



CLINICIAN STRATEGIES AND RESOURCES: CARING FOR AYAS AS THEY TRANSITION TO CANCER SURVIVORSHIP

MAY 9, 2024

AMERICAN CANCER SOCIETY: WWW.CANCER.ORG

THE LEUKEMIA & LYMPHOMA SOCIETY: WWW.LLS.ORG





WELCOMING REMARKS

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Associate Director

Information Resource Center

The Leukemia & Lymphoma Society

Rye Brook, NY





TARGET AUDIENCE

This activity is intended for hematologist/oncologists, APPs, nurses, social workers, and other healthcare professionals involved in the care of adolescent and young adult (AYA) patients with cancer and cancer survivors.

EDUCATIONAL OBJECTIVES

After completing this accredited activity, the participant should be better able to:

- Describe care challenges for AYAs as they transition to survivorship
- Explain the importance of survivorship care, including late effects and how to access long-term follow-up guidelines
- Identify interdisciplinary care team roles in supporting AYA cancer survivors
- Review resources to support AYAs with cancer, their caregivers, and healthcare professionals



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DISCLOSURES

Brittany Hall, PhD, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

Rebecca Eary, DO, MPH, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

Michelle Rajotte, LMSW, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

Michael Roth, MD, has a financial interest/relationship or affiliation in the form of:
Research Grant: Pfizer, HebeCell

Danielle Friedman, MD, MS, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

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Approval for nurses has been obtained by the National Office of The Leukemia & Lymphoma Society under Provider Number CEP 5832 to award 1.0 continuing education contact hour through the California Board of Registered Nursing.

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This activity was planned by and for the healthcare team, and learners will receive 1.0 Interprofessional Continuing Education (IPCE) credit for learning and change.

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Ask a question:

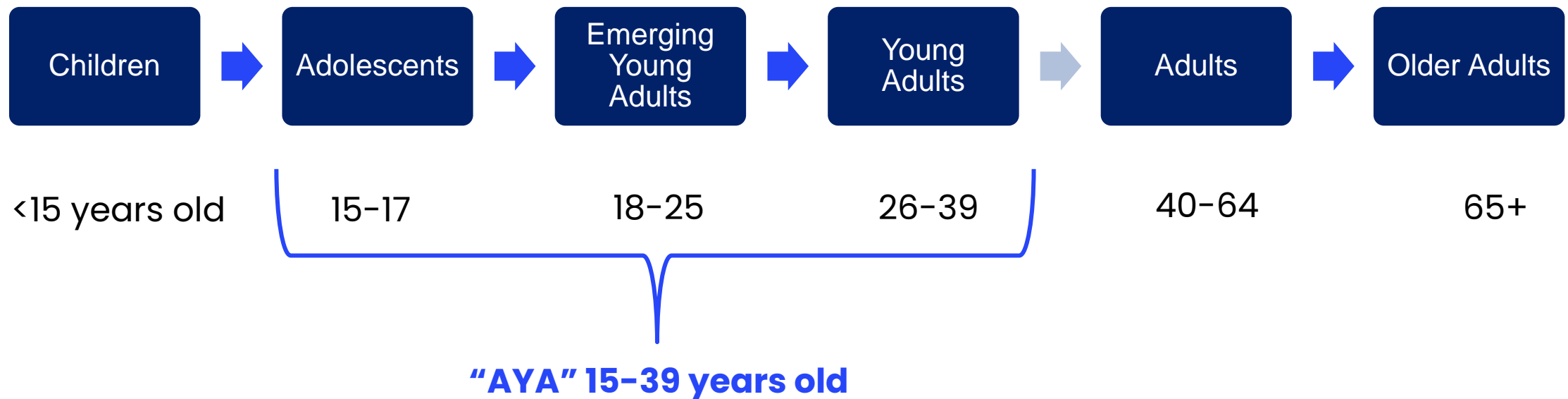
Please type them in the Q&A box and submit.



