

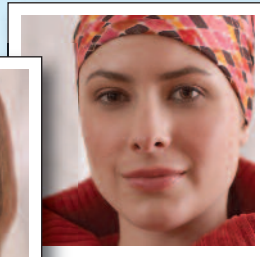
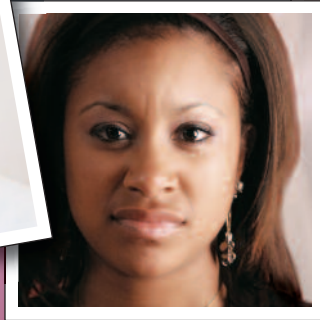


**The Leukemia &  
Lymphoma Society®**  
*Fighting Blood Cancers*

LEUKEMIA

LYMPHOMA

MYELOMA



# Young Adults with Blood Cancers: Managing Treatment and Beyond

CONTINUING EDUCATION IS OFFERED FOR THIS ACTIVITY

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# WELCOME



On behalf of The Leukemia & Lymphoma Society (LLS), thank you for joining us for **Young Adults With Blood Cancers: Managing Treatment and Beyond**, a continuing education activity.

LLS would also like to thank our esteemed speakers for sharing their time and expertise. Through this activity they will define treatment challenges and long-term and late effects of cancer treatment in young adults with blood cancers; explain the need to keep young adults integrated in the healthcare system for follow-up care; cite gaps in services available to young adults with blood cancers; and identify survivorship issues facing these young adults. Finally, through a panel discussion, the speakers will discuss ethical boundaries in communicating with young adult patients.

This workbook includes the presenters' slides and will help guide you through the activity. If you would like to receive 2.0 continuing education hours, please complete and submit the Evaluation form.

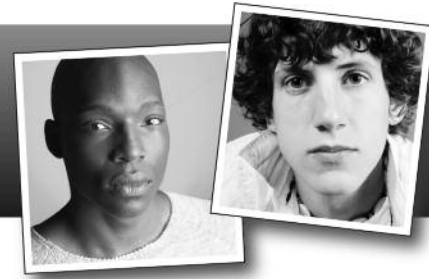
We hope that you will find this activity informative and rewarding.

Sincerely,

**Carson Jacobi, MPH**

*Vice President, National Education Programs*  
The Leukemia & Lymphoma Society

# AGENDA



## **Welcome & Introductions**

### **Carson Jacobi, MPH**

The Leukemia & Lymphoma Society

*Treatment Challenges and Long-Term/Late Effects in Young Adults With Blood Cancers*

### **Michael E. Rytting, MD**

Associate Professor of Pediatrics

The University of Texas MD Anderson Cancer Center  
Houston, TX

*Treatment Adherence and Keeping Young Adults Integrated in the Healthcare System for Follow-Up Care*

### **Nicole Rosipal, RN, MSN, CPNP**

Stem Cell Transplant and Cellular Therapy – Pediatrics  
The University of Texas MD Anderson Cancer Center  
Children's Cancer Hospital  
Houston, TX

*Gaps in Services for Young Adults With Blood Cancers*

### **Eric Cohen, RN, BSN, OCN**

Program Manager, Patient and Family Education  
Life With Cancer®  
Inova Cancer Services  
Fairfax, VA

*Survivorship Issues Facing Young Adults*

### **Sage Bolte, MSW, LCSW, OSW-C**

Oncology Counselor  
Life With Cancer®  
Inova Cancer Services  
Fairfax, VA

## **Panel Discussion:**

Ethical Boundaries in Communicating With Young Adult Patients

# PROGRAM OVERVIEW



## PROGRAM GOAL

Young adults are often underserved in our healthcare system at a time in their life when they are experiencing physical, emotional and financial changes. Add the burden of cancer—and the challenge can be overwhelming.

The incidence of cancer in young adults increased steadily over the past quarter century. Survival improvement trends indicate a worse prognosis for young adults diagnosed with cancer today than 25 years ago, in contrast to all other ages.<sup>1</sup>

This activity will identify treatment challenges for young adults with blood cancer, including the unique physical and psychosocial factors, desire for independence, sexual and fertility issues and lack of and underutilization of insurance. Discussion will focus on the gaps in services for this age group, adherence to treatment and follow-up care, long-term and late effects of treatment, and survivorship issues, to help nurses more effectively communicate with and treat young adult survivors.

<sup>1</sup> Bleyer A, O'Leary M, Barr R, Ries LAG (eds): *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975–2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD; 2006.

## TARGET AUDIENCE

This activity has been designed to meet the educational needs of nurses, social workers, and other healthcare professionals involved in the care of young adults with blood cancers.

