

# Adolescent and Young Adult Cancers

## Cancers Affecting Adolescents and Young Adults (AYAs)

Nearly 69,200 adolescents and young adults, defined as people aged 15-39, were diagnosed with cancer in 2008.<sup>1</sup> The incidence of specific cancer types varies dramatically across the AYA age continuum. For example, leukemias, lymphomas, and germ cell tumors (cancers that begin in cells that give rise to sperm or eggs, such as testicular cancer) are the most common cancer types in younger AYAs. By ages 25-39, these cancers decline in frequency and other cancers, such as cervical, colorectal, and, particularly, breast cancer, increase in older AYAs.<sup>1</sup>

## Incidence and Survival

Cancer is the leading cause of disease-related death in the AYA population; among females it is the most common disease-related cause of death, and among males it is second only to heart disease.<sup>2</sup> In the AYA age group, only unintentional injury, suicide, and homicide claim more lives than cancer.

Incidence rates of cancers in AYAs vary by race and ethnicity. Both incidence rates and 5-year survival are highest among white non-Hispanic AYAs. American Indian/Alaska Native AYAs have the lowest cancer incidence rates, but they also have poor survival rates compared with other racial or ethnic groups, with the exception of African Americans, who have the lowest 5-year survival estimates.

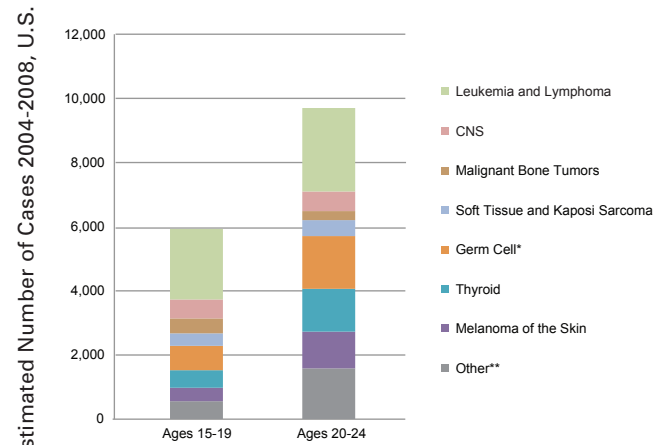
Unlike both younger and older age groups, AYAs have experienced little improvement in survival over the last two decades. Several factors may account for the lack of improved outcomes, including:

- limited access to care and insurance coverage
- delayed diagnosis of primary cancers
- inadequate treatment practices and settings, including inconsistent treatment and follow-up care guidelines
- poor understanding of the biology and etiology of the cancers in this population
- inadequate collection of patients and patient data
- low numbers of clinical trials and poor participation
- unique psychosocial and supportive care needs
- limited emphasis on prevention and early detection.

<sup>1</sup> Data from the Surveillance, Epidemiology, and End Results (SEER) Program (<http://seer.cancer.gov>).

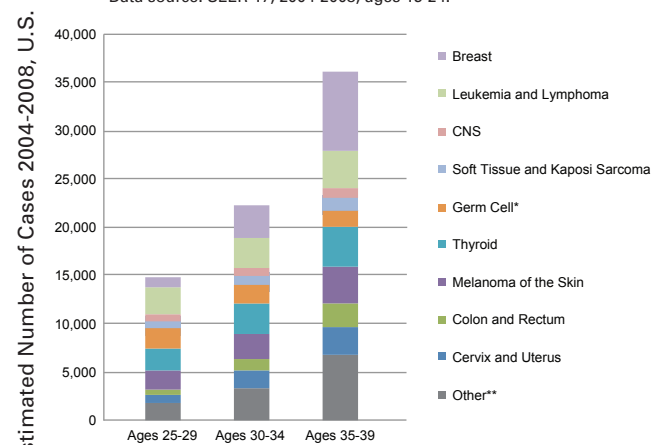
<sup>2</sup> Total U.S. deaths in 2007, ages 15-39, from the SEER Program and the National Center for Health Statistics.

## Common Types of Cancers Affecting AYAs



\* Includes testicular cancer.

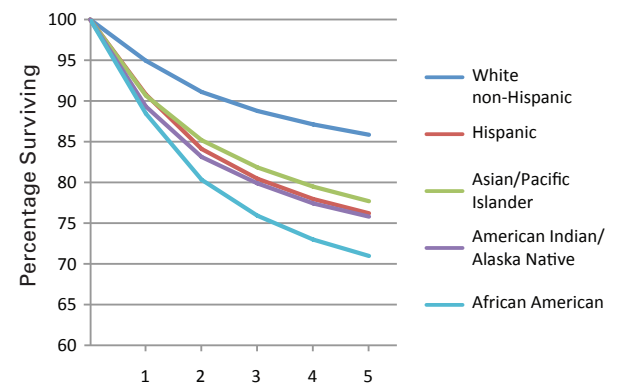
\*\* Includes breast, cervix, colon, and other less prevalent cancers. Data source: SEER 17, 2004-2008, ages 15-24.



\* Includes testicular cancer.

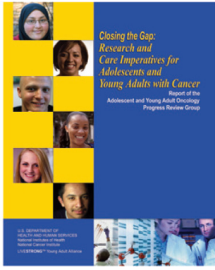
\*\* Includes malignant bone tumor and other less prevalent cancers. Data source: SEER 17, 2004-2008, ages 25-39.