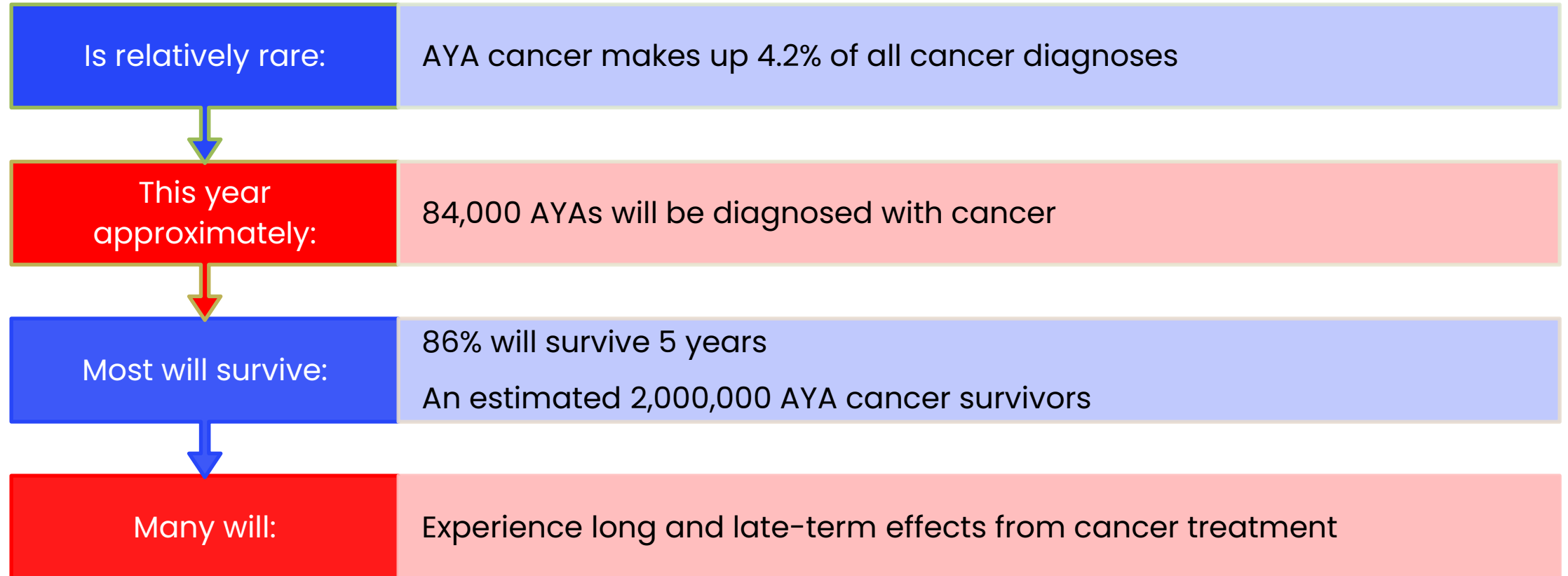
Overview of AYA Cancer

Adolescent and Young Adult (AYA)

refers to individuals diagnosed with cancer between the ages of **15 and 39**



AYA Cancer





POLLING QUESTION 1

Which of the following are long-term psychosocial issues that AYA survivors of cancer experience?

- A. Financial toxicity
- B. Anxiety and depression
- C. Less likely to have children
- D. More likely to use drugs and alcohol
- E. All of the above



Importance of Survivorship Care

What Do We Know about Long-Term and Late Effects among AYA Cancer Survivors?



Physical Issues:

- 2nd Malignancies
- Cardiovascular Disease
- Endocrine Dysfunction
- Neurocognitive Deficits
- Fertility
- Sexual Dysfunction
- Body Disfigurement
- Physical Condition

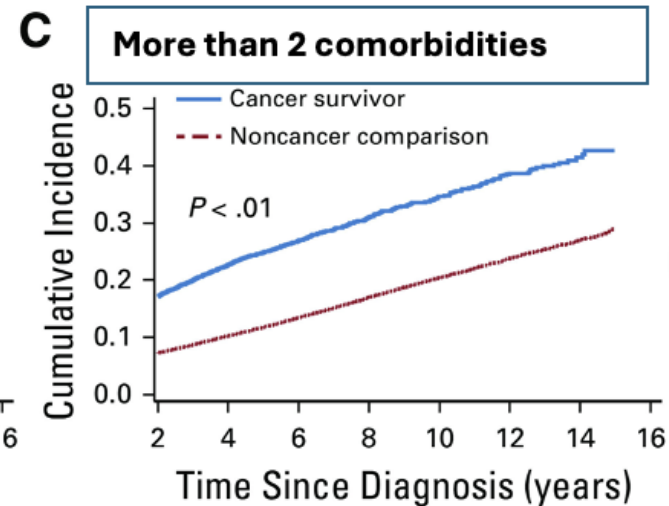
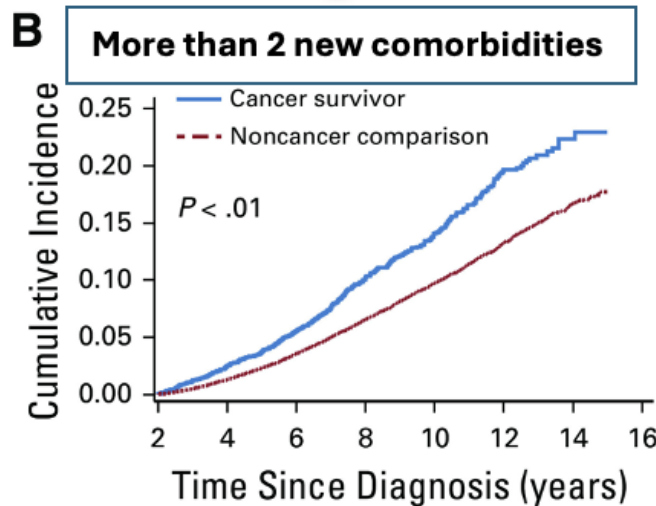
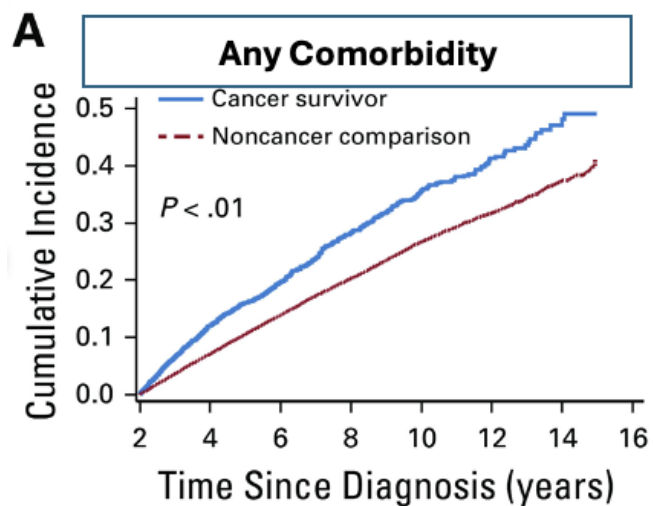
Psychological Issues:

- Distress
- Anxiety & Depression
- Posttraumatic Stress
- Fear of Recurrence
- Body Image Concerns
- Cognitive Impairment
- Loneliness
- Survivor's Guilt
- Drug and Alcohol Use

Social Issues:

