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LIVESTRONG
YOUNG ADULT
ALLIANCE
IMPLEMENTATION
PLAN

A LIVESTRONG FOUNDATION REPORT



ACKNOWLEDGEMENTS

The LIVESTRONG Foundation would like to thank the members of the LIVESTRONG Young Adult Alliance Steering Committee, the Task Forces, and the Working Group Chairs for their time, effort, and unwavering dedication to the Alliance and the adolescent and young adult cancer movement.

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In addition, the **LIVESTRONG** Foundation graciously thanks all current and former members of the **LIVESTRONG** Young Adult Alliance for their dedication and leadership in the field of adolescent and young adult oncology.

This report is dedicated to Randi Rosenberg, a founding member of the Alliance and its first advocate co-chair, a tireless champion for the AYA cancer movement and an inspiration to all who met her.

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EXECUTIVE SUMMARY

Outcomes and survival rates for adolescents and young adults (AYAs) diagnosed with cancer have failed to improve significantly over the past several decades despite advances in cancer prevention, early detection and treatment. Recognizing the need for a coordinated effort to address the gaps in cancer care for AYAs, the National Cancer Institute (NCI) and the LIVESTRONG Foundation established an innovative public-private collaboration in 2005 and 2006 to sponsor the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG). The AYAO PRG was comprised of oncology experts who were charged with reviewing the science to address the research and cancer care needs of adolescents and young adults. This review included the unique biological aspects and psychosocial experiences associated with cancer in the AYA population, which is defined as those diagnosed with cancer between the ages of 15 and 39. The AYAO PRG was asked to provide recommendations for a national agenda to improve cancer prevention, detection, diagnosis, treatment and outcomes for these patients. The Report, *closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*, was printed August 2006. (<http://livestrong.org/pdfs/LAF-YAA-Report-pdf>) The AYAO PRG developed five key recommendations for improving outcomes and survival rates for AYAs with cancer.

Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.

Recommendation 2: Provide education, training and communication to improve awareness, prevention, access and quality cancer care for AYAs.

Recommendation 3: Create the tools to study the AYA cancer problem.

Recommendation 4: Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship and end of life).

Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient.

The AYAO PRG was the first and only progress review group of the 13 PRGs conducted by NCI to have an established, published implementation plan. This report, "Closing the Gap: A Strategic Plan" (referred to in this document as the "Implementation Plan"), (<http://livestrong.org/pdfs/LAF-YAA-Report-pdf>) was a five-year plan of action based on 19 strategies developed at a November 2006 meeting that relate to the AYAO PRG. Many aspects of the plan, as described in the report, were actualized and funded through the **LIVESTRONG** Young Adult Alliance (Alliance), a program of the **LIVESTRONG** Foundation.

What is the Alliance?

The Alliance was developed simultaneously to the AYAO PRG and it became the organized structure to address the needs of the Implementation Plan. The Alliance was a coalition of organizations that included universities and academic medical centers, cancer centers, community hospitals, professional societies, nonprofit and advocacy groups (NP&A), and liaison members from government agencies, such as the NCI and the Centers for Disease Control and Prevention (CDC).

This report, "I Didn't Know I Could Get Cancer: Results of the LIVE**STRONG** Young Adult Alliance Five-Year Implementation Plan," provides information on the Implementation Plan's outlined activities to address the AYAO PRG recommendations. Activities documented in this report were carried out by designated Alliance task forces and working groups, as well as by the NCI and other Alliance member organizations, including the LIVE**STRONG** Foundation.

Alliance members take great pride in the collaboration and individual initiatives that have led to the five-year implementation plan's successful completion.



INTRODUCTION

Due to advances in cancer prevention, early detection and treatment over the past several decades, there have been important improvements in the outcomes and survival rates of children and older adults diagnosed with cancer. However, outcomes and survival rates for adolescents and young adults (AYAs)—individuals between the ages of 15 and 39—have failed to improve significantly. In fact, survival trends show a worse prognosis for young adults diagnosed with cancer today than those in the same age group diagnosed 25 years ago.

For the past 25 years, the incidence of cancer among AYAs in the United States has increased steadily (Bleyer et al., 2006). Nearly 70,000 AYAs were diagnosed with cancer each year (Tricoli, Seibel, Blair, Albritton & Hayes-Lattin, 2011), and cancer remains a leading cause of disease-related death among AYAs (National Cancer Institute (NCI), 2011).