## EDUCATIONAL OBJECTIVES

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

- Define treatment challenges in young adults with blood cancers
- Cite gaps in services available to young adults with blood cancers
- Describe survivorship issues facing young adults
- Explain the need to keep young adults integrated in the healthcare system for follow-up care
- Identify long-term/late effects of cancer treatment
- Describe the ethical boundaries in communicating with young adult patients

## CONTINUING EDUCATION INFORMATION

### *Nurses and Social Workers*

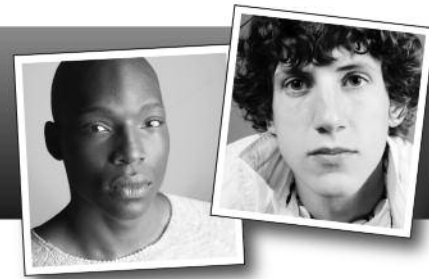
Approval for nurses has been obtained by the National Office of The Leukemia & Lymphoma Society under provider number CEP 5832 to award 2.0 continuing education contact hours through the California Board of Registered Nursing.

The Leukemia & Lymphoma Society (LLS), provider number 1105, is approved as a provider for social work continuing education by the Association of Social Work Boards (ASWB) [www.aswb.org](http://www.aswb.org) Approved Continuing Education Program (ACE). Approval Period: 12/2008–12/2011. LLS maintains responsibility for the program. Social workers should contact their regulatory board to determine course approval. Social workers will receive 2.0 CE (1 clinical and 1 social work ethics) clock hours.

## STATEMENT OF SUPPORT

This program is supported by Cooperative Agreement Number 5U58/DP001105-02 from the Centers for Disease Control and Prevention. Its content is solely the responsibility of The Leukemia & Lymphoma Society and does not necessarily represent the official views of the Centers for Disease Control and Prevention.

## FACULTY BIOGRAPHIES



### **Sage Bolte, MSW, LCSW, OSW-C**

*Oncology Counselor*  
Life With Cancer®  
Inova Cancer Services  
Fairfax, VA



**Sage Bolte, MSW, LCSW, OSW-C**, is an oncology counselor for Life with Cancer®, a nonprofit, community-supported organization dedicated to the education and support of those affected by cancer. After graduating with a dual degree in psychology and social work from Hope College in Holland, Michigan, Ms. Bolte earned a master's degree in social work from the University of Michigan. She is currently pursuing a doctoral degree in social work at The Catholic University in Washington, DC. Ms. Bolte's areas of interest and expertise are sexuality and cancer and the various issues that face the adolescent/young adult population. She was recently awarded the American Cancer Society's Doctoral Training Grant to support her dissertation research on the effect of cancer and its treatments on the young adult cancer survivor's sexuality.

## FACULTY BIOGRAPHIES



### **Eric Cohen, RN, BSN, OCN**

*Program Manager, Patient and Family Education*  
Life With Cancer®  
Inova Cancer Services  
Fairfax, VA



**Eric Cohen, RN, BSN, OCN**, is currently a program manager for patient and family education at Life With Cancer®, a nonprofit, community-supported organization dedicated to the education and support of those affected by cancer. Mr. Cohen received his bachelor's degree from George Mason University. He serves on the national nominating committee of the Oncology Nursing Society (ONS). As a patient educator, Mr. Cohen co-facilitates the Life With Cancer Lymphoma Support Group, Prostate Cancer Group, Caregivers Group, and Young Adult Group. Mr. Cohen is committed to his role as a member of the Lance Armstrong Foundation's Young Adult Alliance, and he has raised money for The Leukemia & Lymphoma Society through his completion of a century ride with Team in Training, a cycling program designed to raise awareness of blood cancers.

## FACULTY BIOGRAPHIES



### **Nicole Rosipal, RN, MSN, CPNP**

Stem Cell Transplant and Cellular Therapy – Pediatrics  
The University of Texas MD Anderson Cancer Center  
Children’s Cancer Hospital  
Houston, TX



**Nicole Rosipal, RN, MSN, CPNP**, is a certified pediatric nurse practitioner for pediatric stem cell transplant and cellular therapy at the University of Texas MD Anderson Cancer Center, Children’s Cancer Hospital. Ms. Rosipal has played an integral role in collaborating with the pediatric and adult stem cell transplant teams to develop a “YA” (young adult) service that aims to address the unique needs of this patient population. She is currently working to initiate a novel video gaming–based exercise protocol to be used by adolescent and young adult (AYA) stem cell transplant patients during their hospitalizations. Ms. Rosipal also recently presented at meetings of the Association of Pediatric Hematology and Oncology Nurses and the American Society for Blood and Marrow Transplantation, where she spoke about the psychosocial needs of AYA.