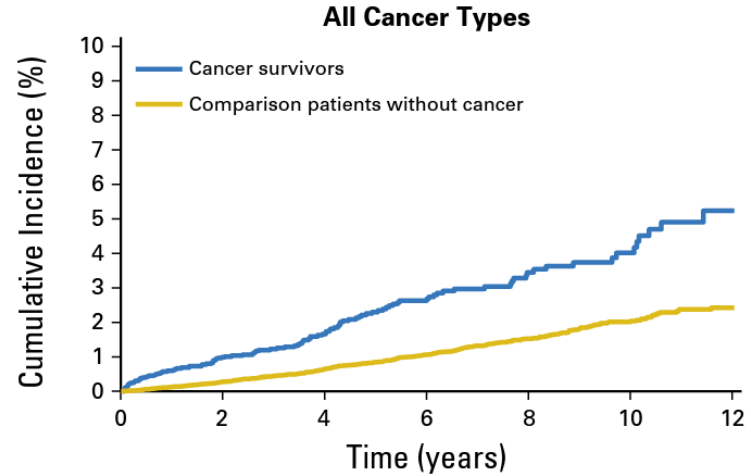
- Education
- Employment Challenges
- Financial Toxicity
- Relationships (romantic and friendships)
- Access to Supportive Services

Long-Term Outcomes for Survivors of AYA Cancer

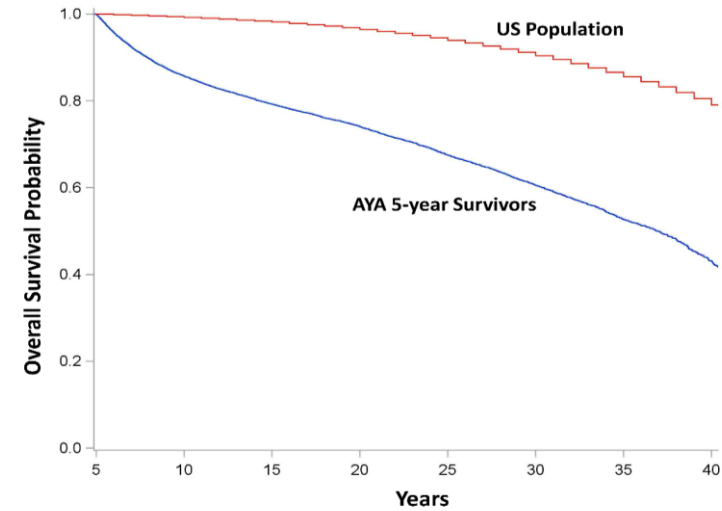


- High risk of developing severe and chronic health conditions due to their cancer treatment exposures
 - Nearly 100% of survivors by age 50 will have 1 or more chronic condition
- Treatment-related late effects are often compounded by the emergence of age-associated chronic conditions

Cardiovascular Disease



Overall Survival



Long-Term Outcomes for Survivors of AYA Cancer

- Increased risk of cardiovascular disease compared to patients without cancer
- Increased risk for early mortality due to late side effects of treatment including cardiovascular disease and subsequent malignancies

Long-Term Psychosocial Outcomes

Compared with the general population, survivors of AYA cancer are:

- More likely to have mood and anxiety disorders
- More likely to have lower income
- Less likely to be married
- Less likely to have children
- More likely to use tobacco products and/or alcohol





Understanding the Psychological Landscape

- Coming out of the fog
 - Less focus on practical concerns & increased awareness of psychosocial needs
- High levels of daily life needs negatively associated with health (Zhang et al, 2023)
 - Acute medical concerns managed, now living with chronic concerns
- Life not returning to pre-diagnosis
 - Reduction of social support compared to active treatment
 - Reduction in communication with medical team
- Top Concerns: Worry about a new cancer & recurrence (Vandraas et al, 2021)



Accessing Long-term Follow-up Guidelines



CHILDREN'S
ONCOLOGY
GROUP

Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

Version 6.0 - October 2023

Website: www.survivorshipguidelines.org
Copyright 2023 © Children's Oncology Group
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Publicly accessible at:
www.survivorshipguidelines.org

This webpage also includes:

- **Health Links:** Patient education materials to accompany the guidelines.
- **Program Resource Guide:** A comprehensive guide designed for institutions interested in establishing and enhancing long-term follow-up programs for childhood cancer survivors.
- **Directory of Long-Term Follow-Up Services**

CHEMOTHERAPY

ANTHRACYCLINE ANTIBIOTICS (CONT)

Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation	Health Counseling/ Further Considerations																				
34	<p>Anthracycline Antibiotics Daunorubicin Doxorubicin Epirubicin Idarubicin Mitoxantrone</p> <p>Dose Conversion Use the following formulas to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose.</p> <p>To estimate cumulative anthracycline dose in doxorubicin isotoxic equivalents</p> <p>1.0 x (doxorubicin total dose) + 0.5 x (daunorubicin total dose) + 0.67 x (epirubicin total dose) + 5.0 x (idarubicin total dose) + 10.0 x (mitoxantrone total dose)</p>	<p>Cardiac toxicity Cardiomyopathy Subclinical left ventricular dysfunction Congestive heart failure Arrhythmia</p>	<p>HISTORY Shortness of breath Dyspnea on exertion Orthopnea Chest pain Palpitations If under 25 yrs: nausea, vomiting</p> <p>Yearly</p> <p>PHYSICAL Blood pressure Cardiac exam</p> <p>Yearly</p> <p>SCREENING Echo (or comparable imaging to evaluate cardiac function)</p> <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><100mg/m²</td> <td><15Gy</td> <td>No screening</td> </tr> <tr> <td><100mg/m²</td> <td>15Gy to <30Gy</td> <td>Every 5 years</td> </tr> <tr> <td>≥100 to <250mg/m²</td> <td><15Gy</td> <td rowspan="2">Every 2 years</td> </tr> <tr> <td>≥100 to <250mg/m²</td> <td>≥15Gy</td> </tr> <tr> <td>Any ≥ 250mg/m²</td> <td>≥30Gy</td> <td>Any</td> </tr> </tbody> </table> <p>*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.</p> <p>EKG (include evaluation of QTc interval) Baseline at entry into long-term follow-up, repeat as clinically indicated</p>	RECOMMENDED FREQUENCY OF ECHOCARDIOGRAM			Anthracycline Dose*	Radiation Dose**	Recommended Frequency	<100mg/m ²	<15Gy	No screening	<100mg/m ²	15Gy to <30Gy	Every 5 years	≥100 to <250mg/m ²	<15Gy	Every 2 years	≥100 to <250mg/m ²	≥15Gy	Any ≥ 250mg/m ²	≥30Gy	Any	<p>HEALTH LINKS Heart Health Cardiovascular Risk Factors Nutrition and Physical Activity</p> <p>COUNSELING Traditional CVRFs significantly increase survivors' risk of cardiomyopathy. Counsel regarding the importance of maintaining blood pressure, BMI, lipids, and glucose levels within goal ranges per general population guidelines. Regarding exercise: <ul style="list-style-type: none"> Exercise is generally safe and encouraged for patients with normal LV systolic function Consult cardiology for survivors with asymptomatic cardiomyopathy to define physical activity limits and precautions. Consider cardiology consultation to define physical activity limits and precautions 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 use of QTc prolonging medications (e.g., tricyclic anti-depressants, antifungals, macrolide antibiotics, metronidazole).</p> <p>POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION Cardiac MRI as an adjunct imaging modality when echo images are suboptimal. Cardiology consultation in patients with subclinical abnormalities on screening evaluations, LV dysfunction, dysrhythmia, or prolonged QTc interval. For patients who are pregnant or planning to become pregnant, additional cardiology evaluation is indicated in patients who received: <ul style="list-style-type: none"> ≥250 mg/m² anthracyclines ≥30 Gy chest radiation, or Anthracycline (any dose) combined with chest radiation (≥15 Gy) Evaluation should include a baseline echo (pre- or early-pregnancy). For those without prior abnormalities and with normal pre- or early-pregnancy baseline echos, follow-up echos 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, and should be monitored periodically during pregnancy, labor and delivery due to increased risk for heart failure.</p> <p>SYSTEM = Cardiovascular SCORE = 1</p>
RECOMMENDED FREQUENCY OF ECHOCARDIOGRAM																								
Anthracycline Dose*	Radiation Dose**	Recommended Frequency																						
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Additional Information

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.

Significant Gaps in Provider Knowledge of Guidelines

Hodgkin Lymphoma Survivor Vignette			
Responses Concordant with COG Guidelines	General Internists (N=1,110; US only)	Family Physicians (N=1,124; US & Canada)	Pediatric Oncologists (N=665; US only)
Breast cancer screening	9%	16%	66%
Thyroid screening	76%	74%	76%
Cardiac screening	15%	10%	57%
Total	5%	2%	33%




Transition Challenges



POLLING QUESTION 2

What is the most common barrier you or your patients experience when an AYA patient transitions to survivorship care?

- A. Lack of provider clarity
- B. Fear and avoidance
- C. Cost or lack of Insurance
- D. Lack of survivorship programs to refer to
- E. Providers not asking the right questions
- F. Other



"Research has shown that without a structured transition process, youth and young adults are more likely to have problems with medical complications, limitations in health and wellbeing, difficulties with treatment and medication adherence, discontinuity of care, preventable emergency department and hospital use, and higher costs of care."

- Updated Clinical Report on Health Care Transitions for Youth and Young Adults from the American Academy of Pediatrics