ADOLESCENT AND YOUNG ADULT ONCOLOGY PROGRESS REVIEW GROUP

Recognizing the need for a coordinated effort to address the gaps in cancer care for AYAs, in 2005 and 2006 the National Cancer Institute (NCI) and the LIVESTRONG Foundation established an innovative public-private collaboration to sponsor the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG). The AYAO PRG was comprised of oncology experts who were charged with reviewing the science to address the research and cancer care needs of AYAs. This review included the unique biological aspects and psychosocial experiences associated with cancer in the AYA population. The review group was asked to provide recommendations for a national agenda to improve cancer prevention, detection, diagnosis, treatment and outcomes for these patients. Those recommendations are in the AYAO

PRG Report, which is available at:

[http://www.livestrong.org/pdfs/AYAO PRG Report 2006 FINAL](http://www.livestrong.org/pdfs/AYAO_PRG_Report_2006_FINAL). The AYAO PRG

developed five key recommendations for improving outcomes and survival rates for AYAs with cancer.

Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.

Many cancers in AYAs have different biological characteristics than those seen in the same cancers in children and older adults. The relative lack of biological research targeted specifically to AYAs with cancer translates to an inability to provide the best treatment. In addition, AYAs have developmental and psychosocial challenges associated with cancer not seen in other age groups. Research is needed to assess the existing gaps fully and to address any unmet needs.

Specific objectives of this recommendation included:

- a. Clarify the unique biologic characteristics of AYA cancers and of AYA patients that affect disease outcome in this population;
- b. Ascertain the AYA life stage/developmental characteristics that influence care seeking, adherence to treatment, and medical and psychosocial outcomes; and
- c. Identify and improve health disparities that AYA cancer patients and survivors experience.

Recommendation 2: Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.

Health providers, the general public and AYAs often are unaware that AYAs can and do get cancer. This lack of awareness leads to delays in diagnosis at multiple levels. The AYA's

delayed visit to the family doctor and the doctor's low suspicion of cancer result in delayed referral to the appropriate specialists. Moreover, training programs for health care providers often do not address AYA-specific issues. There also is a need to educate providers on the importance of increasing the number of AYAs who participate in clinical trials. Advances in treatment will not be possible without the appropriate research. Specific objectives of this recommendation included:

- a. Raise awareness of AYA cancer issues as a first step toward increasing national focus and resource allocation;
- b. Provide targeted education to patients, families/caregivers and the public; and
- c. 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.

The existing infrastructure does not adequately support AYA-specific research. New AYA-specific tools need to be created and utilized. Specific objectives of this recommendation included:

- a. Create a large prospective database of AYA cancer patients to facilitate research on this age group;
- b. Increase the number of annotated specimens to support research progress;
- c. Create/modify needed assessment tools specific to AYA cancer issues;
- d. Improve grant coding and search-term standardization to better evaluate research efforts and progress; and
- e. 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).

This recommendation focuses on standards of care. Standards are dynamic and will change as advances in care are achieved. Specific objectives of this recommendation included:

- a. Develop, evaluate, and disseminate standards of care for AYA cancer patients and survivors to improve outcomes; and
- b. 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.

Effective support of AYAs with cancer must address all aspects of patient care, including the subjective experience of AYAs and their psychosocial needs. Specific objectives of this recommendation included:

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

LIVESTRONG YOUNG ADULT ALLIANCE

Simultaneous to the AYAO PRG's advice to establish a national network of providers and advocates, the LIVESTRONG Foundation established the LIVESTRONG Young Adult Alliance (Alliance). This was a coalition of organizations with members from universities, NCI-designated cancer centers, community hospitals, professional societies, nonprofit and advocacy groups (NP&A), and liaison members from government agencies, such as NCI and the Centers for Disease Control and Prevention (CDC). (See Figure 1, "2011 Membership Structure by Organization.")

