



# SURVIVORSHIP CARE FOR CHILDHOOD AND ADOLESCENT BLOOD CANCER

**JULY 16, 2020**



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## LEARNING OBJECTIVES

- Describe an overview of long-term and late effects of treatment for childhood blood cancers
- Explain the importance of following a care plan, consultation in a survivorship program and communication between the treating pediatrician/family physician and family
- Address survivorship guidelines, including screening and management strategies
- Identify strategies and resources to support survivors, including as they continue their education

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## FACULTY

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## DISCLOSURES

*Survivorship Care for Childhood and Adolescent Blood Cancer*

**Dr. Henderson has received research grants from Seattle Genetics**

**Dr. Friedman has no affiliations to disclose**

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## OUTLINE

1. Epidemiology of childhood cancer survivorship
2. Three patient stories from leukemia and lymphoma survivors
3. Models of risk-based survivorship care
  - \* Resources for the future

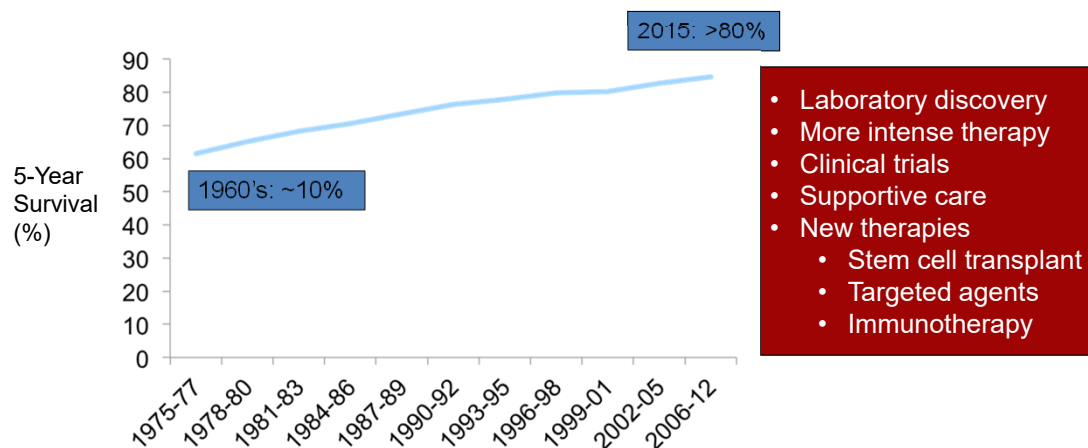
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## THE CHILDHOOD AND ADOLESCENT CANCER SUCCESS STORY



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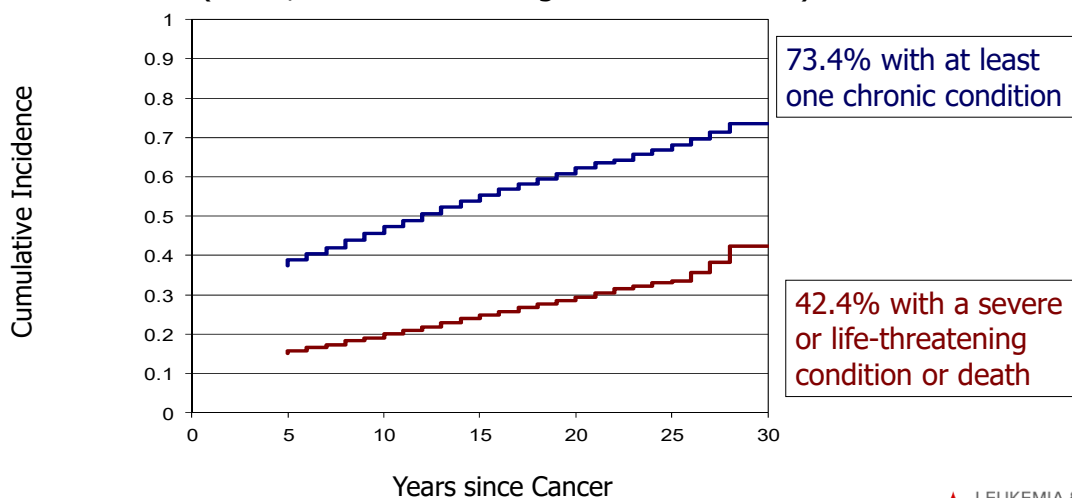
SEER Cancer Statistics, 1975-2011



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## WHAT IS THE COST OF CURE?

Childhood Cancer Survivor Study  
(n=10,397 survivors diagnosed 1970-1986)



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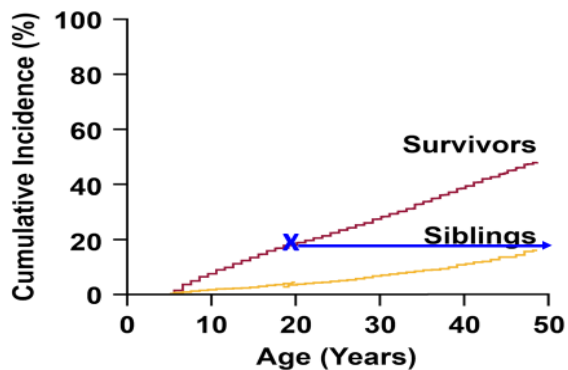
Oeffinger KC, et al. NEJM, 2006



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## SURVIVORS HAVE A PHENOTYPE OF PREMATURE AGING

Cumulative incidence of serious, disabling, life threatening chronic conditions



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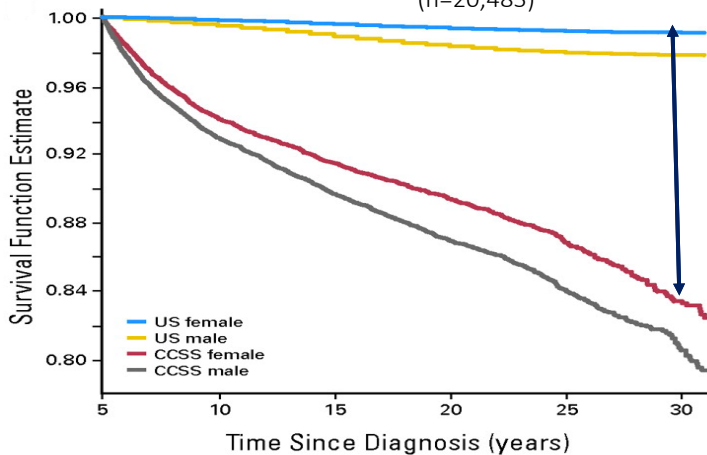
Armstrong GT, et al. JCO, 2014



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## EXCESS RISK OF EARLY MORTALITY PERSISTS OVER TIME

Childhood Cancer Survivor Study  
(n=20,483)



### Cause-specific mortality

- ❖ Subsequent malignancy (SMR = 15.2)
- ❖ Cardiac (SMR = 7.0)
- ❖ Other medical causes (SMR = 2.6)

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Mertens AC, et al. JNCI, 2008  
SMR=standardized mortality ratio



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## CHILDHOOD AND ADOLESCENT CANCER SURVIVORSHIP: A NEW CHRONIC DISEASE PARADIGM

