

# Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer

Report of the Adolescent and Young Adult Oncology  
Progress Review Group

**National Cancer Advisory Board Meeting  
September 6, 2006**

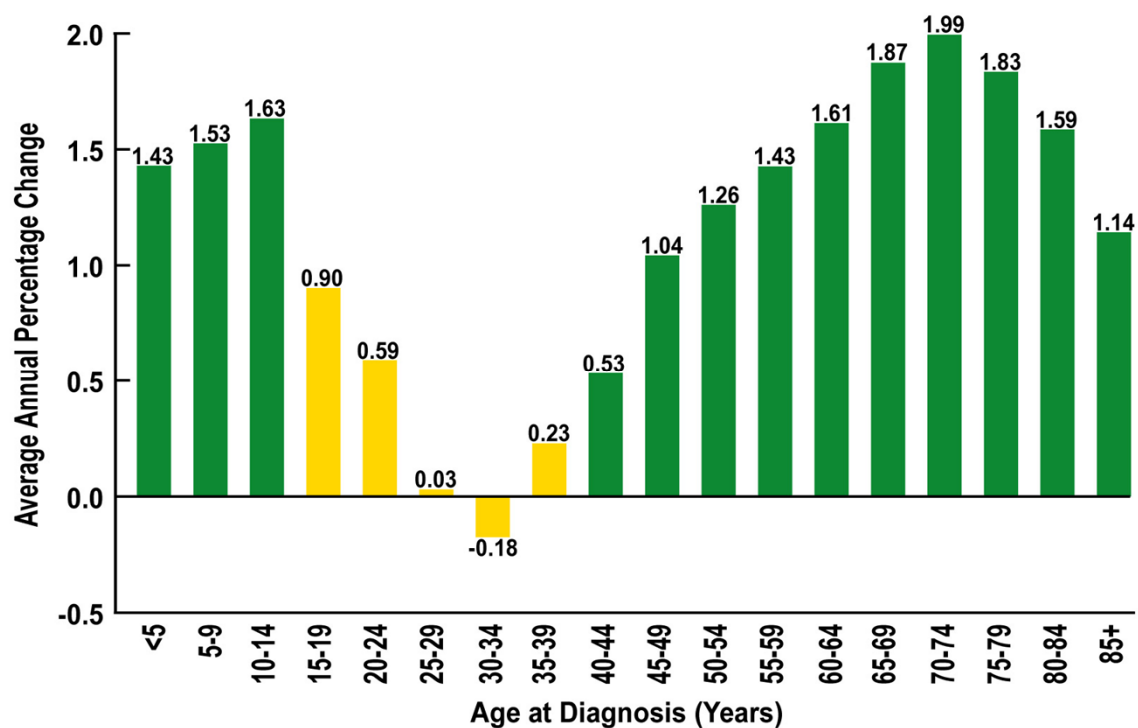
## Presentation Outline

- Overview of the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG)
  - Barry Anderson  
PRG Executive Director
- Priority Recommendations from the AYAO PRG Roundtable
  - Karen Albritton  
PRG Co-Chair
  - Michael Caligiuri  
PRG Co-Chair
- Next Steps: Implementation
  - Doug Ulman  
Lance Armstrong Foundation