## FACULTY BIOGRAPHIES



### **Michael E. Rytting, MD**

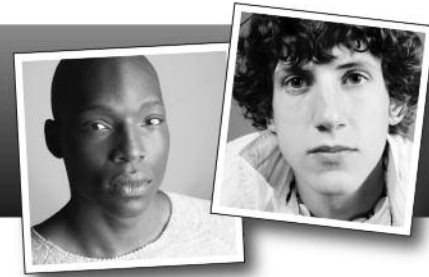
*Associate Professor of Pediatrics*

The University of Texas MD Anderson Cancer Center  
Houston, TX



**Michael E. Rytting, MD**, is an associate professor of pediatrics and holds a joint appointment in adult leukemia at the University of Texas MD Anderson Cancer Center, Children's Cancer Hospital. After graduating from the University of Michigan Medical School, Dr. Rytting went on to complete his residency training in internal medicine and pediatrics at the University of Texas Health Science Center at Houston and a fellowship in pediatric hematology/oncology at the University of Texas MD Anderson Cancer Center. Dr. Rytting specializes in pediatric and young adult leukemia and lymphoma. His clinical research is predominantly focused on acute lymphoblastic leukemia in young adults.

# FACULTY DISCLOSURES




## DISCLOSURE OF CONFLICTS OF INTEREST

All faculty participating in continuing education activities by The Leukemia & Lymphoma Society are expected to disclose to the activity participants any significant financial interest or other relationships with the manufacturer(s) of any commercial product(s) discussed in their presentations. Faculty also are expected to disclose any unlabeled or investigational uses of products discussed in their presentations.


- **Sage Bolte, MSW, LCSW, OSW-C**, has asked that we advise participants in this activity that she has no affiliations at this time.
- **Eric Cohen, RN, BSN, OCN**, has asked that we advise participants in this activity that he has no affiliations at this time.
- **Nicole Rosipal, RN, MSN, CPNP**, has asked that we advise participants in this activity that she has no affiliations at this time.
- **Michael E. Rytting, MD**, has asked that we advise participants in this activity that he has an affiliation with Enzon Pharmaceuticals (*Speakers Bureau*).

# PRESENTATIONS



  
Fighting Blood Cancers

LEUKEMIA | LYMPHOMA | MYELOID



## Young Adults With Blood Cancers: Managing Treatment and Beyond

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Fighting Blood Cancers

## Treatment Challenges and Long-Term/Late Effects in Young Adults With Blood Cancers

Michael E. Rytting, MD  
Associate Professor of Pediatrics  
The University of Texas MD Anderson Cancer Center  
Houston, Texas

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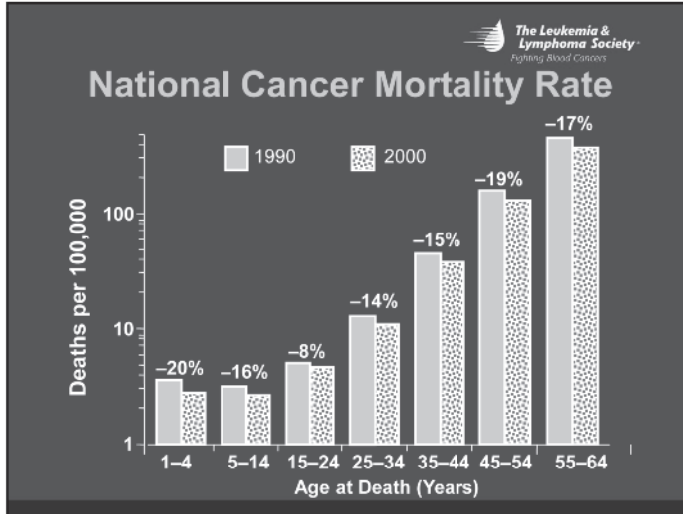
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# PRESENTATIONS



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## Why the Slow Improvement?

- Trial enrollment
  - Teenage Cancer Trust (UK): Zero brain tumor patients in 2006–2007 for teens
  - 7.5% enrollment overall for patients 20–24 years of age
- Care is fragmented
- Insurance issues
- Compliance

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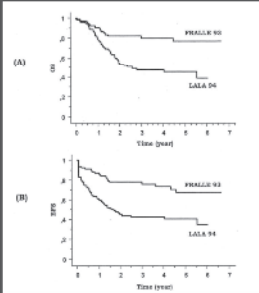
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# PRESENTATIONS



 **The Leukemia & Lymphoma Society**  
Fighting Blood Cancers

### Acute Lymphocytic Leukemia (ALL) Trials: French ALL Group (FRALLE) 93 vs Leucémies Aigues Lymphoblastiques de l'Adulte (LALA) 94



Boissel N, et al. *J Clin Oncol*. 2003;21:774-780; with permission.