- Distinct from classic chronic disease
- Once cured, often no signs of sequelae for many years
- Traditional chronic disease model inadequate to describe evolution of health issues and premature aging in survivors

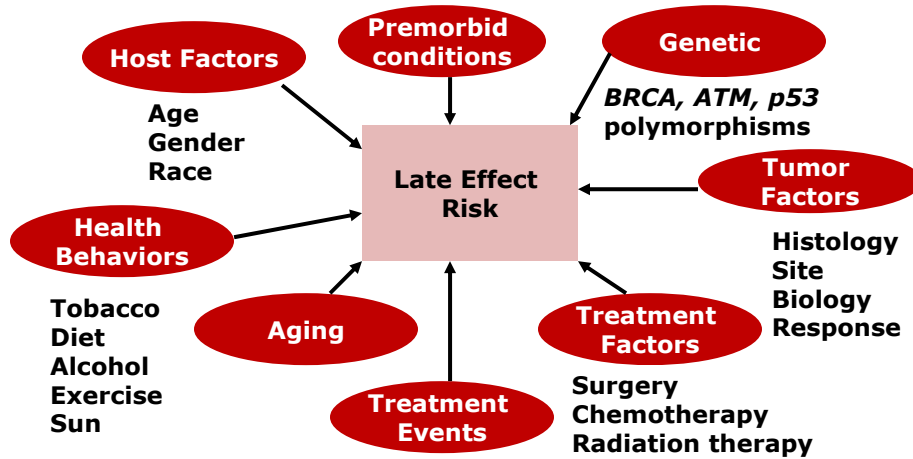
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Oeffinger & Robison, JAMA 2007



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## WHAT CONTRIBUTES TO LATE EFFECTS AFTER CANCER?



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Hudson M, *Cancer*, 2005



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**What are some of the long-term problems, or “late effects,” that can result from being diagnosed and treated for blood cancer during childhood and adolescence?**

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## LATE EFFECTS: PHYSICAL

<b>Growth and Development</b> Linear growth Skeletal maturation Intellectual function Emotional/social maturation Sexual development	<b>Organ Function</b> Cardiac Pulmonary Endocrine GI/Hepatic Genitourinary Musculoskeletal Neurocognitive Neurologic Neurosensory
	<b>Cancer</b> Recurrent (primary) Second cancers
<b>Fertility and Reproduction</b> Sexual function Fertility Health of offspring	

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## LATE EFFECTS: PSYCHOLOGICAL

<b>Mental Health</b> - Depression/mood disorders - Cancer-related anxiety - Post-traumatic stress <b>Physical/Body image</b> - Weight loss/gain - Loss of organs/tissues	<b>Education/Vocation</b> - Academic underachievement - Vocational limitations - Under/unemployment - Loss of job/benefits <b>Insurance Discrimination</b> - Access to health care <b>Financial Toxicity</b> - Debt (medical/other)
	<b>Social Interaction</b> - Family/peer relationships - Social withdrawal/isolation - Intimacy/marriage/family - Cancer-related stigma
<b>Chronic Symptoms</b> - Fatigue/ Low energy - Disrupted sleep - Poor memory/concentration - Chronic pain <b>Self-care</b> - Independent living	


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System	Exposure	Potential Late Effects
<b>Cardiac</b>	Chest radiation Anthracyclines	Valvular disease Pericarditis Myocardial infarction Congestive heart failure
<b>Pulmonary</b>	Radiation therapy CCNU/BCNU Bleomycin	Restrictive lung disease
<b>Endocrine</b>	Cranial radiation Total body irradiation High-dose alkylating agents	Hypothalamic-pituitary dysfunction: GH deficiency, ACTH deficiency, FSH/LH deficiency, TSH deficiency Thyroid dysfunction Ovarian or testicular dysfunction
<b>Metabolic</b>	Abdominal radiation Total body irradiation Cranial radiation	Diabetes mellitus Metabolic syndrome Obesity
<b>Hearing</b>	Platinum agents, cranial radiation	Hearing loss
<b>Renal</b>	Surgery (nephrectomy) Radiation therapy Platinum agents Cyclophosphamide/ifosfamide	Renal insufficiency or failure
<b>Neurocognitive</b>	Cranial radiation Young age at treatment High-dose methotrexate	Learning disabilities Cognitive dysfunction
<b>Subsequent malignancies</b>	Alkylating agents Epipodophyllotoxins Radiation therapy	Leukemias Solid tumors

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**Three Patient Stories**

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 LEUKEMIA & LYMPHOMA SOCIETY

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## STORY 1...

*14-year old male* has been referred to long-term follow up 3 years after completing treatment for standard risk ALL which was diagnosed at age 9.

He received 3 years of multiagent chemotherapy which included low doses of anthracycline, vincristine, cyclophosphamide, asparaginase, 6-MP, methotrexate and steroids.

In taking his history, he notes that he has developed hip pain in the last month and his grades in school have been B's and C's.

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## WHAT TESTS SHOULD HIS PROVIDER ORDER TO INVESTIGATE HIS HIP PAIN/BONY PROBLEMS?

- A. Serum calcium
- B. DEXA scan
- C. Hip x-ray
- D. Parathyroid hormone

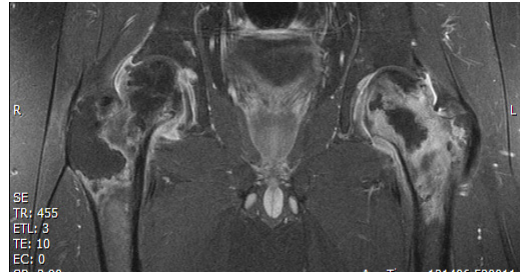
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## SKELETAL COMPLICATIONS

- Osteonecrosis
  - Associated with:
    - Older age
    - Exposure to steroids
    - Exposure to methotrexate
    - Genetics
- Low bone mineral density
  - DEXA scans generally not recommended before age 18 years (results not standardized for pediatric patients)
  - Associated with:
    - Older age
    - Exposure to steroids
    - Exposure to methotrexate



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## HOW SHOULD THE PROVIDER ADDRESS SCHOOL ISSUES?

- A. Don't worry about it, he's a normal kid
- B. Refer to neuropsychology
- C. Screen for depression and anxiety
- D. Both B and C

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## LEARNING PROBLEMS

- Seen most commonly in those treated with radiation to the brain
- Risk is greatest in individuals under age 3-5 years at treatment
- Special neuropsychological testing required with serial educational/vocational assessments over time

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## NEUROPSYCHOLOGICAL OUTCOMES

- Executive functioning (planning, organization, problem solving - not IQ!)
  - Exposure to steroids
  - Exposure to methotrexate
  - Genetics
  - Early screening and social work intervention with schools
- Higher prevalence of adverse psychosocial outcomes in childhood cancer survivors
  - Depression and anxiety
  - Anger
  - Socially withdrawn
  - Early screening and referral to counseling and mental health providers

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## STORY 2...