Barriers to Survivorship Transition

Lack of provider clarity

Skepticism about follow-up care

Autonomy and moving forward

Competing responsibilities

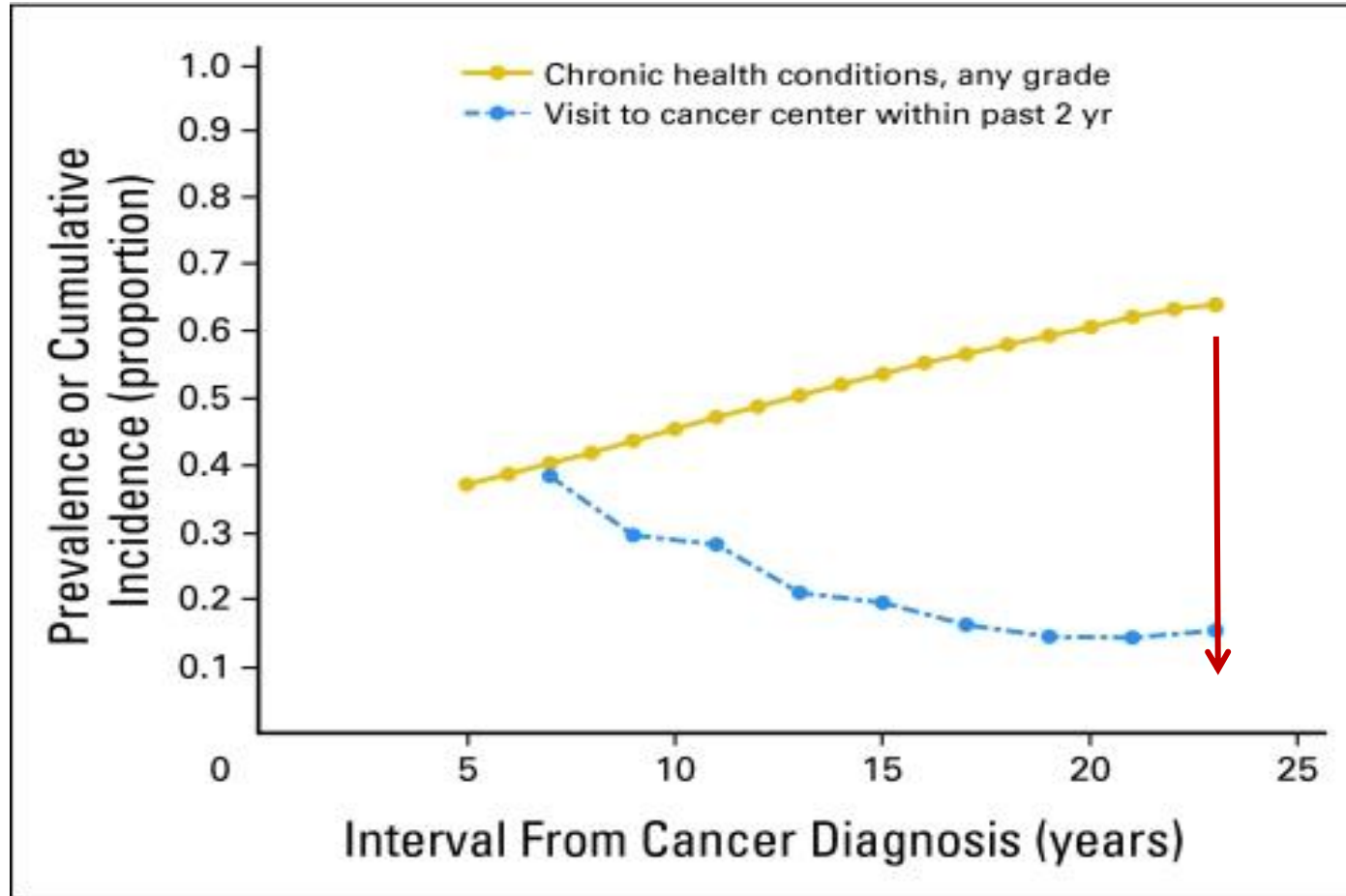
Fear and avoidance

Cost or Lack of Insurance

Lack of survivorship programs to refer to

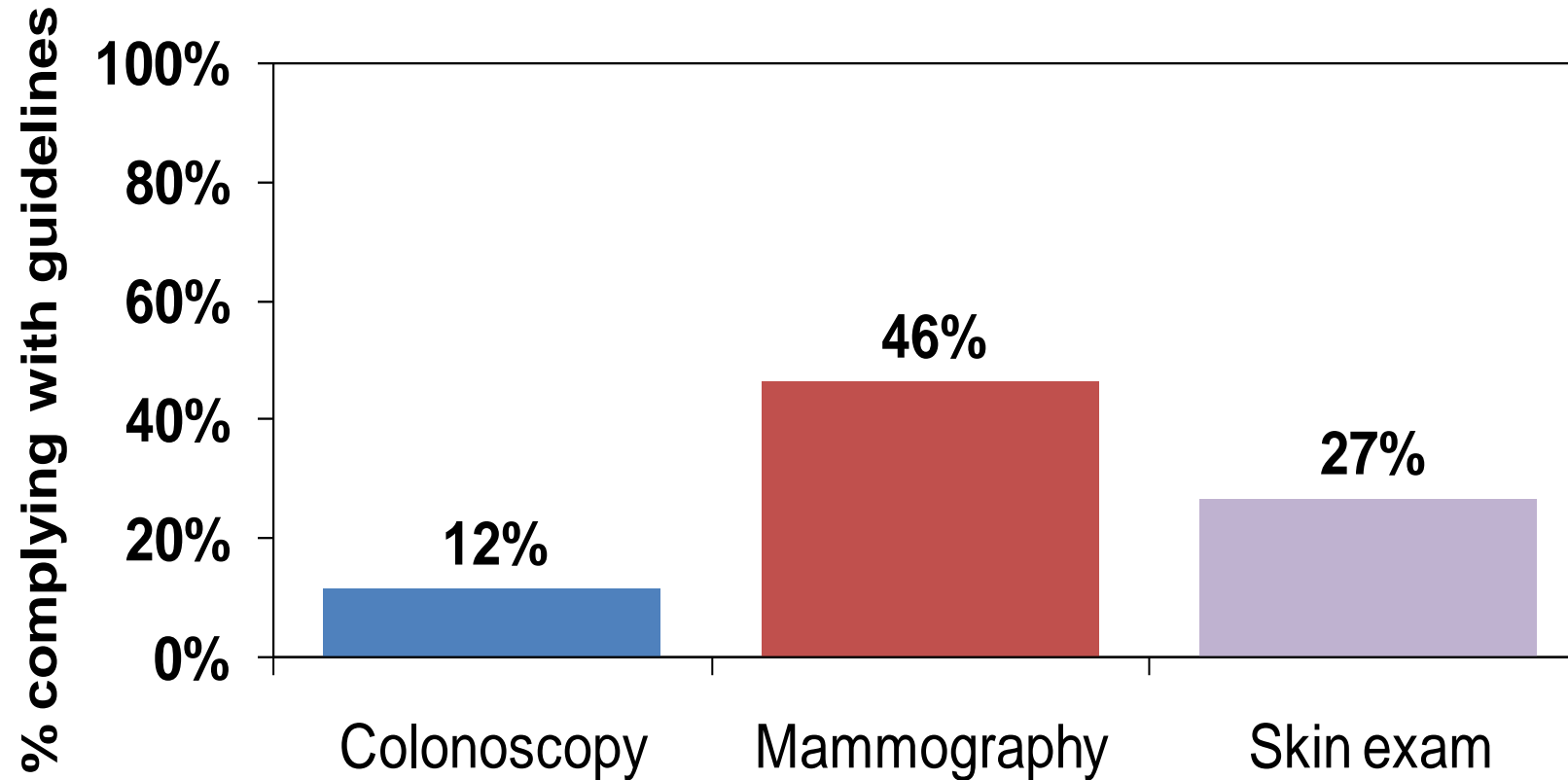
Providers not asking the right questions

Less than Half of Adult-Aged Survivors Remain Actively Involved in Survivorship Care



Among 975 adult cancer survivors, **27.3%** had a cancer-related medical visit within the last 2 years

High-Risk Survivors Are Not Receiving Recommended Screening Tests





POLLING QUESTION 3

What transition strategies do you implement to optimize the transition to survivorship care? Select all that apply.