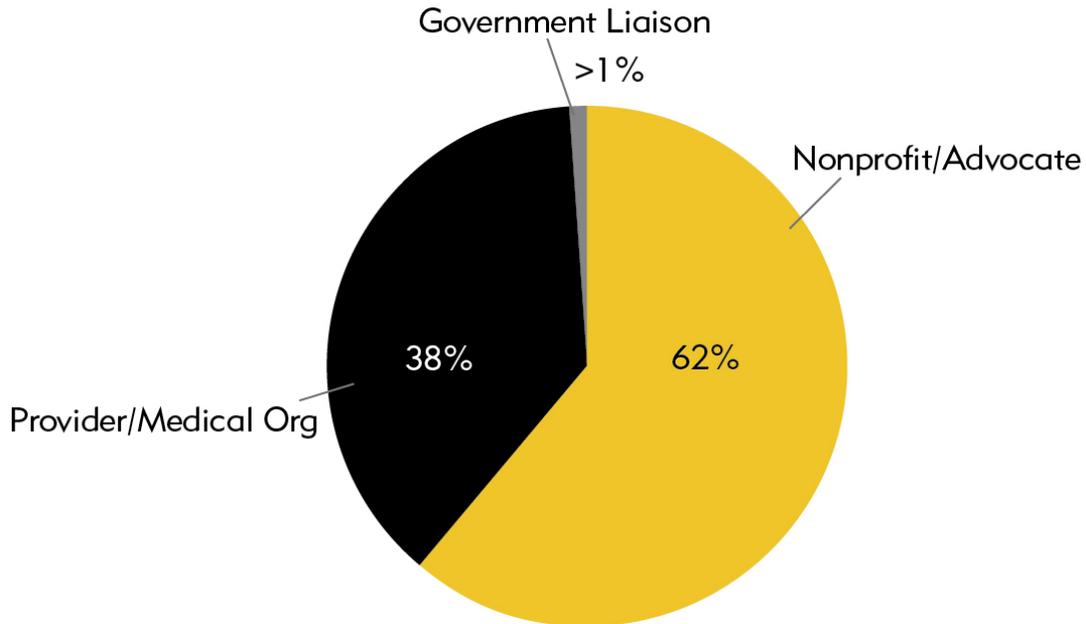


Figure 1. 2011 Membership Structure by Organization

The Alliance's mission was to improve survival rates and quality of life for AYAs with cancer. To achieve that and to put the AYAO PRG recommendations into effect, representatives from founding Alliance member organizations met with PRG members and NCI

staff in November 2006 to draft and publish “Closing the Gap: A Strategic Plan” (to be referred to in this report as the “Implementation Plan”). The AYAO PRG was the first and only progress review group to have an established, published implementation plan that was sponsored by the LIVESTRONG Foundation. The plan can be found at: www.livestrong.org/pdfs/LAF-YAA-Report-pdf.

The Implementation Plan

The Implementation Plan was a five-year plan of action based on strategies developed at the November 2006 meeting that relate to the AYAO PRG recommendations. These strategies were categorized into three themes: science, standards of care and awareness. Planned actions for each theme were listed in order of increasing complexity. Many of the actions could be implemented concurrently; however, in some instances, successfully implementing latter actions was contingent upon the results of earlier actions.

Key players in executing the plan

The Alliance oversaw the plan, and the LIVESTRONG Foundation provided guidance and funding. The Implementation Plan was disseminated to all Alliance members, who were tasked with addressing the plan’s various actions. Many organizations sponsored projects that addressed the PRG recommendations, but it was the Alliance that created an internal structure to execute the plan.

The Alliance addressed the themes of science, standards of care and awareness by developing task forces for each topic. In addition, a membership task force was formed to address organizational issues, such as creating and electing members for the LIVESTRONG Young Adult Alliance Steering Committee. This group drafted the charter for the steering committee and established the Alliance guidelines.

As time progressed, the Science Task Force was renamed the Research Task Force to better reflect the nature of its work. Task forces were supported by LIVESTRONG Foundation staff, but they also received assistance through dedicated volunteers who donated their time. (See **Figure 2**, “Young Adult Alliance Steering Committee.”)

Task force co-chairs were drawn from the membership, with at least one chair per task force sitting on the Alliance steering committee to help oversee the Implementation Plan. The chairs were a motivating force in ensuring the task force work addressed the Implementation Plan and the PRG recommendations. The chairs reported on task force work via monthly teleconferences and quarterly, in-person meetings.