**11-year old female treated for high-risk Acute Lymphoblastic Leukemia when she was 4 years old presenting for LTFU**

She received combination chemotherapy followed by allogeneic stem cell transplantation

- Cytoreduction included **cyclophosphamide, thiotepa,** and **total body irradiation [TBI]** (1375 cGy)

**Missed last year's visit because she felt so well...**

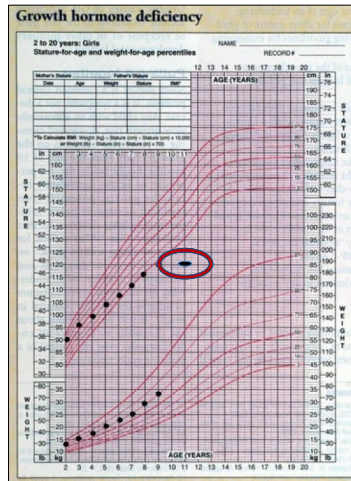


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## GROWTH CURVE AT TODAY'S VISIT



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## WHAT ARE YOUR CONCERNS FOR THIS PATIENT?

- A. Growth hormone deficiency
- B. Primary hypothyroidism
- C. CBC is normal. No concerns.
- D. Both A and B

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### Transplant Population

Prior therapy

Preconditioning  
chemotherapy

TBI

Post SCT chemo

GVHD

### Potential Late Effects

- Endocrinopathies
  - Osteoporosis
  - Osteonecrosis
- Gonadal dysfunction
- Insulin resistance/dyslipidemia
  - Renal insufficiency
- Pulmonary complications
  - Cataracts
- Oral/dental problems
- Gait and balance disturbances

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## Transplant Population

Prior therapy

Preconditioning  
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**TBI**

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## **LATE EFFECTS: ENDOCRINE COMPLICATIONS**

- Most prevalent late effects in survivors of childhood cancer
- Observed in 40-60% of survivors followed into adulthood
- Most often seen in survivors treated with:
  - Radiation impacting the brain (including TBI)
  - High-dose alkylating agents

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## POOR LINEAR GROWTH (1)

### Growth hormone deficiency (endocrine):

- Common after radiation doses  $\geq 18$  Gy impacting the brain
- Children treated with total body irradiation (TBI) doses  $\geq 12$  Gy are also at risk
- Screening: Height should be plotted every 6 months on standardized growth curves and pubertal development should be monitored
- Those with the above risk factors and poor growth rate should undergo formal growth hormone stimulation testing

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## POOR LINEAR GROWTH (1)

### Impaired spinal growth (non-endocrine):

- Patients treated with spinal and/or total body irradiation may demonstrate stunted spinal growth
  - Becomes most apparent during puberty
- Due to radiation-induced direct damage to the growth plate, usually the vertebrae
- Monitor serial sitting heights
  - No clear data on utility of treatment

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## THYROID DYSFUNCTION

- Common after radiation to the neck
- Associated with tyrosine kinase inhibitor exposure (sunitinib, imatinib, etc)
- Risk increases with higher radiation doses
- Risk increases over time
- Screening: Annual TSH
- Easily treated with a single daily pill (levothyroxine)

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## GONADAL DYSFUNCTION

- Risk greatest after:
  - Radiation to the ovaries (or testes for boys)
  - Treatment with high doses of alkylating agents (cyclophosphamide, procarbazine, busulfan, thiotepa)
- In girls, younger age at treatment is protective
- Screening: Monitor serial blood tests of ovarian function as well as pubertal development, menstrual regularity
- Post-treatment egg freezing may be an option for menstruating females

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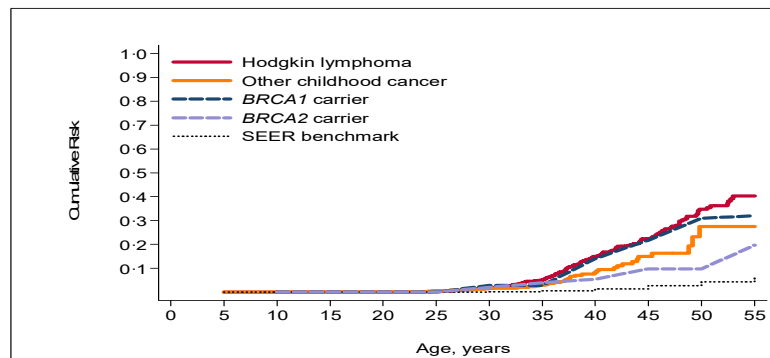
## STORY 3...

26-year old female seeking to establish care in your practice  
 Recently moved to NYC from California  
 History notable for diagnosis of *Hodgkin lymphoma, Stage IIB, Nodular Sclerosing* at age 11

Treatment included multiagent chemotherapy and mantle radiation (25 Gy)

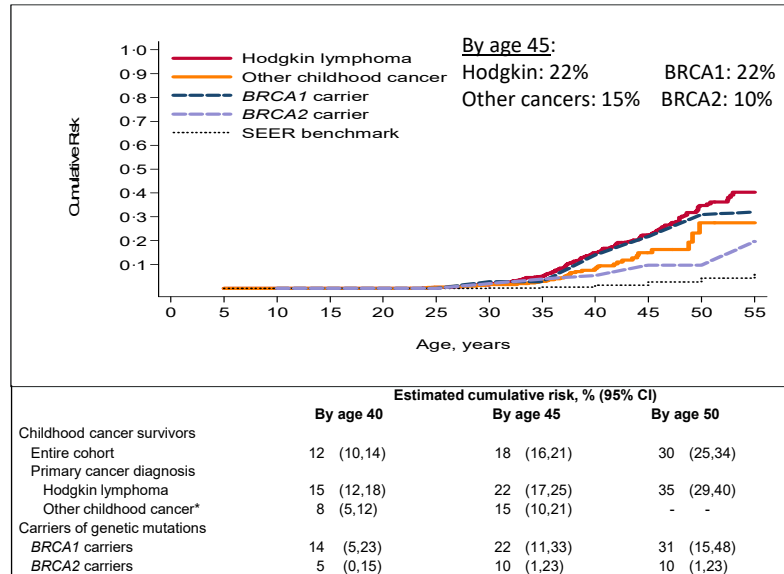
On exam, you palpate a breast mass...