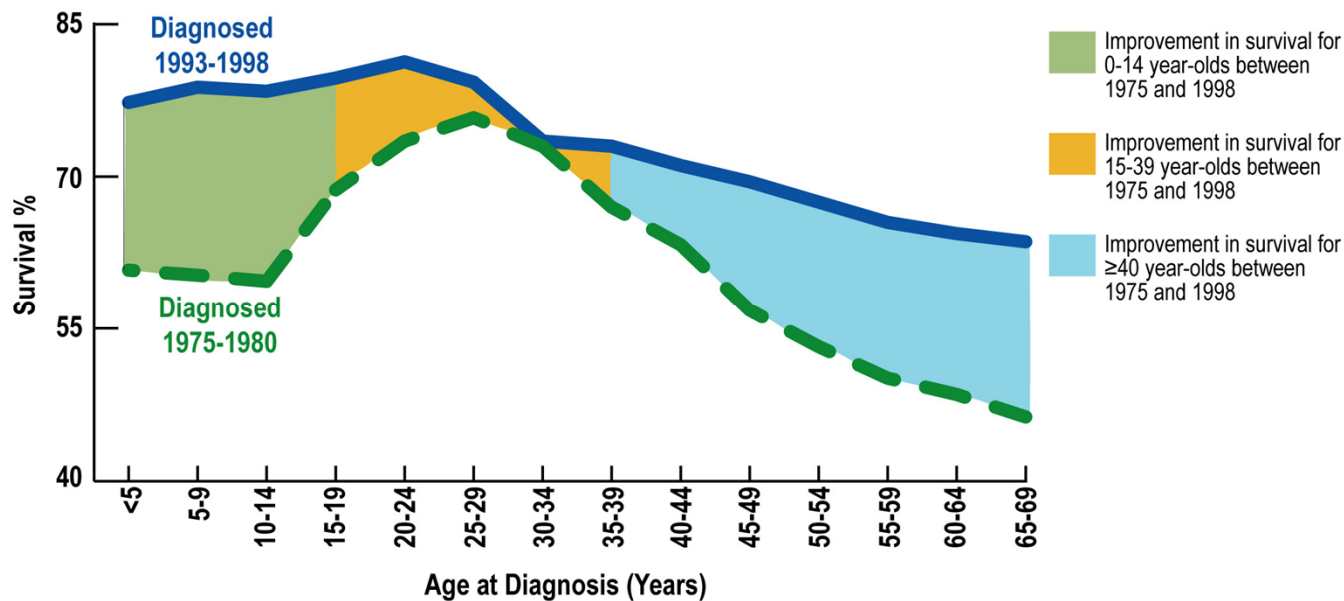
# Why an AYAO PRG?

- Cancer in the AYAO age range is a significant problem.
  - Approximately 68,000 people ages 15 to 39 years were diagnosed with cancer in 2002, almost 8 times more than children under age 15.
  - These cases represent approximately 6 percent of all new cancer diagnoses.
- AYA cancer is without a “home”.
  - Adolescent and young adult cancer patients lack a health care niche.
  - Medicine and society are largely unaware of the AYAO population.
- Survival in the AYAO age range has not improved in more than two decades as illustrated in the AYAO PRG Report.
  - Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975 to 1997
  - 5-Year Survival of Patients with Cancer by Era, SEER, 1975–1998

## Survival Improvement Gap: *Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975–1997*



## Survival Improvement Gap: 5-Year Survival of Patients with Cancer by Era, SEER, 1975–1998



# The AYA0 Age Range

- The AYA0 PRG defined the AYA population as comprising individuals 15 through 39 years of age.
  - The gap in survival improvement is most pronounced in individuals ages 15–39 years.
  - At its initial meeting, the **LIVESTRONG™** Young Adult Alliance concluded that the social delineation of young adults included ages of up to 39 years.
  - Advocacy groups serving the young adult population, e.g., Planet Cancer, Young Survival Coalition, Life Lab, and Fertile Hope, consider their target consumer to be ages 18–39 years.
  - AYAs are a heterogenous population, but no more so than the pediatric and geriatric populations.
  - Programs at institutions serving AYAs with cancer recognize this heterogeneity; developmentally appropriate interventions are used for subsets within this age range.

