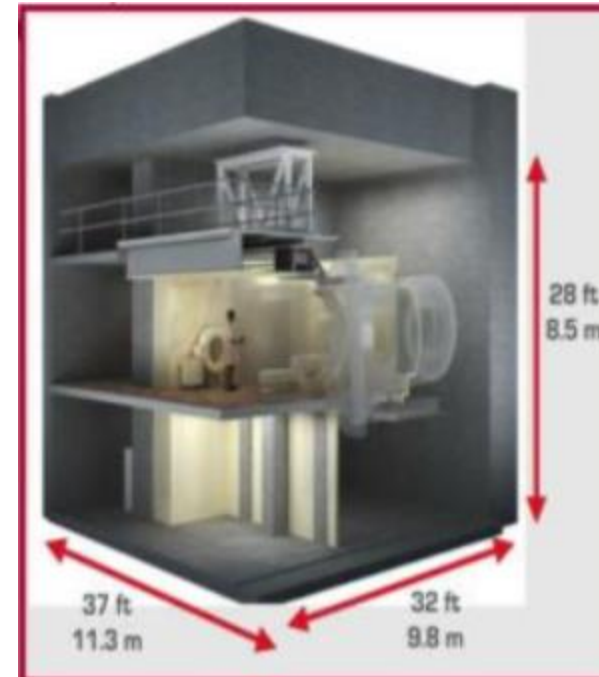


MCW Proton Beam Therapy Program

53 Operating Centers



- Needed bunker size: 1,500-2,000 sq.ft
- Concrete shielding ~6-9 feet to protect against neutron scatter
- Weight of gantry and cyclotron (produces protons) ~120 tons
 - 4,100 full kegs of beer
 - 18 African elephants
 - 1 adult blue whale



Why Protons?

- Protons are charged particles that cause direct DNA damage through double stranded breaks
 - **Not** more effective at cancer killing than photons
- **Advantage of protons due to dose distribution** and NOT radiobiology
- Protons, and other charged particles, **have a finite range**
 - **NO EXIT dose- Main advantage of proton therapy**
 - Modulate based on energy and speed of particle
 - Modulate based on density of medium particle travels through
 - Modulation to treat different depths creates the **Spread-Out Bragg Peak (SOBP)**
 - Result of same beam treating same area at different depths
 - Cumulative effect (dose) of all beams treating most distal to most proximal

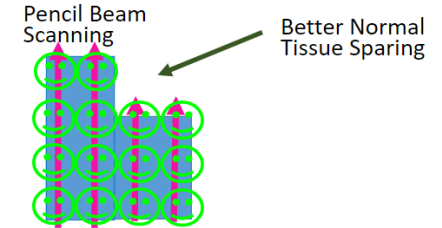
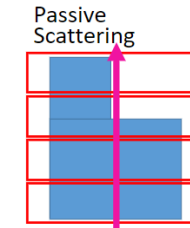
Pencil Beam Scanning

- Analogous to painting by dots
 - Dose painting inverse planning technique
- Dose can be placed more precisely around a target to spare critical organs

****Potential for significant impact on long-term health for cancer survivors depending on target location**

- i.e. brain and pituitary; kidney and bowel, mediastinum and heart or breasts, etc.

Proton General Physics



Each Arrow represents an SOBPs.

Passive Scattering: Stack Layers to Create one Large SOBPs to cover the entire target.

Pencil Beam Scanning: Each Smiley represents a spot. By Stacking Spots in column (in the BEV), individual SOBPs are created according to the width of the target at that location. Example shows 4 individual SOBPs.





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PATHWAYS TO RESILIENCE: **EXPLORING INTEGRATIVE MEDICINE IN PEDIATRIC AND AYA CANCER SURVIVORSHIP**

Adolescent & young adult
virtual survivorship conference

FRIDAY, NOVEMBER 6, 2026

8:30 a.m. - 2:30 p.m. CST



MACC Fund Center
for Cancer & Blood Disorders

Register today at
childrenswi.org/AYAsurvivorship.



PATHWAYS TO RESILIENCE: EXPLORING INTEGRATIVE MEDICINE IN PEDIATRIC AND AYA CANCER SURVIVORSHIP

Adolescent & Young Adult Survivorship Virtual Conference



MACC Fund Center
for Cancer & Blood Disorders

FRIDAY, NOV. 6, 2026

8:30 – 8:35 a.m.	Opening remarks Rachel Phelan, MD, MPH Children's Wisconsin and the Medical College of Wisconsin	12:05 - 12:35 p.m.	Break/Lunch
8:35 – 9:30 a.m.	Nutritional Challenges and Opportunities in Pediatric and AYA Cancer Survivorship Allison Grimes, MD, MSCI UT Health San Antonio	12:35 - 1:35 p.m.	Survivor panel discussion and Q&A: Integrative Medicine
9:30 – 10:25 a.m.	Advancing Integrative Medicine in Pediatric Oncology Jennifer Havens, ND, FABNO (Candidate) Children's Wisconsin and Medical College of Wisconsin	1:35 – 2:30 p.m.	Accelerated Aging in Cancer Survivors: Opportunities for Intervention Kelly Rentscher, PhD Medical College of Wisconsin
10:25 – 11:20 a.m.	Promoting Physical Activity Among Adolescent and Young Adult Cancer Survivors Jason Mendoza, MD, MPH Fred Hutch University of Washington Seattle Children's Cancer Consortium	2:30 – 2:35 p.m.	Closing remarks and wrap up Rachel Phelan, MD, MPH Children's Wisconsin and the Medical College of Wisconsin
11:20 a.m. – 12:05 p.m.	Stronger Together: Building Physical Activity Programs for Survivors Jocelyn Morin, MPH Children's Wisconsin		

Register today at
childrenswi.org/AYAsurvivorship.



Thank you



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Wisconsin

