



**National Cancer Policy Forum/LIVESTRONG Workshop on
Addressing the Needs of Adolescents and Young Adults with Cancer**

Workshop Aims

This workshop will identify gaps and challenges in caring for AYA patients with cancer, and discuss potential strategies and actions to guide stakeholders as they continue their work to improve the quality of care for this population. The workshop will feature discussion panels and invited presentations from clinicians and other advocates working to improve the care and outcomes for the AYA population with cancer. Participants have been invited to discuss topics that will include:

- challenges in developing the evidence base to guide the care of the AYA population,
- the unique psychosocial needs of the AYA population with cancer,
- behavioral health and lifestyle management for the AYA population,
- long-term concerns for survivors of AYA cancers, and
- end of life care and planning in the AYA population.

Workshop Agenda

July 15, 2013	
7:45 am	Breakfast and Registration
8:15 am	<p>Welcome from the IOM National Cancer Policy Forum Patricia Ganz, UCLA Vice Chair, National Cancer Policy Forum</p> <p>Overview of the Workshop Brenda Nevidjon, Duke School of Nursing Ruth Rechis, LIVESTRONG Foundation Workshop Planning Committee Co-Chairs</p>
8:30 am	<p>Session 1: Overview <i>Moderator: Ruth Rechis, LIVESTRONG Foundation</i></p> <p>Epidemiology and Biology of Cancer in the AYA Population</p> <ul style="list-style-type: none"> • Archie Bleyer, OHSU and St. Charles Health System <p>Developmental and Psychological Stages and Disruptions, Ownership of One's Health, and the Role of the Family</p> <ul style="list-style-type: none"> • Karen Fasciano, Dana-Farber Cancer Institute <p>Overview of Progress since the 2006 PRG report</p> <ul style="list-style-type: none"> • Brandon Hayes-Lattin, OHSU <p>Group Discussion</p>

10:00 am	Break
10:15 am	<p>Session 2: Unique Risks & Vulnerabilities of AYA Patients Across the Lifespan <i>Moderator: Ashley Smith, NCI</i></p> <p>AYA Survey Results</p> <ul style="list-style-type: none"> • Ruth Rechis, LIVESTRONG Foundation • Eric Tai, CDC • Lynne Harlan, NCI/DCCPS <p>Socioeconomic Challenges</p> <ul style="list-style-type: none"> • Helen Parsons, The University of Texas Health Science Center at San Antonio • Robin Yabroff, NCI <p>Psychological and Relationship Challenges and Management</p> <ul style="list-style-type: none"> • Bradley J. Zebrack, University of Michigan School of Social Work <p>Group Discussion</p>
12:45 pm	Lunch Break
1:45 pm	<p>Session 3: Treatment and Survivorship Care Planning for AYA patients <i>Moderator: Lynda Beaupin, Roswell Park Cancer Institute</i></p> <p>Long-term and Late Effects Following AYA Cancer</p> <ul style="list-style-type: none"> • Kevin Oeffinger, MSKCC <p>Selecting Treatment Protocols to Optimize Patient Outcomes and Survival</p> <ul style="list-style-type: none"> • Brandon Hayes-Lattin, OHSU <p>Preserving Fertility</p> <ul style="list-style-type: none"> • Jennifer Levine, Columbia University <p>Surveillance for Recurrence and Secondary Cancers</p> <ul style="list-style-type: none"> • Patricia Ganz, UCLA <p>Group Discussion</p>
4:00 pm	Break
4:15 pm	<p>AYA Survivor Panel Discussion <i>Moderator: Heidi Adams, President and CEO of Critical Mass: The Young Adult Cancer Alliance</i></p> <ul style="list-style-type: none"> • Hollie Farrish • Chris Prestano • Benjamin Rubenstein
5:15 pm	Wrap up Day 1 and Adjourn

July 16, 2013

7:30 am	Breakfast and registration
8:00 am	<p>Session 4: Lifestyle Management and Behavioral Health across the Care Continuum <i>Moderator: Karen Fasciano, Dana Farber Cancer Institute</i></p> <p>Diet, Physical Activity, and Weight</p> <ul style="list-style-type: none"> • Bernard Fuemmeler, Duke University School of Medicine <p>Smoking, Alcohol, and Other Risk-Taking Behaviors</p> <ul style="list-style-type: none"> • Karen Emmons, Dana-Farber Cancer Institute <p>Communication with AYA Patients</p> <ul style="list-style-type: none"> • Jackie Casillas, UCLA Medical Center <p>AYA Specific Programs</p> <ul style="list-style-type: none"> • Rebecca Block, OHSU <p>Group Discussion</p>
9:45 am	Break
10:00am	<p>Session 5: Gaps in Quality Care and Models of Care <i>Moderator: Brenda Nevidjon, Duke University School of Nursing</i></p> <p>Transition and Gaps in AYA Survivorship Care</p> <ul style="list-style-type: none"> • David Freyer, Children’s Hospital Los Angeles <p>Palliative and End of Life Care for AYA Patients</p> <ul style="list-style-type: none"> • Justin Baker, St. Jude QOL and Palliative Care Service <p>Gaps in the Evidence Base and Research Priorities for AYA Survivorship Care</p> <ul style="list-style-type: none"> • Melissa Hudson, St. Jude Children’s Research Hospital <p>Health Insurance Challenges Faced by AYA</p> <ul style="list-style-type: none"> • Elyse Park, Massachusetts General Hospital and Harvard Medical School <p>The Impact of the ACA and Future Directions</p> <ul style="list-style-type: none"> • Kavita Patel, Brookings Institution <p>Group Discussion</p>
12:15 pm	<p>Workshop Wrap Up Tom Kean, C-Change</p>
12:30 pm	Lunch/Adjourn