## Three Objectives to Be Met

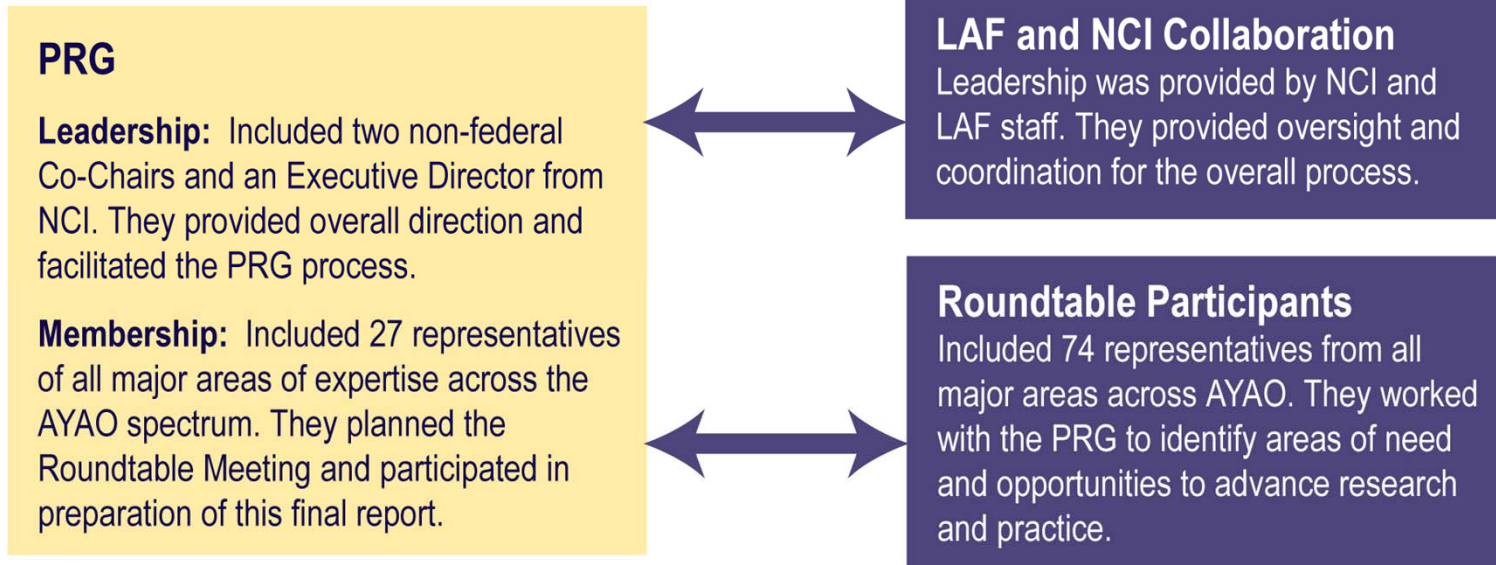
- Define and describe issues unique to the cancers that occur in the AYA population and the issues that distinguish AYA patients from pediatric and older adult cancer patients.
- Gather experts with medical, biological, psychosocial, behavioral, and business knowledge regarding the AYA population and AYA cancers. Identify what needs to be learned and implemented to promote cancer prevention and improve their survival and quality of life.
- Facilitate the adoption and implementation of cancer research, social and health policy, community programs, and clinical interventions focused on AYA cancer prevention and treatment and evaluate the impact of these efforts.

## Why a Co-Sponsored PRG?

- The AYAO PRG—a unique partnership between NCI and the **LIVESTRONG** Young Adult Alliance.
  - The collaboration has allowed NCI to better leverage its resources and has facilitated the PRG process. The **LIVESTRONG** Young Adult Alliance's commitment to the PRG enhances the potential of realizing many of the PRG recommendations.
  - The collaboration has allowed the **LIVESTRONG** Young Adult Alliance the opportunity to address a top priority issue for LAF through a process that is firmly established and well recognized.



# Participants in the PRG Process



# A Three-Phase PRG Process



# Adolescent and Young Adult Oncology Roundtable

- Eleven Breakout Groups organized into core topics and cross-cutting sections:
  - Core Topic Breakout Groups:
    - Biology
    - Prevention/Cancer Control/Epidemiology/Risk
    - Insurance
    - Clinical Care Models
    - Psychosocial/Behavioral Factors
    - Long-term Effects
  - Cross-cutting Breakout Groups:
    - Access
    - Clinical Trials/Research
    - Health-related Quality of Life
    - Special Populations
    - Awareness

# Priority Recommendations



# Recommendation 1

## **Identify the characteristics that distinguish the unique cancer burden in the AYA O patient.**

- Elucidate unique biologic characteristics of AYA cancers and AYA O patients that affect disease outcome in this population.
- Elucidate AYA life-stage/developmental characteristics that influence care seeking, adherence to treatment, and medical and psychosocial outcomes.
- Identify and ameliorate health disparities experienced by AYA cancer patients and survivors.