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 **The Leukemia & Lymphoma Society**  
Fighting Blood Cancers

### Comparison of Children's Cancer Group (CCG) vs Cancer and Leukemia Group B (CALGB)

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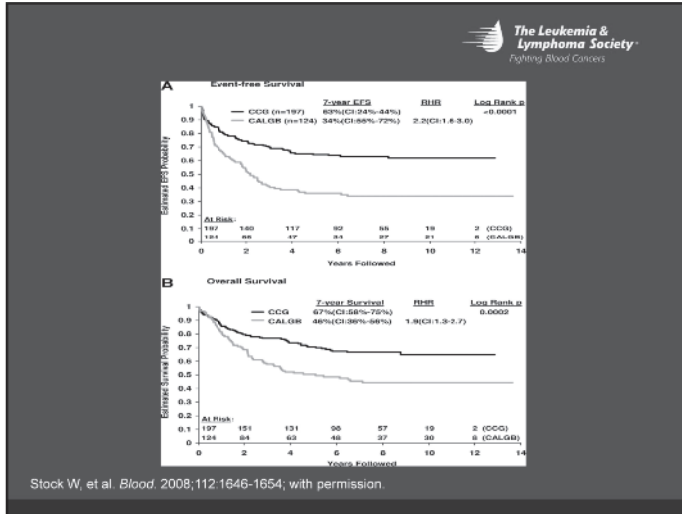
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# PRESENTATIONS



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**The Leukemia & Lymphoma Society**  
*Fighting Blood Cancers*

## ALL Biological Risk Factors

- Cytogenetics
  - Philadelphia chromosome
  - Hyperdiploidy
  - Triple trisomies
- Epigenetics?

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# PRESENTATIONS



## Response to Therapy

- From Spain: “justifies the age-unrestricted use of pediatric regimens”<sup>1</sup>
- From France: pediatric therapy “markedly improves outcome”<sup>2</sup>
- US CALGB trial is open to assess the efficacy of pediatric-based regimen in this group

1. Ribera J-M, et al. *J Clin Oncol*. 2008;26:1843-1849.  
 2. Huguet F, et al. *J Clin Oncol*. 2009;27:911-918.

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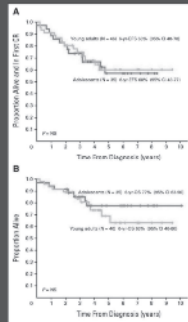
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## Spain: Event-Free and Overall Survival Curves in Adolescents and Young Adults



Ribera J-M, et al. *J Clin Oncol*. 2008;26:1843-1849; with permission.

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# PRESENTATIONS



## Augmented Berlin-Frankfurt-Munster Protocol in ALL (2006-0375)

- Adults  $\leq 40$  years of age
- Completed induction: 41
- Rapid responders (remission achieved by 2 weeks): 34 (83%)
- Slow responders (remission achieved by day 29): 4 (9%)
- Extended induction: 2 (5%)
- Failed therapy: 1 (2%)

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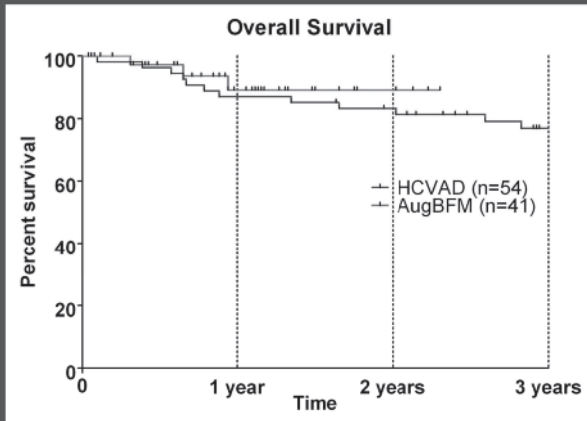
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# PRESENTATIONS



## Treatment-Related Toxicities (Current)

- Avascular necrosis
- Hepatic dysfunction
- Central nervous system toxicity
- Infectious complications
- Thrombosis
- Allergic reactions
- Noncompliance (is this a toxicity?)

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## Following Up

- Fertility
  - Who is at risk for impaired fertility?
  - What are the options for fertility preservation?
  - What are the risks of success?

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# PRESENTATIONS



## Following Up

- Risk for impaired fertility
  - Alkylator regimens
  - Radiation (testes, ovaries)
- Preserving fertility
  - Sperm banking
  - Intracytoplasmic injection
- Risk of success?
  - No apparent increase in cancer risk in children of survivors

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## Following Up

- Second malignancies
  - AML: can follow alkylators or epipodophylotoxins
  - As a whole: 30-year cumulative incidence is about 9% (median age, 34 years)

Meadows A, et al. *J Clin Oncol*. 2009;Mar 2 [Epub ahead of print].

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# PRESENTATIONS



## Following Up

- Skeletal problems
  - Avascular necrosis: Notable problem in teens, perhaps less for young adults
  - Osteoporosis: Recognized more and more as a late effect
- Cardiac late effects: Can the patient take heart?
  - Studies of cardiac late effects are mixed

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## Following Up

- Cognitive impairment
  - About 50% of survivors are at risk
  - Major culprits: methotrexate, radiation
  - Testing
- Social outcomes: Information is emerging but limited
- [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

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# PRESENTATIONS



## Treatment Adherence and Keeping Young Adults Integrated in the Healthcare System for Follow-Up Care

Nicole Rosipal, RN, MSN, CPNP  
Stem Cell Transplant and Cellular Therapy–Pediatrics  
The University of Texas MD Anderson Cancer Center  
Houston, Texas