## BREAST CANCER AFTER CHEST RADIATION



	Estimated cumulative risk, % (95% CI)		
	By age 40	By age 45	By age 50
Childhood cancer survivors			
Entire cohort	12 (10,14)	18 (16,21)	30 (25,34)
Primary cancer diagnosis			
Hodgkin lymphoma	15 (12,18)	22 (17,25)	35 (29,40)
Other childhood cancer*	8 (5,12)	15 (10,21)	-
Carriers of genetic mutations			
BRCA1 carriers	14 (5,23)	22 (11,33)	31 (15,48)
BRCA2 carriers	5 (0,15)	10 (1,23)	10 (1,23)

## BREAST CANCER AFTER CHEST RADIATION



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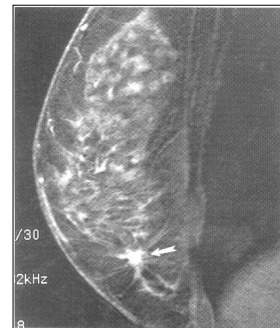
Moskowitz CS, et al. *JCO*, 2014



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## BREAST CANCER SCREENING GUIDELINES AFTER CHEST RADIATION

- For all females exposed to chest-directed radiation (including TBI):
  - **Clinical breast exam** by a health care provider annually from puberty to age 25; then every 6 months after age 25
  - **Annual breast MRI and mammogram** beginning at age 25 or 8 years after completion of therapy, whichever occurs later



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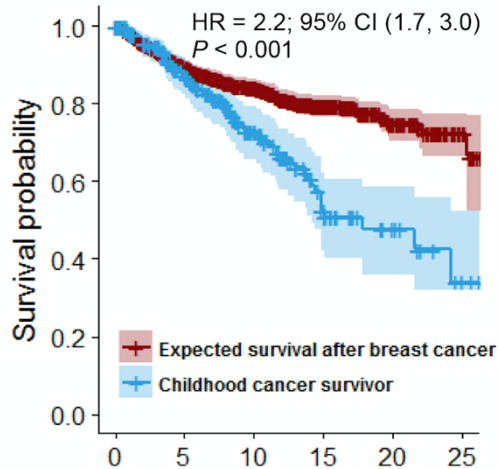
[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)



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## BREAST CANCER MORTALITY



- Comparing 274 childhood cancer survivors with breast cancer to 1095 women with *de novo* breast cancer:
  - Breast cancer specific mortality modestly elevated (HR=1.3, 95% CI 0.9-2.0)
  - 5 times (HR=5.5, 95% CI 3.4-9.0) more likely to die of other health-related causes
    - SMN
    - Cardiovascular disease
    - Pulmonary disease

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Moskowitz et al J Clin Oncol 2019.



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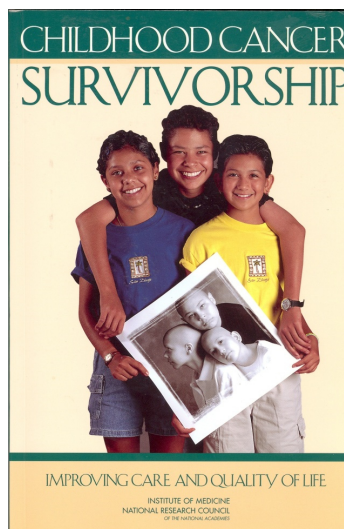
**How do we ensure that the health care of childhood and adolescent blood cancer survivors is maximized..... so health risks are minimized, and quality of life is optimal?**

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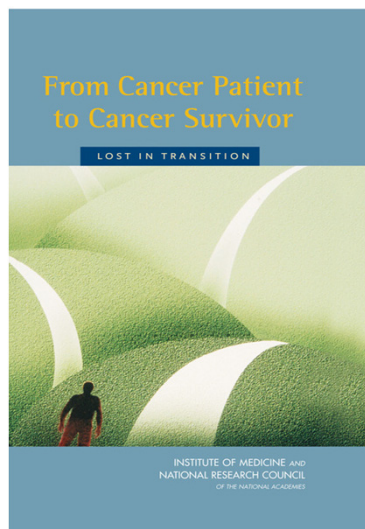


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## INSTITUTE OF MEDICINE CALL TO ACTION



2003



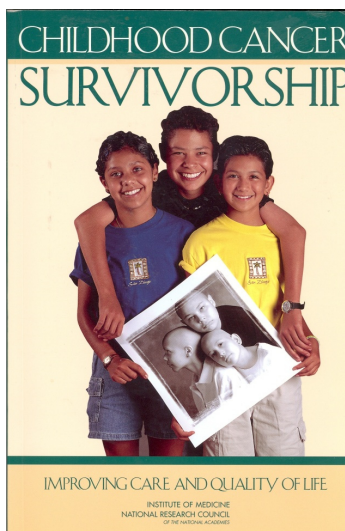
2005

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## INSTITUTE OF MEDICINE CALL TO ACTION



2003

### 2003 Recommendations:

- Risk-based health care
  - Monitor for cancer recurrence
  - Surveillance and intervention for late effects and second cancers
- Prevention/education
  - Lifestyles, health behaviors
  - Education
  - Assistance with financial challenges

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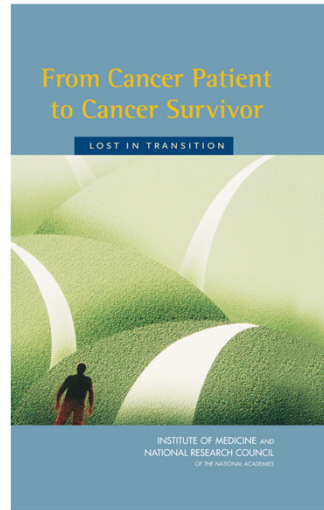


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# INSTITUTE OF MEDICINE CALL TO ACTION

## 2005 Recommendations:

- Survivorship Care Plan for all cancer survivors
  - Roadmap for post-treatment care
  - Created by oncology provider
  - For survivor, primary care providers



2005

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CHILDREN'S

world's childhood cancer experts

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- 166 sections detailing exposure-based potential late effects and screening recommendations
- Grading of evidence linking exposure to potential late effect
- Second (adult) cancer screening recommendations for standard and high-risk groups
- Health Links for patient education