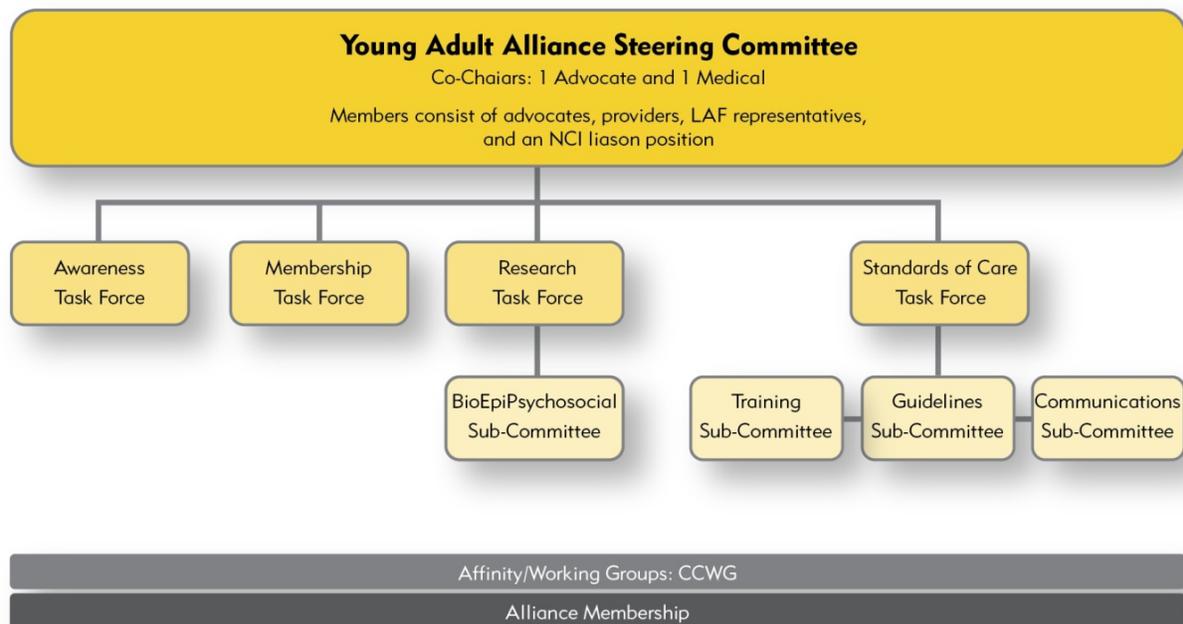


Figure 2. Young Adult Alliance Steering Committee

Affinity/working groups also were established to assist the task forces in carrying out specific actions that were better handled by smaller, dedicated groups.

The Alliance members met yearly to highlight current research and programs for AYAs, address task force projects and create new networks to address burdens experienced by AYAs. The steering committee held quarterly meetings, and task forces and affinity groups organized ad hoc in-person meetings and teleconferences.

Reviewing and tracking progress

To assess the progress of the Implementation Plan, several data collection processes were used, including:

- Surveys of Alliance members who were asked to submit information about their progress, as well as their approach to and impact on the AYA community;
- Survey of NCI-designated cancer centers, conducted by an affinity group called AYA Champion and the Cancer Centers Working Group (described in more detail later in the report);
- Abstracts presented at the LIVESTRONG Young Adult Alliance Annual Meeting; and
- Summaries and published articles drafted by task forces and affinity groups.

PROJECTS

This report provides an overview of the significant actions accomplished by the task forces, working groups and Alliance member organizations. It offers examples of the work carried out under each of the five recommendations. The projects listed in this report are not intended to be a comprehensive list for review.

Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.

This recommendation bore out of the fact that cancer in AYAs differs with age and is biologically different from the same types of cancers in other age groups (Bleyer, 2011). The most common tumors in AYAs are breast cancer, lymphoma, germ cell tumors (including testicular cancer), thyroid carcinoma, sarcoma (soft tissue and bone), melanoma, cervical carcinoma, colorectal carcinoma, leukemia and central nervous system tumors. (See **Figure 3**, “Types of Cancer in Older Adolescents and Young Adults by Five-Year Age Intervals.”).

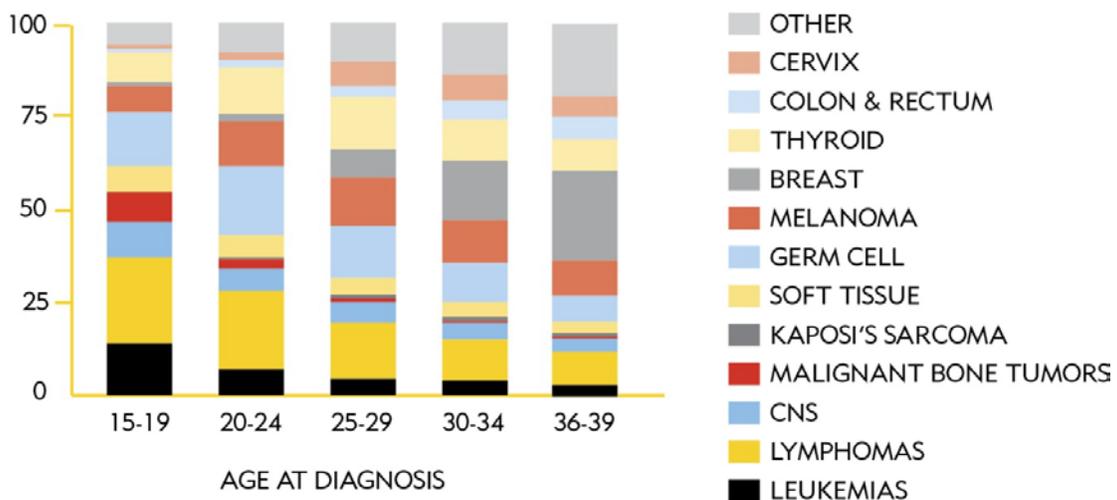


Figure 3. Types of Cancer in Older Adolescents and Young Adults by Five-Year Age Intervals.