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## Objectives

- The treatment challenges of adherence
  - Definition
  - Rates
  - How to assess
  - Interventions to prevent or overcome
- The need for long-term follow-up
  - Rationale for importance
  - Challenges
  - Interventions for challenges
  - Resources

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# PRESENTATIONS



## Adolescent/Young Adult (AYA) Developmental Milestones

- Independence
- Individualization
- Intimacy vs isolation
- Identity development
- Body image
- Development of self care and beliefs (including health)



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## Compliance vs Adherence

- Compliance
  - Behavior coincides with medical advice
  - Connotation of coercion or submission
- Adherence
  - Patient actively accepts the responsibility of self care
  - Patient cooperation and collaboration rather than obedience
  - A behavior and an attitude
- Persistence
  - Duration of time from start to finish of therapy

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# PRESENTATIONS



## Nonadherence

- Rates
  - Range of 25%–60% of patients are nonadherent with their medications
    - 16%–100% nonadherence with oral chemotherapy
  - 25% of patients do not contact medical staff for fever or diarrhea
- Adverse effects
  - Increased physician visits
  - Higher hospitalization rates and longer stays
  - Drug toxicities and flawed dosing recommendations
  - Inaccurate conclusions on clinical trials
  - Relapse

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## Model of Adherence and Persistence



Ruddy K, et al. *CA Cancer J Clin*. 2009;59:56-66; with permission.

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# PRESENTATIONS



## Review of the Literature

- 44 AYA patients with varying cancers
- Trimethoprim/sulfamethoxazole serum assays
- Survey of health attitudes and behavior
- Results
  - Nonadherent patients
  - Higher depression scores
  - Lower self-esteem levels
  - Patient mood
  - Family incongruence
  - Decreased survival in the nonadherent group
  - Adolescents are reliable reporters of their own adherence

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## Review of the Literature (*continued*)

- 50 AYA patients with acute lymphocytic leukemia (ALL) or Hodgkin lymphoma
- Prednisone and penicillin serum assays
- Instruments measuring
  - Intellectual screening
  - Knowledge of illness
  - Perceived vulnerability
  - Denial
  - Locus of control
  - Future orientation
- Results
  - Noncompliers
    - More reassured by the absence of symptoms
    - More prone to the use of denial
  - Compliers had a more understandable organization of their future

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# PRESENTATIONS



## How to Assess?

- Ask the PATIENT!
  - Assess understanding of disease, rationale for plan of care and lifestyle modifications
  - Report names/dose of medications
  - Ongoing monitoring
- Unbiased questioning
- Relationships: family, peers, social support
- Social and economic factors
- Psychological, psychiatric and “mood” factors
- Health belief model
  - Individual’s evaluation of health condition, disease severity and perceived vulnerability
  - Risks/benefits of adherence to medications
  - Stimulus prompt to take medication

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## Predictors of Good Adherence

- Realistic conceptions of illness, prognosis and vulnerability
- Consistent caregiver/social support
- Understanding of abstract concepts, such as subclinical disease
- Ability to endure side effects and control factors affecting own health
- Ability to plan for the future

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# PRESENTATIONS



## Predictors of Poor Adherence

- Missed appointments and unfilled prescriptions
- Poor relationship with provider and/or staff
- Adverse effects from medications
- High medication costs and/or hospital bills
- Depression
- Lack of belief in need of treatment
- Mistrust in healthcare system
- Use of denial as a coping mechanism
- Lack of understanding of impact of subclinical disease

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## Interventions to Prevent/Overcome Nonadherence

- Accessibility
  - Convenient appointments and access to pharmacist/support staff
- Medications
  - Simple schedule, pill boxes, reminders (link to a daily activity)
  - [www.mymedschedule.com](http://www.mymedschedule.com)
  - [www.medactionplan.com](http://www.medactionplan.com)
- Education to increase patient (and family) understanding
  - Disease, prognosis, risks/benefits of treatment, medications
- Strong family support
  - Coordination in planning and medications, communication
- Empower the AYA individual – balance of autonomy
- Medical staff initiatives
  - Simplify medication regimens
  - Collaborate with the patient to foster a trusting and respectful relationship
  - Learn about financial issues
  - Reinforce adherent behavior
  - Use of a multidisciplinary team

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# PRESENTATIONS



## Long-Term Follow-Up? “I thought I was done!”

- 1 in every 168 Americans between 15 and 30 years of age will develop invasive cancer
- 1 in every 640 adults between 20 and 39 years of age is a pediatric cancer survivor
- 73% will develop at least 1 chronic health condition within 30 years after their diagnosis
- 42% will develop a severe or disabling condition or die of a chronic condition
- Increased risk of morbidity and mortality when compared with general population
- All organ systems are at risk

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## Rationale for Long-Term Follow-Up

- Early diagnosis and intervention should improve outcomes and quality of life
  - Example: Cardiomyopathy (echocardiogram, management and risk counseling)
- How is the aging process altered by radiation and chemotherapy?
  - Example: Skin cancer
- What is the impact on the progression of common adult health problems?
  - Example: Osteoporosis/bone density (exercise and calcium needs)
- Early detection of morbidity