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Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation	Health Counseling/ Further Considerations																								
33	<p><b>Anthracycline Antibiotics</b> Daunorubicin Doxorubicin Epirubicin Idarubicin Mitoxantrone</p> <p><b>Dose Conversion</b> To gauge the frequency of screening, use the following formulas to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose. Clinical judgment should ultimately be used to determine indicated screening for individual patients. Doxorubicin: Multiply total dose x 1 Daunorubicin: Multiply total dose x 0.5 Epirubicin: Multiply total dose x 0.67 Idarubicin: Multiply total dose x 5 Mitoxantrone: Multiply total dose x 4</p>	<p>Cardiac toxicity Cardiomyopathy Subclinical left ventricular dysfunction Congestive heart failure Arrhythmia</p>	<p><b>HISTORY</b> Shortness of breath Dyspnea on exertion Orthopnea Chest pain Palpitations If under 25 yrs: abdominal symptoms (nausea, vomiting) Yearly</p> <p><b>PHYSICAL</b> Blood pressure Cardiac exam Yearly</p> <p><b>SCREENING</b> ECHO (or comparable imaging to evaluate cardiac function)</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-bottom: 10px;"> <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</td> <td>&lt; 15 Gy or none</td> <td>No screening</td> </tr> <tr> <td></td> <td>≥ 15 &lt; 35 Gy</td> <td>Every 5 years</td> </tr> <tr> <td></td> <td>≥ 35 Gy</td> <td>Every 2 years</td> </tr> <tr> <td>&lt; 250 mg/m<sup>2</sup></td> <td>&lt; 15 Gy or none</td> <td>Every 5 years</td> </tr> <tr> <td></td> <td>≥ 15 Gy</td> <td>Every 2 years</td> </tr> <tr> <td>≥ 250 mg/m<sup>2</sup></td> <td>Any or none</td> <td>Every 2 years</td> </tr> </tbody> </table> <p><small>*Based on daunorubicin isotoxic equivalent dose. See dose conversion instructions in section 33. **Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole], TB). See section 75.</small></p> <p><b>EKG (include evaluation of QTc interval)</b> Baseline at entry into long-term follow-up, repeat as clinically indicated</p>	Recommended Frequency of Echocardiogram			Anthracycline Dose*	Radiation Dose**	Recommended Frequency	None	< 15 Gy or none	No screening		≥ 15 < 35 Gy	Every 5 years		≥ 35 Gy	Every 2 years	< 250 mg/m <sup>2</sup>	< 15 Gy or none	Every 5 years		≥ 15 Gy	Every 2 years	≥ 250 mg/m <sup>2</sup>	Any or none	Every 2 years	<p><b>HEALTH LINKS</b> Heart Health Cardiovascular Risk Factors Diet and Physical Activity</p> <p><b>COUNSELING</b> Maintain appropriate weight, blood pressure and heart-healthy diet. Regarding exercise: - Regular exercise is generally safe and should be encouraged for patients who have normal LV systolic function. - Survivors with asymptomatic cardiomyopathy should consult cardiology to define limits and precautions for physical activity. - Cardiology consultation may be reasonable to define limits and precautions for physical activity for high risk survivors (i.e., those requiring an ECHO every 2 years) who plan to participate in intensive exercise. If QTc interval is prolonged: Caution regarding use of medications that may further prolong the QTc interval (e.g., tricyclic anti-depressants, antifungals, macrolide antibiotics, metronidazole).</p> <p><b>POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION</b> Cardiac MRI as an adjunct imaging modality when echocardiographic images are suboptimal. Cardiology consultation in patients with subclinical abnormalities on screening evaluations, left ventricular dysfunction, dysrhythmia, or prolonged QTc interval. Female patients only: For patients who are pregnant or planning to become pregnant, additional cardiology evaluation is indicated in patients who received: - ≥250 mg/m<sup>2</sup> anthracyclines - ≥35 Gy chest radiation, or - Anthracycline (any dose) combined with chest radiation (≥15 Gy) Evaluation should include a baseline echocardiogram (pre- or early-pregnancy). For those without prior abnormalities and with normal pre- or early-pregnancy baseline echocardiograms, follow-up echocardiograms may be obtained at the provider's discretion. Those with a history of systolic dysfunction or with pre- or early-pregnancy systolic dysfunction are at highest risk for pregnancy-associated cardiomyopathy. Such individuals should be monitored periodically during pregnancy and during labor and delivery due to increased risk for cardiac failure.</p> <div style="text-align: center; background-color: #2e7d32; color: white; padding: 5px; margin-top: 10px;"> <b>SYSTEM = Cardiovascular SCORE = 1</b> </div>
Recommended Frequency of Echocardiogram																												
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<p><b>Additional Information</b></p> <p>Although Mitoxantrone technically belongs to the anthracenedione class of anti-tumor antibiotics, it is related to the anthracycline family and is included in this section because of its cardiotoxic potential.</p>																												

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## Are survivors receiving risk-based health care, such as early breast cancer screening for women exposed to chest radiation, after treatment for childhood blood cancer?

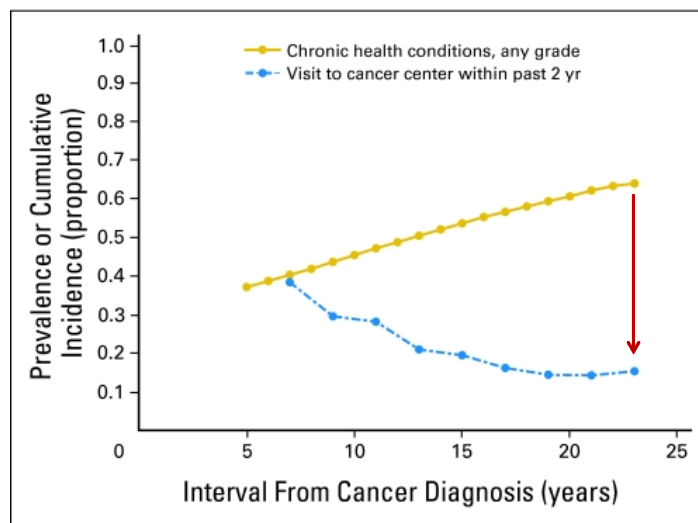
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## MOST SURVIVORS ARE NOT FOLLOWED IN A CANCER CENTER



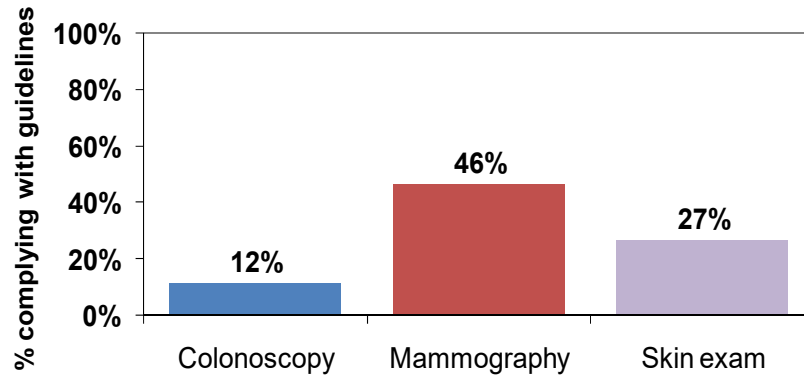
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Nathan PC, et al. JCO, 2009



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## HIGH-RISK SURVIVORS ARE NOT COMPLIANT WITH GUIDELINES



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*Nathan et al. Ann Intern Med. 2010.*



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## Are physicians aware of available long-term follow-up guidelines for childhood and adolescent blood cancer survivors?

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## PERSPECTIVES ON SURVIVORSHIP CARE

- In a recent survey of 1110 internists, on average, primary care providers reported being:
  - **“Somewhat uncomfortable”** caring for childhood cancer survivors
  - **“Somewhat unfamiliar”** with available surveillance guidelines

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Suh E, et al. *Ann Intern Med*, 2014



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## PERSPECTIVES ON SURVIVORSHIP CARE: PCPS

- However, in response to a clinical vignette:
  - **90.6%** of respondents did not appropriately recommend yearly breast cancer surveillance
  - **85.1%** did not appropriately recommended cardiac surveillance
  - **23.6%** did not appropriately recommend yearly thyroid surveillance

**Table 2. Clinical Vignette Questions and Physician Responses**

Question and Answer Choices	Responses, n (%)†
<b>Breast cancer surveillance</b>	
In thinking about C.L.'s medical care, how would you approach breast cancer screening?	
I would follow current accepted guidelines for average-risk individuals and ask her to begin yearly mammograms when she turns 50.	220 (20.0)
I would recommend yearly mammograms starting this year.*	196 (17.8)
I would recommend every-other-year mammograms starting this year.	123 (11.2)
I would recommend yearly breast magnetic resonance imaging and mammograms starting this year.*	103 (9.4)
Don't know or unsure	458 (41.6)
Missing	10
<b>Cardiac surveillance</b>	
You see that C.L. had an echocardiogram 5 years after chemotherapy. The echocardiogram was normal. How would you approach cardiac care for this patient?	
I would not proceed with further testing.	567 (51.5)
I would refer her at this time to a cardiologist for evaluation and stress testing.	81 (7.4)
I would recommend every-other-year echocardiogram.*	164 (14.9)
I would recommend yearly echocardiogram.	85 (7.7)
Don't know or unsure	205 (18.6)
Missing	8
<b>Thyroid surveillance</b>	
You review C.L.'s past laboratory results and see that she has undergone yearly thyroid function tests. They have all been normal. What would be your approach to thyroid screening?	
I would repeat thyroid-stimulating hormone and free thyroxine test and plan to check both yearly.*	843 (76.4)
I would check thyroid-stimulating hormone this year and then discontinue if test is normal.	56 (5.1)
I would discontinue thyroid function tests since they have been normal.	70 (6.3)
Don't know or unsure	135 (12.2)
Missing	6

\* Correct answers.  
† Percentages were not calculated for answers deemed "missing."