- A. Provide education and encouraging self-advocacy
- B. Coordinate and collaborate with multidisciplinary health care teams
- C. Provide patient navigation services to guide AYA survivors through the transition process
- D. Offer psychosocial support services to address the needs of AYA survivors
- E. Provide a personalized survivorship care plan
- F. Refer survivors to specialized survivorship clinics
- G. All of the above
- H. Other

Transition Strategies

Education and Empowerment

- Educate AYA cancer survivors about the importance of survivorship care and need for long-term follow-up.
- Empower survivors to advocate for their needs.

Care Coordination

- Coordinate care among multidisciplinary health care teams.
- Establish clear communication channels.
- Share treatment summaries and collaborate on care plans.

Patient Navigation

- Provide patient navigation services to guide AYA cancer survivors through the transition process.
- Navigators can assist with understanding care plans, scheduling follow-up appointments, accessing services, and navigating the health care system.

Psychosocial Support

- Offer psychosocial support services to address the needs of AYA survivors during transition to survivorship care.
- Provide counseling, facilitate support groups, and incorporate psychosocial management into care plans.

Survivorship Care Plans

- All survivors should have personalized care plans that outline recommended follow-up care, screening schedules, and strategies for managing late effects.
- Know where specialized survivorship clinics are to refer survivors to.



Interdisciplinary Care Team Roles

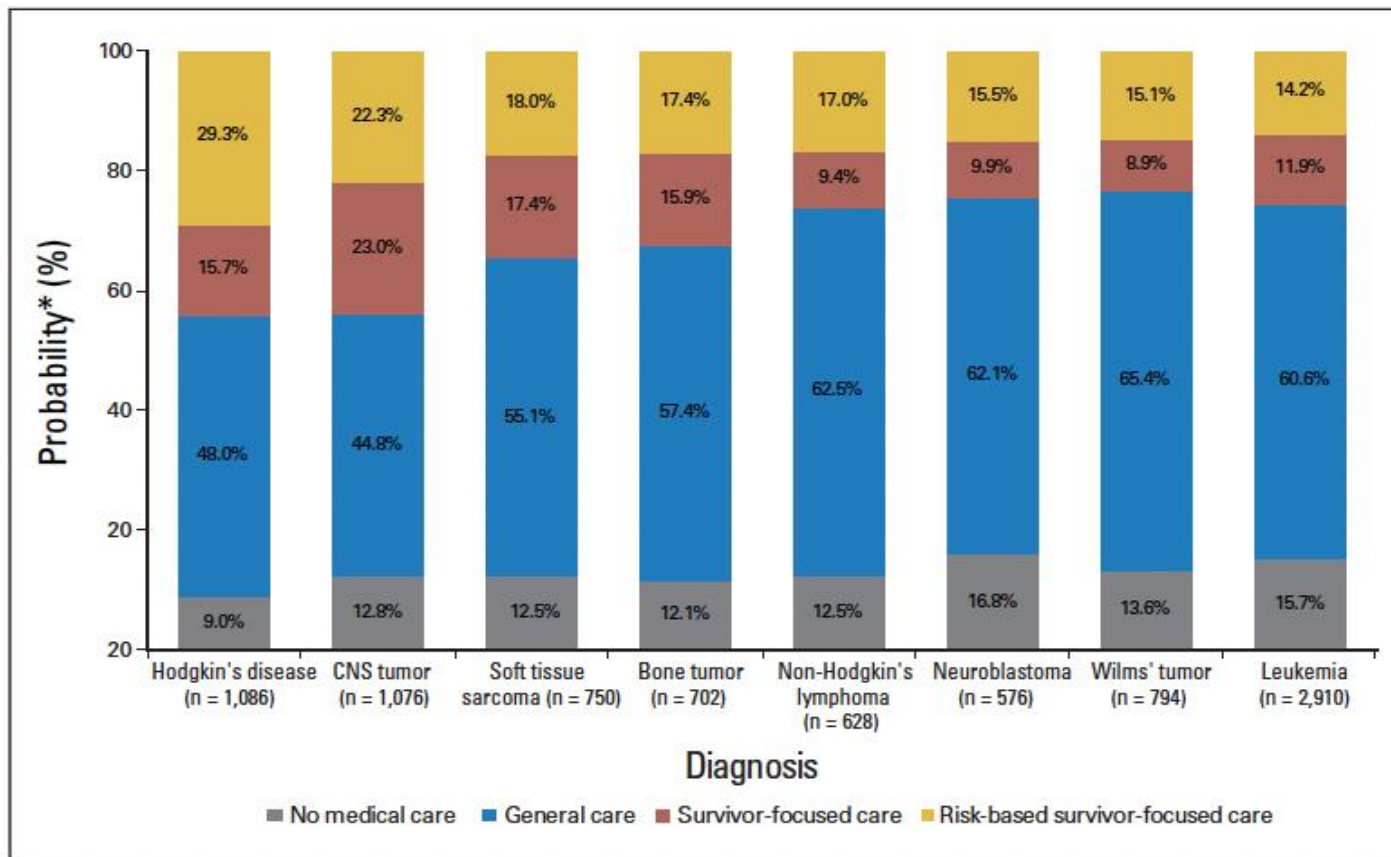


Fig 1. Probability of reporting a particular level of medical care according to initial cancer diagnosis. (*) Probabilities adjusted for sex, age at diagnosis, and age at time of interview using a generalized logit model.