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# PRESENTATIONS



The Leukemia & Lymphoma Society  
Fighting Blood Cancers

## Chronic Health Conditions and Follow-Up

The graph plots two variables against the interval from cancer diagnosis in years (0 to 25). The y-axis represents the prevalence or cumulative incidence (proportion) from 0 to 1.0. The first series, 'Chronic health conditions, any grade', starts at approximately 0.4 at year 5 and increases steadily to about 0.65 at year 25. The second series, 'Visit to cancer center within past 2 yr', starts at approximately 0.4 at year 5 and decreases steadily to about 0.15 at year 25.

Fig 2. Percentage of survivors with a visit to a cancer center in the past 2 years and cumulative incidence of any chronic condition by years since cancer diagnosis.

Nathan PC, et al. *J Clin Oncol*. 2009;Mar 2[Epub ahead of print]. with permission.

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The Leukemia & Lymphoma Society  
Fighting Blood Cancers

## Optimum Care

- Diagnosis to end of life
- Plan of care incorporates
  - Previous cancer
  - Cancer therapy
  - Genetic predispositions
  - Lifestyle behaviors
  - Comorbid health conditions
- Education regarding diagnoses, treatment, exposures and late effects
- Continuity of care, “medical home”
  - Coordination of services by single provider

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# PRESENTATIONS



 **The Leukemia & Lymphoma Society**  
*Fighting blood cancers*

## Interventions to Enhance Long-Term Follow-Up

- Knowledge deficit of survivors
  - Communicate a follow-up plan
  - Educate: diagnosis, treatment, risks of late effects and resources
- Knowledge deficit of professionals
  - Regional educational and survivorship programs, Internet
- Interventions for psychological factors
  - Introduce concept of long-term follow-up before treatment is completed
  - Anticipate planned transitions in care
  - Empower survivor to be proactive and establish healthy lifestyle
- Interventions for healthcare system
  - Outreach to community providers
- Financial/insurance
  - Assistance from social work for community resources and referrals
- Evidence-based guidelines for screening
- National healthcare policy

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 **The Leukemia & Lymphoma Society**  
*Fighting blood cancers*

## Models for Center of Care for the Survivor

- Cancer center
  - Primary oncology care
  - Specialized long-term follow-up clinic
  - Shared care: primary oncologist, long-term follow-up and specialists
- Young adult transition
  - Formalized transition program
  - Adult oncology-directed care
- Combined approach (shared care model)
  - First follow-up in cancer center-based program, establish Survivorship Care Plan then transition to primary care
    - Endorsed by Institute of Medicine
- Need-based care

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# PRESENTATIONS



## Resources

- Childhood Cancer Survivor Study (CCSS)
  - 25 institutions
  - Funded by National Institute of Health
  - Follows >14,000 long-term survivors diagnosed between 1970–1986
- Children’s Oncology Group
  - [www-survivorshipguidelines.org](http://www-survivorshipguidelines.org)
- Institute of Medicine
- Robert Wood Johnson Foundation
  - Studying barriers to long-term follow-up

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## Gaps in Services for Young Adults With Blood Cancers

Eric Cohen, RN, BSN, OCN  
*Program Manager, Patient and Family Education*  
Life With Cancer®  
Inova Cancer Services  
Fairfax, Virginia

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# PRESENTATIONS



## Social Factors That Impact Young Adults (YAs) as Cancer Patients

- Many emotional, developmental and social changes and transitions during this stage of life
  - **Self-consciousness** – concerned about body changes and body image
  - **Mortality** – confronted with this idea for the first time
  - **Isolation** – few peers among other patients
  - **Independence** – having to move back home; medical decision-making
  - **Financial Burdens** – insurance, inability to work or attend school
  - **Children** – they may have their own

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## Gaps in Services for Young Adults With Cancer

- Psychosocial and Supportive Care – abundant in pediatric settings, available in adult settings, but not YA specific
- Lack of support during and after treatment may be a factor in YAs' decreased adherence to treatment and follow-up care
- Prevention, early detection and overall cancer awareness are not typically discussed by physicians and other health educators
- Lack of nursing school education on impact of disease on YAs

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# PRESENTATIONS



 **The Leukemia & Lymphoma Society**  
*Fighting Blood Cancers*

## Young Adults Want Support and Education

- Young adults are at the leading edge of the technology revolution
- They want to get their own information and they often seek that information at all hours of the day and night



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 **The Leukemia & Lymphoma Society**  
*Fighting Blood Cancers*

## Technology

*"I'd been avoiding the discussion about prognosis with my doc. I really didn't want to know anything at first. Then one night I woke up at two in the morning, scared to death, and had to talk to somebody who could understand what I was feeling."*  
– Pat, 25-year-old acute lymphoblastic leukemia patient

