

Overview of Progress Since the 2006 Report of the Adolescent and Young Adult Oncology Progress Review Group

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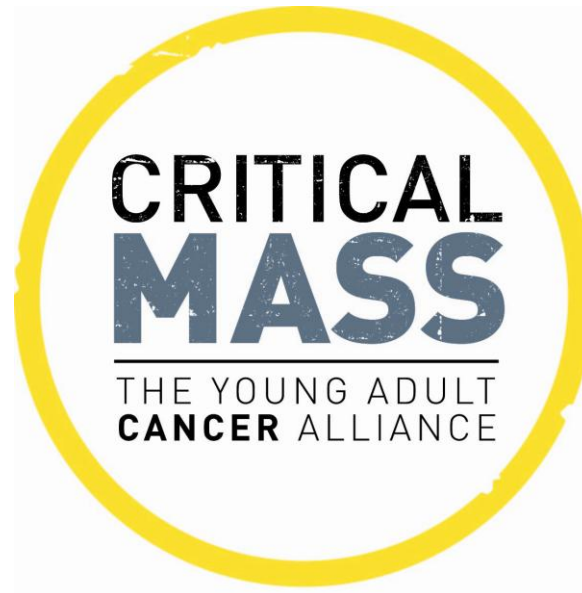
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NCI PRG Recommendations

1. Identify the characteristics that distinguish the unique cancer burden in the AYA patient.
2. Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.
3. Create the tools to study the AYA cancer problem.
4. Ensure excellence in service delivery across the cancer control continuum.
5. Strengthen and promote advocacy and support of the AYA cancer patient.

L I V E S T R O N G TM

YOUNG ADULT ALLIANCE



1. Distinguishing Characteristics

- Elucidate unique biologic characteristics of AYA cancers and AYA 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.

1. Distinguishing Characteristics

- Disease-specific retrospective analyses
 - Osteosarcoma, colorectal cancer, ALL, breast cancer, testicular cancer, thyroid cancer
- NCI Biology Workshop (Tricoli, J NCI 2011)
- Health-related QOL (Smith, JCO 2013)
- Epidemiology (Johnson, JAMA 2013)
- Toxicity (Gupta, Cancer 2012)
- Distress (Kwak, JCO 2013)

2. Education, Training, and Communication

- 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.

2. Education, Training, and Communication

- ASCO: Focus Under Forty
- Nurse Oncology Education Program (NOEP): At The Crossroads
- Adolescent and Young Adult Oncology Training for Health Professionals: A Position Statement (Hayes-Lattin, JCO 2010)
- National Young Adult Cancer Awareness Week

3. Tools

- 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.

3. Tools

- Age-eligibility efforts
- ALL study: CALGB, SWOG, ECOG 10403
- AYA Cohort feasibility
- PubMed AYA Cancer hits
 - 2002: 210
 - 2012: 5232

4. Service Delivery

- 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.

4. Service Delivery

- LIVESTRONG Young Adult Alliance/Critical Mass
- Fertile Hope Centers of Excellence
- Quality cancer care for adolescents and young adults: a position statement (Zebrack, JCO 2010)
- NCCN AYA Guidelines

5. Advocacy and Support

- 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.

5. Advocacy and Support

- Critical Mass Annual Meeting
 - Alliance membership 350
- International Charter of Rights for Young People with Cancer (<http://cancercharter.org>)

Continuing Opportunities

1. Characteristics

- Support research in unique biology of tumors and hosts
- Support research in the influence of life stage/development on outcomes
- NCI Workshop: September 16-17, 2013

2. Education/Training/Communication

- Evolve from “raise awareness” to requirement in educational curricula and certification standards

Continuing Opportunities

3. Tools

- Remain a need:
 - 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.

Continuing Opportunities

4. Service Delivery

- Coordination of efforts to certify programs and apply guidelines
- Document impact on outcomes

5. Advocacy and Support

- Map the network
- Support evaluation of programs/services

Future Efforts

- Coordination
 - Critical Mass
- National Clinical Trials Network
 - COG and SWOG AYA Committees
- Research Priorities
 - NCI Workshop
- Units
 - Teenage Cancer America
- Recognition
 - Change It Back Center of Excellence

Top 3 Priorities

- Research
 - Formalize internal efforts at NCI and CDC
- Tools
 - Fund large-scale prospective effort inclusive of biology, therapy, support and outcomes
- Evaluation
 - Document outcomes and effect of AYA-specific efforts