In addressing Recommendation 1, the Research Task Force conducted **retrospective analyses on nine diseases**. The disease groups included: breast, Hodgkin's lymphoma, non-Hodgkin's Lymphoma, germ cell tumors (including testicular), sarcoma (Ewing and osteosarcoma), colorectal, melanoma, acute myeloid leukemia and acute lymphoblastic leukemia. The diseases were chosen based on incidence or severity within the AYA population; two of the diseases—osteosarcoma and leukemia—already had data showing evidence that the disease has a different biology and markedly different outcomes when exhibited in AYAs.

Subcommittees were formed for all nine diseases; each subcommittee reviewed existing publications and databases for evidence of previously unnoticed differences in epidemiology, outcomes and biology. The subcommittees then produced several abstracts and articles, the content of which was presented to groups such as the American Society of Clinical Oncology and the International Society of Paediatric Oncology. Results from this work indicate that for some types of cancer, the progression of the disease is distinctly different for AYAs.

Also, on June 9-10, 2009, the NCI and the **LIVESTRONG** Foundation co-hosted the **NCI/Lance Armstrong Foundation Biology Workshop** to review data on breast, colon and acute lymphocytic leukemia in the AYA population. A summary of this workshop was published in the "Journal of the National Cancer Institute" by Tricoli et al, 2011. The general consensus was that there are differences in acute lymphocytic leukemia, including variances in outcomes for AYAs treated on pediatric versus adult regimens. It also was noted, however, that there most likely is not a difference in the biology for colon and breast cancer. Additional studies are needed, particularly in colon cancer.

Other collaborative research projects were initiated under Recommendation 1, to include:

- **The Adolescent and Young Adult Oncology Treatment and Survivorship Cohort Study.** This three-year, multi-institutional study was initiated through the Research Task Force. The

overall goal was to determine whether a multi-institutional cohort of AYA oncology patients could be established, followed, and assessed for medical and psychosocial outcomes in diagnosis, treatment and long-term survivorship at several time points in one year. The study collected real-time “on therapy” data from pediatric and medical oncologists treating AYAs diagnosed with leukemia, lymphoma and sarcoma at four sites accruing patients: Oregon Health and Science University, Seattle Children’s Hospital, Northwestern University and Vanderbilt University. Data was collected through February 2012, at which point 99 patients had enrolled. Final assessments will occur in March 2013.

- **Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE)**

Study. Supported by the LIVESTRONG Foundation, AYA HOPE

(<http://outcomes.cancer.gov/surveys/aya>) was a NCI-sponsored feasibility study. It included investigators from seven population-based Surveillance, Epidemiology and End Results (SEER) cancer registries. The study was designed to identify best practices for obtaining consent, collecting outpatient and inpatient medical records and surveying recently diagnosed AYA cancer patients in population-based community settings. The seven participating SEER registries were Los Angeles, Seattle-Puget Sound, Iowa, Louisiana, Detroit, Northern California and Greater California.

The study was open to AYAs at diagnosis with germ cell cancer, specific sarcomas (Ewings, osteosarcoma and rhabdomyosarcoma), acute lymphoblastic leukemia, Hodgkin’s lymphoma and non-Hodgkin’s lymphoma. Forty-three percent (525) of patients responded, 39 percent refused, and 17 percent were lost to follow-up (Harlan, L.C., Lynch, C.F., Keegan, T.H., Hamilton, A.S., Wu, X.C., et al, 2010). It was concluded that, with the use of extensive resources, it is feasible to achieve a response rate that allows for population-based research. Additional manuscripts are being developed (i.e., Bellizzi , K.M., Smith, A.W., Schmidt, S., Keegan, T., et al, in press; Keegan, T.H.M.,

Lichtensztajn, K.Y., Kato, I., Kent, E.E., et al, in press; and Parsons, H.M., Harlan, L.C., Lynch, C.F., Hamilton, A.S., et al, in press).

- **AYA Biorepository.** The Research Task Force initiated a retrospective cataloguing of existing AYA tissue samples in six institutions: Vanderbilt, Oregon Health and Science University, Kaiser Permanente, Indiana University, Nationwide Children’s Hospital and MD Anderson. The project highlighted some of the inherent challenges in working with retrospective analyses of stored specimens, including IRB restrictions on data sharing, age at collection versus at diagnosis and securing additional consent for those younger than 18 at date of collection. It was concluded that an effective biorepository would require a significant funding source, highly engaged researchers and dedicated staff at each participating institution.
- **AYA Monograph.** This monograph, developed by NCI and titled “Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, including SEER Incidence and Survival: 1975-2000,” was published in 2006. It described the unique cancer burden among older adolescents and young adults. It was the first SEER publication to break out AYAs as an age group for cancer statistics.
- **BioEpiPsychosocial Subcommittee (BEPS).** BEPS was created in response to the stated need for collaboration in epidemiology, health services and quality of life research. The Research Task Force subcommittee included 18 representatives from academic institutions, government agencies, medical practices and nonprofit associations. Research included topics such as challenges in getting AYAs to adhere to treatment and barriers to social reintegration and life planning. BEPS held a meeting in June 2011 to discuss funding proposals for two research questions on developmental milestones and fertility in AYAs with cancer.