Primary Care Utilization among survivors

- Nearly all cancer survivors will return to primary care at some point in their lifetime (Pinheiro, 2022)
- Survivors more likely to access care in community primary care practices versus survivorship focused clinics (Nathan, 2008)
- In a large cohort of AYA survivors, nearly 30 percent of patients had no follow up with oncology or primary care within the first year completing treatment (Hahn, 2023)



Need for Primary Care

Reduction of modifiable risks and health promotion

Screening for second primary cancers

Optimizing control of chronic conditions

Addressing late effects

Linking to specialist care – referrals

Assessing psychological and mental health needs

Patients who have a PCP live longer and have decreased mortality from cancer, cardiovascular, and respiratory disease compared to those who only receive specialty care (Basu, 2019).



Role of Psychosocial Providers


Individual & Group Therapy

- Referrals to peer support

Referrals To Appropriate Providers

Program Development & Evaluation

- Screening & Intervention programs
- Identifying & supporting referrals to meet psychosocial needs
- Increasing optimization of services

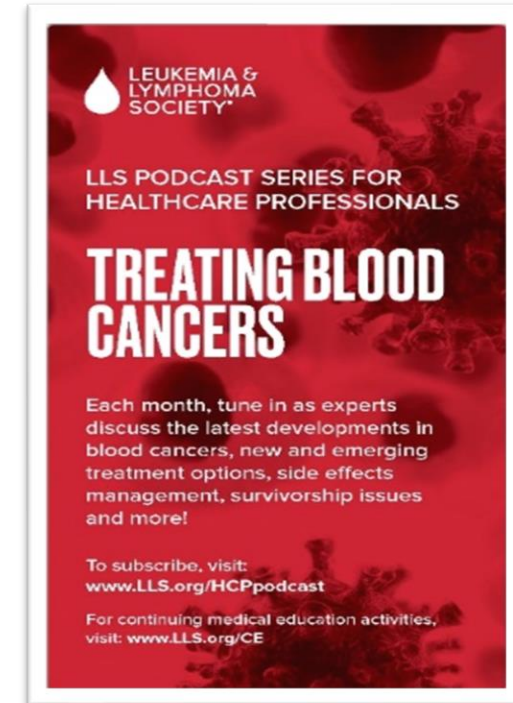
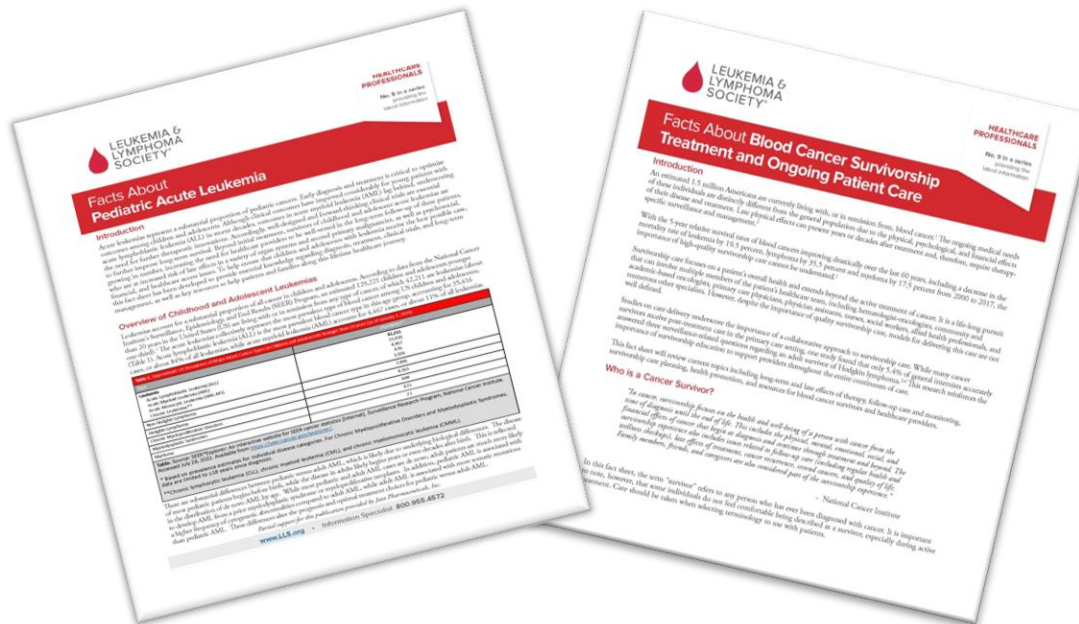


RESOURCES



FREE LLS RESOURCES FOR HEALTHCARE PROVIDERS

- ❑ CME and CE courses: www.LLS.org/CE
- ❑ Staying Connected®: www.LLS.org/StayingConnected
- ❑ Fact Sheets for HCPs: www.LLS.org/HCPbooklets
- ❑ Videos for HCPs: www.LLS.org/HCPvideos
- ❑ Podcast series for HCPs: www.LLS.org/HCPpodcast



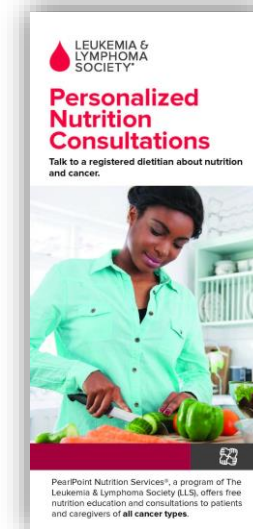
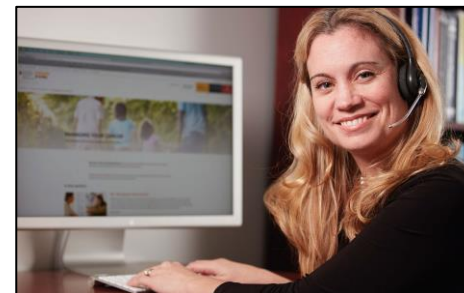
FREE LLS RESOURCES FOR PATIENTS

- ❑ **Information Specialists** – Personalized assistance for managing blood cancer treatment decisions, side effects, and dealing with financial and psychosocial challenges (IRC).