## 5-Year Survival of AYAs With Cancer

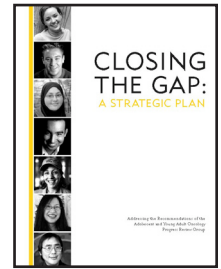


Hispanic ethnicity is independent of race and can overlap with African Americans, Asians/Pacific Islanders, or American Indians/Alaska Natives. White is limited to non-Hispanic white. Analysis was based on any death from any cancer site in both sexes and all races, ages 15-39. Data Source: SEER 13 Areas, 1992-2007.

## Strategies to Improve AYA Cancer Outcomes



- In 2005-2006, the National Cancer Institute (NCI) partnered with the Lance Armstrong Foundation (LAF) to address the special research and cancer care needs of AYAs and to solicit recommendations for a national agenda to improve cancer prevention, early detection, diagnosis, treatment (including survivorship care), and outcomes among AYAs. The progress review group (PRG) report, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*, can be found at [http://planning.cancer.gov/library/AYAO\\_PRG\\_Report\\_2006\\_FINAL.pdf](http://planning.cancer.gov/library/AYAO_PRG_Report_2006_FINAL.pdf).



- Representatives from NCI and LAF's LIVESTRONG Young Adult Alliance also developed strategies for transitioning the PRG recommendations into reality. These strategies are detailed in the 2007 report: *Closing the Gap: A Strategic Plan*, <http://www.livestrong.org/pdfs/LAF-YAA-Report-pdf>.
- NCI's **Trans-Divisional AYA Oncology Working Group** was formed to address recommendations in the PRG report and the subsequent strategic plan. This group of NCI staff meets monthly to develop and support research and activities to address cancer in young people and AYAs.

## Examples of NCI Activities Relevant to AYA Cancers

### Selected Clinical Trials in AYA Cancer Research:

- **Phase II Study of Cediranib (AZD 2171) in Patients with Alveolar Soft Part Sarcoma** is testing whether the experimental drug cediranib is effective in slowing or stopping the growth of alveolar soft part sarcoma (ASPS), a rare type of soft-tissue sarcoma that typically affects teenagers and young adults. <http://www.cancer.gov/ncicancerbulletin/081010/page6>
- **Sutinib or Cediranib for Alveolar Soft Part Sarcoma** is testing the safety and effectiveness of these two drugs to treat ASPS. <http://www.cancer.gov/clinicaltrials/search/view?cdrid=703753&protocolsearchid=9623123&version=patient>
- **Combination Chemotherapy in Treating Patients with Non-Metastatic Extracranial Ewing Sarcoma** is a phase III trial studying a combination chemotherapy regimen of three drugs. <http://www.cancer.gov/clinicaltrials/search/view?cdrid=687639&protocolsearchid=9623136&version=patient>
- **The Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE) Study** is a population-based cohort study funded by NCI with support from LAF. The study collected medical record and survey data from over 500 newly diagnosed AYA cancer patients with

germ cell, Hodgkin and non-Hodgkin lymphoma, acute lymphoblastic leukemia, or sarcoma. [http://outcomes.cancer.gov/surveys/aya/aya\\_hope\\_fact\\_sheet.pdf](http://outcomes.cancer.gov/surveys/aya/aya_hope_fact_sheet.pdf)

- In 2009, the NCI AYA working group co-hosted (along with LAF) a joint workshop entitled **Unique Characteristics of AYA Cancers: Focus on Acute Lymphoblastic Leukemia, Breast Cancer, and Colon Cancer**. As a result of the Workshop, plans are under way to study a series of AYA colon cancer specimens. NCI is also supporting a study entitled **Genomic Analysis of AYA Acute Lymphoblastic Leukemia**. [http://ctep.cancer.gov/industryCollaborations/aya\\_biology\\_workshop.htm](http://ctep.cancer.gov/industryCollaborations/aya_biology_workshop.htm) and <http://www.ncbi.nlm.nih.gov/pubmed/21436065>
- The **NCI Adolescents and Young Adults with Cancer Portal** provides information on AYA cancers, treatment and clinical trials, coping and support, survivorship, resources, reports, and other related topics. <http://www.cancer.gov/cancertopics/aya>

## Selected Advances in AYA Cancer Research

- Using data from the NCI Patterns of Care Study, researchers have identified that **factors associated with AYA cancer patients' low levels of participation in clinical trials** include being uninsured, being of older age, or being treated by nonpediatric oncologists. <http://www.ncbi.nlm.nih.gov/pubmed/21931022>
- The AYA HOPE Study has demonstrated that it is **feasible to conduct research in AYA cancer survivors** identified through population-based registries, but researchers must be realistic in their expectations as the AYA population is mobile and difficult to contact. <http://www.ncbi.nlm.nih.gov/pubmed/21274648>
- The NCI Cancer Bulletin's **Special Issue: Adolescent and Young Adult Cancers** had articles, interviews and videos on AYA issues such as cancer biology, clinical trials, psychosocial challenges, survivorship, and resources for adolescent and young adult patients. <http://www.cancer.gov/ncicancerbulletin/072611/>
- The NCI Cancer Bulletin has also published two AYA-related articles: **Overcoming Age Limits in Cancer Clinical Trials** (<http://www.cancer.gov/ncicancerbulletin/051810/page8>) and **Preserving Fertility While Battling Cancer** (<http://www.cancer.gov/ncicancerbulletin/011111/page5>).