- **Advancing Clinical Trials.** This Research Task Force project used EmergingMed's comprehensive trial listing and SEER age-incidence data to identify potential gaps in clinical trials for AYA cancers.

Findings suggest that sarcomas and thyroid cancer are least represented among clinical trials for AYA cancers, regardless of age. Acute lymphoblastic leukemia and Hodgkin's lymphoma are underrepresented among trials for AYA cancer patients ages 15 to 17. Breast cancer, melanoma and non-Hodgkin's lymphoma are relatively overrepresented among clinical trials available to AYAs ages 18 and older. The greatest deficit is among AYAs ages 15 to 17, who have access to the fewest number of clinical trials, regardless of type of cancer.

The Research Task Force submitted two abstracts with this data—one to the American Society for Clinical Oncology (ASCO) and one to the International Society for Paediatric Oncology (SIOP). The first abstract addressed clinical trial availability for AYAs compared to oncology incidence rates for certain cancers. The second addressed the lack of clinical trials for leukemia and lymphoma patients age 15-17 years in the United States and Canada.

Overall, significant progress was achieved for Recommendation 1; however, challenges also were identified, such as how to navigate the requirements put forth by various institutions when conducting collaborative research and how to ensure that both clinical science and behavioral science are addressed in AYA-specific research.

It was agreed that providing evidence of the unique nature of AYAO is a key component to distinguishing it as a separate field from pediatric and adult oncology. This evidence can be used to help secure buy-in for provider training and awareness, which was addressed under Recommendation 2.

Recommendation 2: Provide education, training, and communication to improve awareness, prevention, access and quality cancer care for AYAs.

Recommendation 2 covered a broad range of activities targeted to diverse audiences, ranging from the general public to treatment providers. The Alliance found challenges in effectively communicating to first-line health providers. However, it was encouraged by the general increase in public awareness of AYAs with cancer, as evidenced by an increase in the number of news articles, movies and other media devoted to the topic.

Some of the actions taken toward Recommendation 2 included:

- **Produced a documentary “Missed” about the young adult cancer experience.** In an effort to increase health care providers’ early recognition of AYA cancers and referrals to appropriate specialists, the LIVESTRONG Foundation collaborated with Alpheus Media to produce “Missed,” a short documentary about the young adult cancer experience. The film was featured at the Lights, Camera, Help Film Festival and was supported by Cooperative Agreement Number 5U50DP001689-02 from the Centers for Disease Control and Prevention.

**The film’s contents, findings and conclusions are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.*

**Missed:
Young Adults with Cancer**

We traveled across the U.S. to connect with college students and young adults, as we explored how they deal with the specific issues they face when diagnosed with cancer.



[Watch](#)

- **Developing a position statement that addressed training for health professionals.** This statement expressed a distinct need for AYAO curriculum for all health professionals, as well as consideration of AYA fellowships where relevant (Hayes-Lattin, B., Mathews-Bradshaw, B., & Siegel, S.E., 2010).
- **Developing a position statement on quality of care issues specific to AYAs.** This statement pointed out the lack of evidence-based guidelines for this population, as well as the need for standards of care (Zebrack, B., Mathews-Bradshaw, B., & Siegel, S.E., 2010).
- **Creating an AYA cancer portal.** NCI's website was designed to reach newly diagnosed AYA patients and their families with evidence-based information to help them (1) learn more about treatment options; (2) participate in treatment-related decisions; (3) explore clinical trial options; (4) get emotional/coping support; and (5) learn about organizations that provide information and support to AYAs (www.cancer.gov/cancertopics/aya).
- **Assessing the perceptions of health care providers.** In partnership with StrategyOne, a communications consulting firm, the Awareness Task Force conducted a survey of college health-care providers who work on college campuses. Results from this survey, which indicated cancer is not top of mind for college health professionals, were integrated into the Alliance's awareness campaigns.
- **Assessing the perception of AYAs.** In 2009, the LIVESTRONG Foundation created and distributed a survey to AYAs ages 18 to 24 who never had been diagnosed with cancer. The survey's goal was to better understand how the AYA population perceives cancer, understands risk and evaluates preventive behaviors. Results showed that those surveyed had less awareness of cancer warning signs and they expressed confusion over cancer prevention information. The results were used to

develop age-appropriate educational cancer materials for AYAs. (See the sidebar on the “Missed” documentary for more information.)