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Suh E, et al. *Ann Intern Med*, 2014

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## PERSPECTIVES ON SURVIVORSHIP CARE: PCPS

- However, in response to a clinical vignette:
  - **90.6%** of respondents did not appropriately recommend breast cancer surveillance
  - **85.1%** did not appropriately recommend yearly thyroid surveillance
  - **23.6%** did not appropriately recommend yearly thyroid surveillance

**5.4%**  
answered in full accordance with  
COG guidelines

*Table 2. Clinical Vignette Questions and Physician Responses*

Question and Answer Choices	Responses, n (%) <sup>*</sup>
<b>Breast cancer surveillance</b>	
In thinking about C.L.'s medical care, how would you approach breast cancer screening?	
I would follow current accepted guidelines for average-risk individuals and ask her to begin yearly mammograms when she turns 50.	220 (20.0)
I would not proceed with further testing.	196 (17.8)
I would refer her at this time to a cardiologist for evaluation and stress testing.	123 (11.2)
I would recommend every-other-year echocardiogram. <sup>†</sup>	103 (9.4)
I would recommend yearly echocardiogram.	458 (41.6)
Don't know or unsure	10
Missing	8
<b>Thyroid surveillance</b>	
You review C.L.'s past laboratory results and see that she has undergone yearly thyroid function tests. They have all been normal. What would be your approach to thyroid screening?	
I would repeat thyroid-stimulating hormone and free thyroxine test and plan to check both yearly. <sup>*</sup>	843 (76.4)
I would check thyroid-stimulating hormone this year and then discontinue if test is normal.	56 (5.1)
I would discontinue thyroid function tests since they have been normal.	70 (6.3)
Don't know or unsure	135 (12.2)
Missing	6

<sup>\*</sup> Correct answers.  
<sup>†</sup> Percentages were not calculated for answers deemed "missing."

BEATING CANCER IS IN OUR BLOOD. Suh E, et al. *Ann Intern Med*, 2014

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## SIGNIFICANT GAPS IN PROVIDER KNOWLEDGE

**AYA Hodgkin Lymphoma Survivor Vignette**

Responses Concordant with COG Guidelines	General Internists (N=1110)	Family Physicians (N=1124)	Pediatric Oncologists (N=665)
Breast cancer screening	27%	16%	66%
Thyroid screening	76%	74%	76%
Cardiac screening	15%	10%	57%
<b>Total</b>	<b>5%</b>	<b>2%</b>	<b>33%</b>

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Henderson, et al. *J Clin Oncol* 2010; Nathan P, et al. *J Cancer Surv* 2013; Suh E et al, *Ann Intern Med* 2014



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## How do we overcome barriers to survivors receiving risk-based health care?



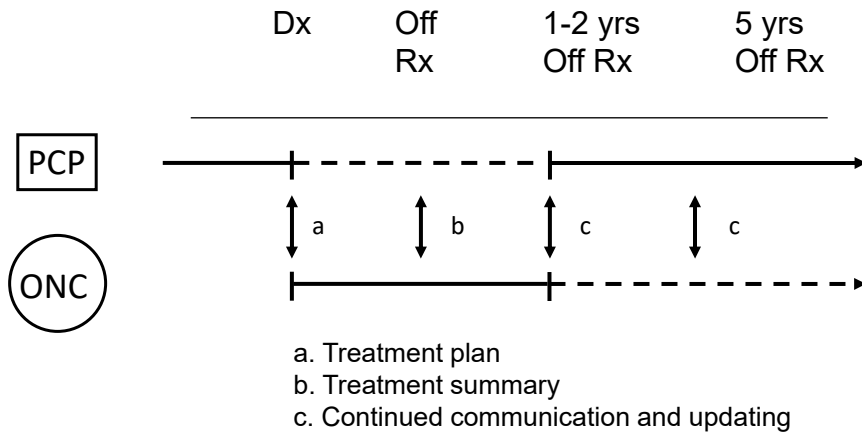
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## STRATIFIED CARE OF LOW-RISK SURVIVORS



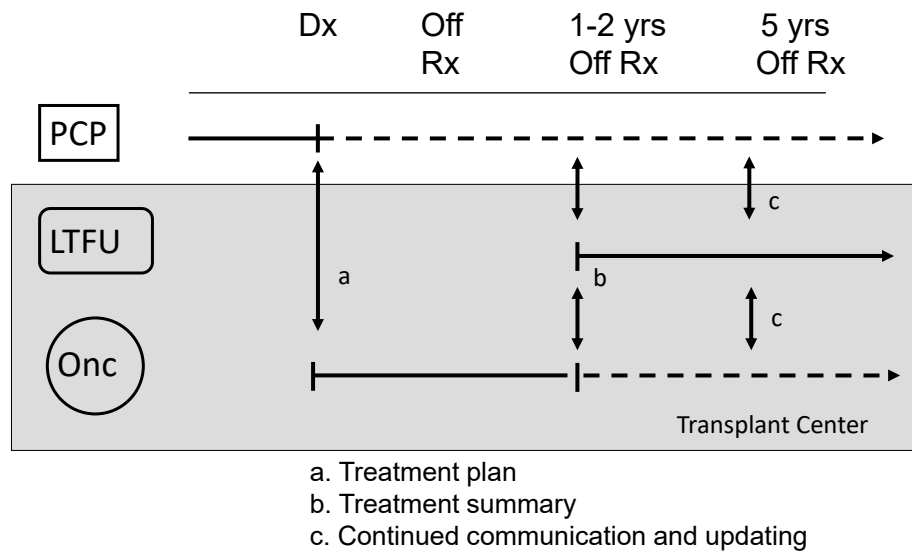
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Oeffinger KC et al, ASCO Ed Book, 2014



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## STRATIFIED CARE OF HIGH-RISK SURVIVORS



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## STRATEGIES FOR OPTIMIZING CARE

- Provide longitudinal, stratified risk-based health care for survivors of childhood blood cancer
  - Dedicated LTFU Programs
  - Partnerships with local providers
- Investigate the health outcomes and health care needs of this population
  - Research is key!
- Educate health care professionals regarding health care of survivors
  - More sessions like this one!