- ❑ **Clinical Trial Nurse Navigators** – RNs and NPs provide a personalized service for patients with blood cancer seeking treatment in a clinical trial, sift through the information and provide information to bring back to their HC team (CTSC).
 - www.LLS.org/CTSC

- ❑ **Nutrition Education Services Center (NESC)** – LLS provides **Nutrition Education Services** to patients and caregivers of all cancer types. *Our **registered dietitians** have expertise in oncology nutrition.* To schedule a free consultation:
 - visit www.LLSnutrition.org
 - call 877-467-1936

- ❑ **Reach out Monday–Friday, 9 am to 9 pm ET**
 - Phone: (800) 955-4572
 - Live chat: www.LLS.org/IRC
 - Email: infocenter@LLS.org
 - HCP Patient Referral Form: www.LLS.org/HCPreferral



FREE LLS RESOURCES FOR PATIENTS AND CAREGIVERS

❑ www.LLS.org/YoungAdults

❑ **Webcasts, Videos, Podcasts:**

➤ www.LLS.org/Webcasts

➤ www.LLS.org/EducationVideos

➤ www.LLS.org/Podcast

❑ **Support Resources**

❑ Financial Assistance: www.LLS.org/Finances

❑ Other Support: www.LLS.org/Support

- LLS Regions

- Live Online Weekly Chats: “Young Adults”

▪ Facilitated by Oncology SW

- LLS Community Social Media Platform

- First Connection Peer to Peer Program



FREE LLS RESOURCES FOR YOUR PATIENTS

The collage features several LLS resources:

- Acute Myeloid Leukemia in Children and Teens** (English)
- Acute Lymphoblastic Leukemia in Children and Teens** (English)
- Fertility and Cancer** (English Fact Sheet)
- A Teen's Guide to EVERYTHING CANCER** (English Booklet)
- NECESITA INFORMACIÓN, APOYO O AYUDA ECONÓMICA? ¡COMUNIQUESE CON LLS!** (Spanish Language Resource)
- 11 Tips to Advocate for Your Care** (English Booklet)
- Back to School** (English Booklet)
- Tips to Manage Side Effects** (English Booklet)
- Treatment Day** (English Booklet)
- Navigation Life During and After a Blood Cancer Diagnosis** (English Booklet)
- Navigation Life During and After a Blood Cancer Diagnosis** (Spanish Language Booklet)

BOOKLETS AND FACT SHEETS

English – www.LLS.org/Booklets

Spanish – www.LLS.org/Materiales





Vision: End cancer as we know it, for everyone.

Mission: Improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer.



Educating and advocating for healthy lifestyles and environments, including promotion of regular screening, and trusted source of screening recommendations for health care professionals

Partnering with **200** health systems and health plans nationwide to increase cancer screening and HPV vaccination



24/7 access to answers and hope via cancer.org and our free helpline at **1-800-227-2345**



Free rides to treatment through our **Road To Recovery**® program and transportation grants



Information, resources, and support through **ACS CARES™** navigation program and mobile app



More than **\$6M** investment focused on advancing high-quality cancer care through capacity building and support of oncology patient navigation



Advocating for high-quality, affordable health care for everyone, including closing the Medicaid coverage gap, through our **American Cancer Society Cancer Action Network™**



Collaboration with **community partners and health systems** to identify and address disparities in prevention, screening, diagnosing, and treating cancer

Free nights of lodging for people with cancer and their caregivers traveling for treatment through **Hope Lodge**®



Peer-to-peer support from breast cancer survivors through our **Reach To Recovery**® support program

Online **Cancer Survivors Network**®: a supportive online community for nearly one million people affected by cancer type



cancer.org | 1.800.227.2345

Every journey. Every step. Every day.



ACS LION™

Transform care through a new navigation training and credentialing program

The American Cancer Society Leadership in Oncology Navigation (ACS LION) is a standardized training and credentialing program that helps patient navigators deliver essential nonclinical support to individuals, caregivers, and families facing cancer.

Now available, the program meets the Centers for Medicare & Medicaid Services (CMS) training requirements for "Principal Illness Navigation" reimbursement, as introduced in the 2024 CMS Physician Fee Schedule, and is aligned to professional oncology navigation (PONT) standards.

Learn more about the program and enrollment



Visit cancer.org/NavigationCredential or scan the QR code to learn more about ACS LION and how to enroll.

The program is \$495 per learner. Opportunities for program access assistance are available. Please email ACSLION@cancer.org for more information.





SAVE THE DATE

Orientation | June 26th, 2024 | 1:00–2:00 PM EST

Pediatric, Adolescent, and Young Adult Cancer Survivorship ECHO

Four Principles of the ECHO Model



Use technology to leverage scarce resources



Apply case-based learning to master complexity



Share best practices to reduce disparities



Evaluate and monitor outcomes



Learn more at
echo.cancer.org

Additional Resources for Healthcare Providers:

- Relevant Training and Educational Programs for HCPs (some providing CE)
 1. GW School of Medicine & Health Sciences: [Cancer Survivorship E-Learning Series](#)
 2. Harvard University: [Cancer Survivorship: Optimizing Care and Outcomes](#)
 3. Cancer Support Community: [Cancer Transitions: Moving Beyond Treatment™ Program](#)
- National Cancer Institute [Pediatric and Adolescent and Young Adult Cancer Survivorship Information](#)
- Canteen's [Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process Manual](#) (includes *Psychosocial Survivorship Screening Tool* on page 20)
- [Six Core Elements of Health Care Transition](#) from Got Transition: for use by clinicians to assist youth and young adults as they transition to adult health care
- COG's [Directory of Long-term Survivorship Programs](#)

THANK YOU

Instructions For Credit

Participants must complete the evaluation to receive credit.
After completing this process, your certificate will automatically generate.

For questions or concerns, please contact Profeducation@lls.org