- **Raising awareness through collaborative efforts and individual efforts of each organization.** An example of this work was the Break Cancer Campaign. The Alliance and RecordSetter (formerly The Universal Record Database) joined forces to create Break Cancer, a campaign to raise awareness around adolescent and young adult cancer by setting or breaking world records. This awareness campaign kicked off in November 2010 at the LIVESTRONG Young Adult Alliance Annual Meeting. Every record submission had to be quantifiable and breakable and include indisputable media evidence (video recorded or photographed), which was shared through social media channels. From November 2010 to November 2011, almost 13 million views, media impressions and social media likes/acknowledgements occurred, exposing viewers to messages about AYAs and cancer.

Recommendation 2 covered a wide range of components focused on communicating the AYA message to health care providers and the public. Communication strategies ranged from surveys and webpages to social media tools, such as Facebook and Twitter. In all instances, the message was communicated successfully that AYAs can and do get cancer and that these are some of the disease’s warning signs.

Recommendation 3: Create the tools to study the AYA cancer problem.

Recommendation 3 was a broad directive that focused on clinical trial activity within the AYA age group. The Alliance addressed several strategies to increase AYA clinical trial activity and participation. Some of those strategies included:

- Conducting the “The Adolescent and Young Adult Oncology Treatment and Survivorship Cohort Study”;

- Working with the NCI's Division of Cancer Treatment and Diagnosis to increase AYA patient accrual in appropriate trials within the Children's Oncology Group and adult clinical trial cooperative groups; and
- Creating an Institutional Review Board (IRB) toolkit to encourage IRBs to consider AYAs when reviewing clinical trial submissions. The toolkit contains an AYA checklist for IRB administrators, an informed consent checklist and a document that briefly outlines the importance of health care powers of attorney for AYAs. The toolkit recommends an AYA oncology expert on the IRB, or cross-representation of pediatric and adult oncologists when an AYA specialist is not available.

Recommendation 4: Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship and end of life).

Actions under this recommendation focused on standards of care. Experts spent a significant amount of time reviewing and discussing standards and related processes. These discussions highlighted the complexities of establishing standards and guidelines in a developing field with limited data.

It was generally agreed that a thorough evidence review should be the first step for any additional evaluations. To this end, funding was provided for a "literature search" to identify existing AYAO models of care. A total of 869 articles were identified and 274 were analyzed. Search categories included medical health, mental health and survivorship.

In addition to the evidence review, Alliance organizations made substantial contributions by providing targeted AYA training and support to health care providers of varying expertise. In March 2012, the National Comprehensive Cancer Network released guidelines for adolescent and young adult oncology to educate health care professionals on diagnosing and treating cancer in AYA patients.

Other initiatives to further the goals of Recommendation 4 included the following programs:

- **Focus Under Forty CME.** This joint effort between the LIVESTRONG Foundation and the American Society of Clinical Oncology (ASCO) is offered at no cost to participants through ASCO University's eLearning program. As of December 2011, 849 health care providers had taken at least one Focus Under Forty course, and 2,361 curriculum-specific page views were registered on the ASCO University eLearning platform.
- **Nurse.com's accredited continuing education.** The LIVESTRONG Foundation joined forces with Gannett/Nurse.com in January 2011 to sponsor eight free, accredited continuing education (CE) webinars and two print CE courses that focused on AYA issues. The CE courses were offered between January and August 2011 through Nurse.com. The webinars addressed topics such as "A Guide to Grief for Nurses and Surviving Family" and "Cancer Disparity and Detection in AYAs: What Nurses Need to Know." Print courses focused on issues such as how to reach teenage smokers and how to answer questions about clinical trials. In the end, 23,572 unique individuals took 39,606 AYA courses through Nurse.com.
- **"At the Crossroads: Cancer in Ages 15-39."** This is an accredited continuing nursing education (CNE) video course. It was made possible in 2010 through CDC funding and a partnership involving the LIVESTRONG Foundation, the Nurse Oncology Education Program (NOEP) and Alpheus Media. The course helps nurses—many of whom work in primary care settings—update their knowledge on the unique physical, emotional and practical needs of AYAs diagnosed with cancer. As of December 2011, 4,105 nursing professionals had taken the course, and 3,611 had completed a feedback form on the course.

Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient.

To achieve the goals of Recommendation 5, many of the projects listed below were highlighted at Alliance annual meetings. This work was presented to all Alliance members, providing organizations the benefit of exposure to the latest in AYAO research and programs. These organizations provide many valuable direct services to AYAs within the community. The Alliance found that its greatest strength was in its diversity and collaborative nature; this encouraged the development of a forum for member organizations to improve and focus their targeted support services to AYAs, such as peer-to-peer and patient navigation programs.