- Google
- Wiki's
- Social networking
  - Facebook, MySpace, Twitter
- Blogs
- YouTube

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# PRESENTATIONS



## Face-to-Face Support

*"Sometimes intensity is good. I'm always having to put on a strong face for my family and friends. The group is the one place I can be real."*  
—Cherie, 34-year-old metastatic renal cell carcinoma patient

- Support groups for YAs
- Happy Hours
  - I2Y
- Retreats for YAs
  - Planet Cancer
  - Camp Māk-A-Dream



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## After Treatment Ends

*"I had cancer ten years ago, when I was living in Michigan; I moved here a couple of years ago, and this year my primary care doc asked if I'd had a baseline mammogram. I hadn't, so I went... when they told me I have breast cancer, I thought how can this be? I already had cancer!"*

—Judy, 35-year-old Hodgkin lymphoma and breast cancer patient

- Long-term effects/late effects education
- Survivorship care plans
  - Portable document with treatment history and follow-up care plans
- Survivorship clinics

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# PRESENTATIONS



## Community Service

- Team-In-Training®
- Other community-sponsored fundraising and awareness events
- College campus programs



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## Survivorship Issues Facing Young Adults

Sage Bolte, MSW, LCSW, OSW-C  
*Oncology Counselor*  
Life With Cancer®  
Inova Cancer Services  
Fairfax, Virginia

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# PRESENTATIONS



## What's So Unique About the Young Adult Population?

- On the cusp of so many milestones
  - Graduating high school
  - Developing independence/autonomy and separation from parents
  - Going to college
  - Starting and developing a career
  - Exploring relationships
  - Getting married or finding long-term partnerships
  - Family planning

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## What's So Unique About the Young Adult Population? *(continued)*

- Challenges
  - Usually are the most underinsured and financially unstable population
  - Transient: Difficult to follow for treatment and post-treatment follow-up
  - Sense of "invincibility" may lead to ignoring symptoms or paying attention to other care needs
  - Heightened sense of loss: friends, autonomy, fertility, naivety
  - Some of these young adults had cancer as a child
  - **Multiple losses!**

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# PRESENTATIONS



## Highest Identified Needs

- Health care needs in treatment
  - Having adequate health insurance coverage
  - A multidisciplinary approach to the delivery of oncology care
  - Treatment decisions that account for risks to the successful achievement of developmental tasks facing this population, such as education, family planning, career development and employment
  - Clinical trials and state-of-the-art treatment protocols designed specifically for cancers diagnosed in adolescents and young adults

These needs continue long after treatment is done!

Zebrack B, et al. *Cancer*. 2006;107:2915-2923.

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## Highest Identified Needs (*continued*)

- In-treatment counseling and supportive care needs
  - Individualized information about disease, treatment, side effects and late effects
  - Informational resources that are appropriate for the developmental stage/age of this population
  - **Opportunities to meet other young adult cancer patients/survivors**
  - **Support from family and friends**

These needs continue long after treatment is done!

Zebrack B, et al. *Cancer*. 2006;107:2915-2923.

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# PRESENTATIONS



## Highest Identified Needs (continued)

- Off-treatment health care needs
  - Having adequate health insurance
  - Ongoing medical monitoring for long-term effects
  - A system for transitioning care from oncologists to primary care providers
  - Evidence-based guidelines for long-term follow-up care

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## Highest Identified Needs (continued)

- Off-treatment counseling and supportive needs
  - Individualized information provided at completion of therapy detailing course of treatment, risks of recurrence and potential late effects, and other survivorship issues
  - **Information about sexuality, fertility and reproductive risks**
  - **Opportunities to meet with other survivors**
  - **Ability to express and cope with feelings about cancer, including the desire to return to normal or find a new sense of normal**

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# PRESENTATIONS



## Common Concerns

- Do I have to tell my cancer history?
- Can an employer not hire me because I've had cancer?
- My job sucks but I have to stay for the health insurance
- How long do I have to see the doctor?
- What if I want to move?
- When do I tell someone I have/had cancer?
- Will I ever be able to have children?
- My friends don't get it, and I love my parents but it sucks being home
- The theme of "loss"



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## Instrumental/Practical Issues

- Interruptions of school and/or work
  - How does this affect their view of self and goals?
- Concrete needs
  - Transportation, lost wages, child care, accessing disability benefits and support
- Restricted abilities
  - Special needs protected by law (workplace accommodations)
  - Future employment concerns

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# PRESENTATIONS



## Interpersonal Issues

- Relationship with parents and family support
  - Role reversal
  - Interruption to autonomy
  - Boundaries between parents and “child”
- Social involvement and relationships with peers and partners
  - Dating, socializing, sex, intimacy
  - Having/managing a family
  - Managing career
  - Role reversal

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## Interpersonal Issues (*continued*)