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# CANCER TREATMENT SUMMARY

SUMMARY OF CANCER TREATMENT			
Date of preparation: 01/25/05			
Name: Jane Doe		Date of Birth: 01/01/1961	
Cancer Diagnosis: Hodgkin's Lymphoma			
Treatment Center: Children's Hospital of Philadelphia			
Date of Diagnosis: 01/01/1976		Age at Diagnosis: 14 years	
Date of Completion of Therapy: 06/01/1976			
Surgery			
Date	Procedure		
01/20/1976	Biopsy of node		
02/10/1976	Exploratory laparotomy Open liver biopsy Splenectomy Multiple lymph node biopsies Biopsy of bone marrow		
Radiation Therapy			
Date start	Date Stop	Field	Dose (cGy)
03/01/1976	03/24/1976	Neck/Chest	3600
Chemotherapy			
Drug Name	Dose (units or mg/m <sup>2</sup> )		
Cyclophosphamide (Cytosan)	Yes - 6528 mg/m <sup>2</sup>		
Prednisone	Yes		
Procarbazine	Yes - 7241 mg/m <sup>2</sup>		
Vincristine	Yes		
Screening Recommendations			
Any cancer history	Complete physical exam every year		
Second cancers, especially breast cancer	Inspection and palpation of irradiated skin and soft tissues every year. Breast self-exam every month Clinician breast exam every 6 months Mammogram every year starting at age 25		
Heart problems	Baseline EKG at 2 or more years after completion of therapy Echocardiogram every 2 years		
Lung problems	Baseline pulmonary function tests at 2 or more years after completion of therapy		
Thyroid problems	Thyroid profile (free T <sub>4</sub> and TSH) every year		
Life-threatening infection	Seek medical attention with fever 101°F for blood culture and antibiotics.		

\*\*Screening recommendations from the CureSearch Children's Oncology Group Long-Term Follow-Up Guidelines at <http://www.survivorshipguidelines.org>.  
See Project Vision website [www.netresolutions.com/ocsvic](http://www.netresolutions.com/ocsvic) for further information about health risks following treatment for Hodgkin's disease.

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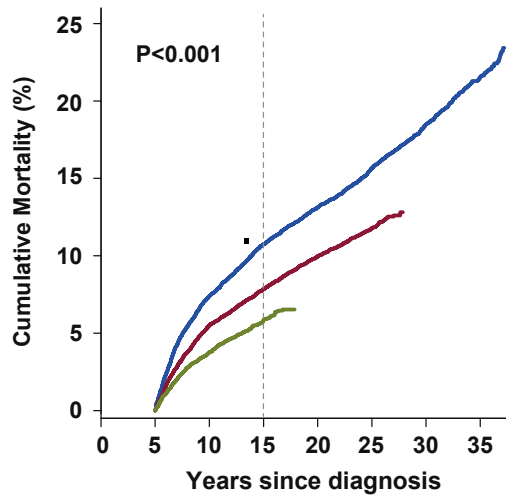
How does the understanding of long-term outcomes of cancer survivors impact cancer treatments?

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## WE ARE DOING BETTER WITH MODERN THERAPIES



### 15-Year Cumulative Mortality

**1970s**  
10.7% (10.1 - 11.4)

**1980s**  
7.9% (7.4 - 8.3)

**1990s**  
5.8% (5.4 - 6.3)

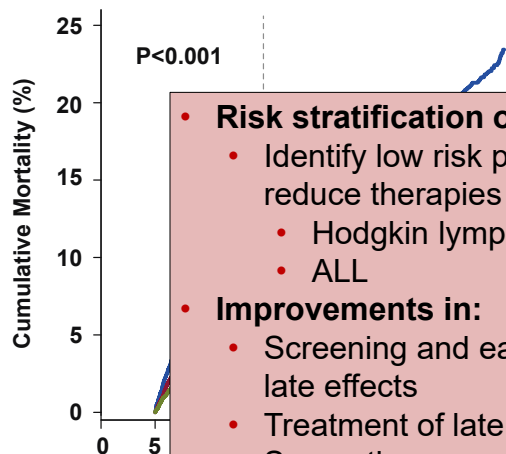
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Armstrong GT et al. *NEJM* 2016.



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## WE ARE DOING BETTER WITH MODERN THERAPIES



### 15-Year Cumulative Mortality

**1970s**  
10.1 - 11.4)

**1980s**  
7.4 - 8.3)

**1990s**  
5.4 - 6.3)

- **Risk stratification of therapy**
  - Identify low risk patients and reduce therapies
    - Hodgkin lymphoma
    - ALL
- **Improvements in:**
  - Screening and early detection of late effects
  - Treatment of late effects
  - Supportive care

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Armstrong GT et al. *NEJM* 2016.



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## SUMMARY

- Survivors of childhood and adolescent blood cancer face lifelong, long-term risks
- Many late effects are modifiable
- Goal of risk-based survivor care:
  - Reduce morbidity and mortality
  - Enhance quality of life
- Importance of shared-care model involving oncologist/survivorship team, primary care provider, and the patient/family

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## RESOURCES FOR HCPS

- ❑ Free CME & CE courses – [www.LLS.org/CE](http://www.LLS.org/CE)
- ❑ Podcasts – [www.LLS.org/HCPpodcast](http://www.LLS.org/HCPpodcast)
- ❑ Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment – [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected)



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## RESOURCES FOR HCPS AND PATIENTS

- ❑ LLS Online Community  
HCP, Patient/Survivor & Caregiver account types:  
[www.LLS.org/community](http://www.LLS.org/community)
  
- ❑ LLS Children's Initiative: Cures & Care for Children  
\$100 million multi-year endeavor to attack pediatric blood cancer
  
- ❑ Global precision medicine clinical trial/pediatric acute leukemia in collaboration w/NCI & COG:  
[www.LLS.org/PedAL](http://www.LLS.org/PedAL)



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## FOR PATIENTS AND CAREGIVERS

- ❑ Follow-up care for childhood cancer survivors  
[www.LLS.org/ChildhoodFollowUp](http://www.LLS.org/ChildhoodFollowUp)
  
- ❑ Childhood & YA cancer resources  
[www.LLS.org/ChildhoodYAResources](http://www.LLS.org/ChildhoodYAResources)
  
- ❑ Education programs – web, video, telephone  
[www.LLS.org/Programs](http://www.LLS.org/Programs) & [www.LLS.org/Educationvideos](http://www.LLS.org/Educationvideos)
  
- ❑ Support: [www.LLS.org/Support](http://www.LLS.org/Support)
  - ❑ Financial Assistance, Referral to Medication Access programs
  - ❑ Online chats (Live, weekly, for Caregivers, Young Adults)
  - ❑ Peer-to-Peer First Connection Program
  - ❑ One-On-One Free Nutrition Consultations