## Recommendation 2

**Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care to AYAs.**

- Raise awareness of AYA cancer issues as a first step toward increasing national focus and resource allocation to address the AYA cancer problem.
- Provide targeted education to patients, families/caregivers, and the public about AYA cancer issues.
- Educate multidisciplinary providers who work with AYAs to improve referrals and services to this population.

## Recommendation 3

### **Create the tools to study the AYA cancer problem.**

- Create a large prospective database of AYA cancer patients to facilitate research on this age group.
- Increase the number of annotated specimens to support research progress.
- Create/modify needed assessment tools specific to AYA cancer issues.
- Improve grant coding and search term standardization to enable evaluation of research efforts and progress.
- Expand clinical trials for AYAs to increase treatment choices and accelerate treatment advances.

## Recommendation 4

**Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).**

- Develop, evaluate, and disseminate standards of care for AYA cancer patients and survivors to improve outcomes.
- Establish a national network or coalition of providers and advocates seeking to achieve a standard of excellence in AYA cancer care.



## Recommendation 5

### **Strengthen and promote advocacy and support of the AYA cancer patient.**

- Address the subjective experience of AYA patients.
- Build the capacity of existing resources to address AYA psychosocial needs.
- Evaluate existing programs and develop new interventions.

# Implementation Meeting

- Phase II of the PRG Process begins with the Implementation Meeting scheduled for November 10–12, 2006 in Austin, Texas.
- The **LIVESTRONG** Young Adult Alliance is sponsoring and coordinating this meeting of stakeholders in the cancer care community.
- The cross-disciplinary nature of this PRG process will be continued at this meeting, where diverse stakeholders from all backgrounds will meet:
  - Clinicians and researchers—AYA specialists, pediatricians, gerontologists, and disease-specific experts
  - Cancer survivors
  - Advocacy groups
  - Statisticians
  - Pharmaceutical industry representatives
  - Government agencies such as NCI and the Department of Defense

# AYAO PRG Leadership

- **Karen Albritton, M.D.**, *PRG Co-Chair*, Dana Farber Cancer Institute
- **Michael Caligiuri, M.D.**, *PRG Co-Chair*, Ohio State University
- **Barry Anderson, M.D., Ph.D.**, *PRG Executive Director*, Cancer Therapy Evaluation Program, NCI
- **Cherie Nichols, M.B.A.**, *NCI Representative*, Office of Science Planning and Assessment, NCI
- **Doug Ulman**, *LAF Representative*, Lance Armstrong Foundation

# AYAO PRG Members

- **Heidi Adams**, Planet Cancer
- **Lodovico Balducci, M.D.**, H. Lee Moffitt Cancer Center
- **Ronald Barr, M.B., Ch.B., M.D.**, McMaster University
- **Archie Bleyer, M.D.**, St. Charles Medical Center
- **Maryann Carouso, F.N.P., R.N.**, Memorial Sloan-Kettering Cancer Center
- **William Hicks, M.D.**, Ohio State University
- **Marion Lee, M.P.H., Ph.D.**, University of California, San Francisco
- **Steven Lipkin, M.D., Ph.D.**, University of California, Irvine
- **Mary McCabe, R.N.**, Memorial Sloan-Kettering Cancer Center
- **Michael Moore, M.D.**, Nationwide Insurance
- **Peter Pisters, M.D.**, M.D. Anderson Cancer Center
- **Brad Pollock, M.P.H., Ph.D.**, University of Texas Health Science Center
- **Amelie Ramirez, Dr.P.H.**, Baylor College of Medicine
- **Lynn Ries, M.S.**, SEER Program, NCI
- **Lorna Rodriguez-Rodriguez, M.D., Ph.D.**, Cancer Institute of New Jersey
- **Lydia Shrier, M.P.H., M.D.**, Children's Hospital Boston
- **Muneesh Tewari, M.D., Ph.D.**, Fred Hutchinson Cancer Center
- **Beth Virnig, M.P.H., Ph.D.**, University of Minnesota School of Public Health
- **Karen Weiss, M.D.**, U.S. Food and Drug Administration
- **Bruce Williams**, Enzon Pharmaceuticals
- **Brock Yetso**, The Ulman Cancer Fund for Young Adults
- **Brad Zebrack, Ph.D.**, University of Southern California