- Relationships with healthcare providers
  - Needs to look different, communication needs to be more direct and with the patient (not their parents)
  - Don't assume that the young adults do or don't want their parents/significant other present when they are getting information (at diagnosis and after)
  - Don't use medical jargon: don't talk down to them, connect with them in their language (e-mail, text message through their wireless server, be aware of their therapy time)

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# PRESENTATIONS



## Interpersonal Issues *(continued)*

- Relationships with healthcare providers
  - Offer them fertility and support resources up front, don't assume that it will "freak them out"
  - Talk to them about the sexual changes they may experience (reinforce the importance of safe sex)
  - Start a young adult group in your area or make sure to have a list of online support groups
  - Develop a common rule of follow-up treatment for your young adult population, have it in writing and e-mail it to them as well

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*I don't have any quotes or anything to share with them. I've had such a positive experience with everyone in the medical community. It's funny because I miss seeing my friends in the infusion clinic and at my doctor's office. Interaction with people was what I wanted the most when I was sick, and with leukemia you become so limited in terms of where and who you can visit that I always looked forward to talking to the nurses, doctors, assistants, secretaries...everyone! Maybe if you just want to remind everyone that when appropriate, humor can indeed be the best medicine. I loved that everyone joked with me...it was so nice to pretend that things weren't so serious!!*

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# PRESENTATIONS



## What Can I Offer Them?

1. Support!
  - Face to face
  - Networking/time to connect
  - Education in their time and in their language
2. Resources
  - [www.youngadultcancer.ca](http://www.youngadultcancer.ca)
  - [www.youngsurvival.org](http://www.youngsurvival.org)
  - [www.livestrong.org](http://www.livestrong.org)
  - [www.planetcancer.org](http://www.planetcancer.org)
  - [www.imtooyoungforthis.org](http://www.imtooyoungforthis.org)
  - [www.LLS.org](http://www.LLS.org)
  - [www.campdream.org](http://www.campdream.org) (Camp Māk-A-Dream young adult retreat week)

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## Panel Discussion

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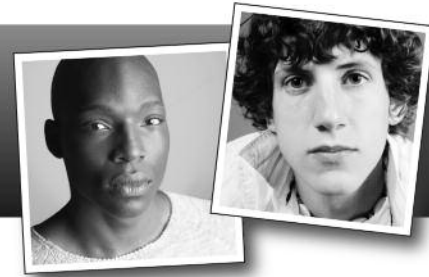
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# NATIONAL RESOURCES



## Resources for Young Adults With Cancer

The Leukemia & Lymphoma Society (LLS)\*  
[www.LLS.org](http://www.LLS.org)

Young Adult Cancer Canada\*  
[www.youngadultcancer.ca/](http://www.youngadultcancer.ca/)

Young Survival Coalition (breast cancer)  
[www.youngsurvival.org/](http://www.youngsurvival.org/)

LiveStrong—The Lance Armstrong Foundation  
[www.Livestrong.org](http://www.Livestrong.org)

Planet Cancer\*  
[www.Planetcancer.org](http://www.Planetcancer.org)

I'm Too Young For This\*  
[www.imtooyoungforthis.org](http://www.imtooyoungforthis.org)

Camp Māk-A-Dream  
[www.campdream.org](http://www.campdream.org)

Life With Cancer®  
[www.lifewithcancer.org](http://www.lifewithcancer.org)

Fertile Hope  
[www.fertilehope.org](http://www.fertilehope.org)

Imerman Angels\*  
[www.imermanangels.org](http://www.imermanangels.org)

Prepare to Live\*  
[www.preparetolive.org](http://www.preparetolive.org)

The Ulman Cancer Fund for Young Adults\*  
[www.ulmanfund.org](http://www.ulmanfund.org)

Redes En Acción  
[www.redesenaccion.org](http://www.redesenaccion.org)

Bone Marrow Transplant Resources\*  
[www.bmtresources.org](http://www.bmtresources.org)

## Resources for Nurses and Healthcare Professionals

The Children's Oncology Group  
(long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers)  
[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

CureSearch  
[www.curesearch.org](http://www.curesearch.org)

Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults With Cancer  
[http://planning.cancer.gov/disease/AYAO\\_PRG\\_Report\\_2006\\_FINAL.pdf](http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf)

**\*Note:** These resources are often available on Twitter® to keep patients better informed, connected, and updated. Many of these resources have blogs as well. Search for these organizations on [www.twitter.com](http://www.twitter.com) to follow them there.



***The Leukemia &  
Lymphoma Society***<sup>®</sup>  
*Fighting Blood Cancers*

**Mission Statement**

The Leukemia & Lymphoma Society's mission:  
Cure leukemia, lymphoma, Hodgkin's disease  
and myeloma, and improve the quality of life  
of patients and their families

**For information on leukemia, lymphoma  
and myeloma, call The Leukemia & Lymphoma  
Society's Information Resource Center at  
(800) 955-4572 or visit [www.LLS.org](http://www.LLS.org).**

The Leukemia & Lymphoma Society  
1311 Mamaroneck Avenue  
White Plains, NY 10605