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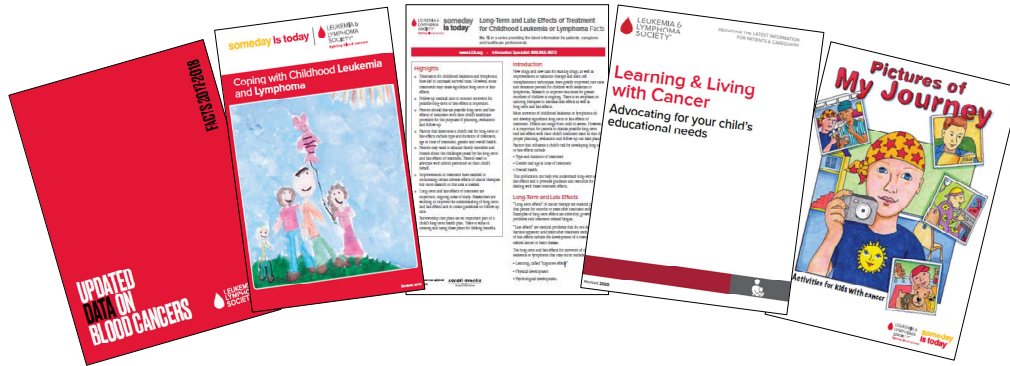
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## FREE GUIDES, BOOKLETS, AND FACT SHEETS

For Patients, Caregivers and Professionals

[www.LLS.org/Booklets](http://www.LLS.org/Booklets)



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## ADDITIONAL RESOURCES

**Information Resource Specialists:** one on-one information & support on treatment, financial & psychosocial resources [www.LLS.org/IRC](http://www.LLS.org/IRC)

**Clinical Trial Nurse Navigators:** RNs with expertise in blood cancers work one-on-one with patients, caregivers or HCPs, or You can Refer a patient [www.LLS.org/CTSCreferral](http://www.LLS.org/CTSCreferral)



*An extension of your team, providing support to you & your patients*

- ☐ Phone: (800) 955-4572, M-F, 9 am to 9 pm ET
- ☐ Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)
- ☐ Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

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# CDN'S PRIMARY ACTIVITIES

## RESEARCH

We accelerate research translation. CDN has over 25 years of experience developing, conducting, implementing and evaluating practice-based research with Community Health Centers and other safety-net practices.

## EDUCATION

We provide peer support through training and education that integrates online and on-site didactic and experiential learning. Collaborate with us to meet your training needs.



## PARTNERSHIP

We conduct research and educational activities in partnership with government, academic, not-for-profit, and for-profit organizations. CDN has an extensive network of multidisciplinary researchers, clinicians, clinical leaders and policy-makers.

## DISSEMINATION

We provide dissemination services through webcasts for public health and clinical research projects. CDN has extensive experience disseminating research and training programs to our extensive network of multidisciplinary researchers, clinicians, clinical leaders and policy-makers.



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## CDN WEBCASTS, DISSEMINATION, TRAINING, SUPPORT TOOLS & CONTINUING MEDICAL EDUCATION (CME)

TRANSLATING PRACTICE INTO RESEARCH™

SUMMER 2020

### UPCOMING WEBINAR SCHEDULE

### PREVIOUS TOWN HALLS/WEBINARS

**Thursday, July 16, 2020, 1:00 PM - 2:00 PM ET**  
**Survivorship Care for Childhood and Adolescent Blood Cancer**  
**Presenters:** Tara O. Henderson, MD, MPH, FASCO, Professor of Pediatrics, Director, Childhood, Adolescent and Young Adult Survivorship Center, Cancer Survivorship and Co-Leader, Cancer Prevention and Control Program, Comprehensive Cancer Center, The University of Chicago, Chicago, IL  
 Danielle Novetsky Friedman, MD, MS, Assistant Member, Pediatric Long-Term Follow-Up Program, Memorial Sloan Kettering Cancer Center, New York, NY  
**Sponsored by:** The Leukemia & Lymphoma Society (LLS) and Clinical Directors Network, Inc. (CDN)

**Friday, July 17, 2020, 12:00 PM - 1:00 PM ET**  
**Opioid Prescribing in the Era of COVID-19**  
**Presenter:** Joanna L. Starrels, MD, MS, FACP, Associate Professor of Medicine, Division of General Internal Medicine, Albert Einstein College of Medicine and Montefiore Medical Center  
 Hector R. Perez, MD, MS, Assistant Professor of Medicine, Division of General Internal Medicine, Albert Einstein College of Medicine and Montefiore Medical Center  
**Sponsored by:** The Opioid Post-Marketing Requirements Consortium (OPC), Syneos Health™, N<sup>o</sup>. Virtual Training Series (AHRQ, Grant No. 1P30-HS-021667) and Clinical Directors Network, Inc. (CDN)

**Tuesday, July 21, 2020, 1:00 PM - 2:00 PM ET**  
**Sex in the Time of COVID-19**  
**Presenter:** Kenneth H. Mayer, M.D. Medical Research Director, Fenway Health, Co-Director, The Fenway Institute, Professor of Medicine, Harvard Medical School, Attending Physician, Infectious Disease Division, Beth Israel Deaconess Hospital  
**Sponsored by:** CDN Center of Excellence (P30) for Practice-based Research and Learning, N<sup>o</sup>. Virtual Training Series (AHRQ, Grant No. 1P30-HS-021667) and Clinical Directors Network, Inc. (CDN)

**COVID-19 Virtual Town Hall: Leading in a Time of Rapid Change**  
**Presenters:** Erin E. Sullivan, PhD, Research Director, Center for Primary Care at Harvard Medical School, Lecturer, Department of Global Health and Social Medicine, Harvard Medical School  
 Alden Lai, PhD, MPH, Assistant Professor of Public Health Policy and Management, School of Global Public Health, Stern School of Business (affiliated), NYU  
**Discussion:** 1) Cultivating team culture and resilience; 2) Maintaining relationships and meaning in work

**COVID-19 Virtual Town Hall with CDN Board of Directors: Addressing Mental Health Issues for Staff and Patients & Reductions in Workforce and Patient Volume**  
**Presenters:** CDN Board of Directors  
**Discussion:** 1) Mental health of their staff and patients, 2) implementing stress management techniques, and 3) handling rapid reductions in patient volume

**Prescription Pain Medication Use in the Community**  
**Presenter:** Linda B. Cottler, PhD, MPH, FACE, Associate Dean for Research, College of Public Health and Health Professions and Dean's Professor of Epidemiology at the University of Florida  
**Sponsored by:** The Opioid Post-Marketing Requirements Consortium (OPC), Syneos Health™, N<sup>o</sup>. Virtual Training Series (AHRQ, Grant No. 1P30-HS-021667) and Clinical Directors Network, Inc. (CDN)

**The Beatrice Renfield Lecture in Research Nursing: Diversity and Inclusion in Clinical Research**  
**Presenter:** Sylvia Trent-Adams, PhD, RN, FAAN, Rear Admiral, US Public Health Service Commissioned Corps, Principal Deputy Assistant Secretary for Health  
**Sponsored by:** The Heilbrunn Family Center for Research Nursing, Rockefeller University Center for Clinical and Translational Science (NIH-NCATS Grant No. #UL1-TR-000043), Clinical Directors Network, Inc. (CDN) and the N<sup>o</sup> PBRN Virtual Training Series (AHRQ #1P30-HS-021667)

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## Q & A

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## THANK YOU

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