Some of the actions taken under this recommendation included:

- **Environmental Scan of AYAO Patient Navigator and Peer-to-Peer Programs.** In 2008, the LIVESTRONG Foundation entered a contract with NOVA Research Company for an environmental scan of AYA-specific patient navigator and peer-to-peer programs. Based on NOVA's data (obtained through a literature and Internet search), there were 28 programs with trained patient navigators or age-matched peers (11 patient navigator programs and 17 peer-to-peer programs). NOVA identified seven of these programs—six in the United States and one in Australia—as potential models for the development of standards for patient navigation and peer-to-peer networks.
- **Young Adult Program @ Dana-Farber Cancer Institute (YAP@DFCI):** YAP@DFCI is an AYA-specific website, created by DFCI, that aims to provide access to psycho-educational materials and clinical services and create a mechanism for peer support. This site leverages social networking systems commonly used by young adults to put psychological, self-help and emotional support resources in the hands of AYAs. These resources promote positive coping strategies, community building, and ownership over one's care and well-being. Website content includes support and psychosocial resources at DFCI; special interest groups; a real-time, online

- support group; interactive and do-it-yourself assessments and modules; and user-submitted humor, art and tips on things to do in Boston, Mass., where DFCI is located.
- **Breast Cancer Navigation Flowchart.** Developed by Sharsheret, this flowchart is a tool that provides information for every stage of breast cancer by outlining details of routine screenings, pathology reports, diagnosis and staging, surgical and treatment options and follow-up care. The flowchart empowers young women with an understanding of their diagnoses and prompts them to ask their doctors questions that can determine the course of their treatments. The flowchart also outlines medical tests, procedures and medications often associated with breast cancer treatment. In developing the Breast Cancer Navigation Flowchart, Sharsheret utilized data and feedback from more than 15,000 young women facing breast cancer, their caregivers and the health care professionals on Sharsheret’s medical advisory board.
 - **Unmet Informational and Service Needs of Adolescent and Young Adult Cancer Survivors: A Population-Based Cancer Registry Study.** This study involved the collaboration of several Alliance institutions. It examined supportive care services provided in pediatric oncology versus adult oncology settings, and the extent to which they meet the needs of recently diagnosed AYA cancer patients. A total of 215 AYAs (a 75 percent response rate) recruited from pediatric and adult care settings were assessed based on the need for and utilization of informational resources, emotional support services and practical support services. Statistical analyses examined differences in service use and unmet needs across age and treatment settings, such as children’s hospitals and adult-oriented cancer centers. The study also examined differences in service use and unmet need by race, employment/school status, gender, relationship status, cancer type and treatment-related side effects. Findings suggested a greater likelihood of service use and satisfaction of need for younger patients treated in pediatric care settings,

particularly with regard to infertility information, diet/nutrition information and professional mental health services.

- **Ulman Cancer Fund for Young Adults.** The Ulman Cancer Fund’s mission is to support, educate, and connect young adults and their loved ones affected by cancer. The one-on-one cancer support services connect more than 200 AYAs per year. In 2007, the Ulman fund formed a partnership with Imerman Angels to enhance its services.
- **Imerman Angels.** Imerman Angels matches a person currently affected by cancer with a “mentor angel,” or someone who has fought and survived the same type of cancer. Cancer caregivers—such as spouses, parents, children and friends—also can benefit from one-on-one connections with other caregivers and survivors. The service is free and available to anyone affected by cancer.
- **CanTeen Programs and Activities.** CanTeen runs programs that vary from weeklong or weekend camps to shorter recreational day activities. All programs, regardless of length, are about building peer support networks. This happens through meeting others in similar situations while sharing experiences along the way. Program activities range from recreational to educational sessions. CanTeen also offers psychosocial-facilitated activities, such as discussion groups and reflection sessions. The group operates an online community, providing peer support as well.

The greatest strength that all stakeholders brought to the Implementation Plan was their support for adolescents and young adults with cancer. This, combined with the collaborative nature of the Alliance as a whole, has led to many programs that provide direct assistance to young adults diagnosed with cancer.

As illustrated in Figure 5, “LIVESTRONG Alliance Member Projects,” some projects overlapped with more than one recommendation. This illustrates the breadth and depth of the work accomplished in response to the AYAO PRG Report and Implementation Plan. It also shows the range of each project across the recommendations and strategies.

	Alliance Annual Meeting	AYA Monograph	AYAO Treatment and Survivorship Cohort Study	BioEpiPsych Sub-committee (BEPS)	Biorepository	BreakCancer/SXSWI	Breast Cancer Navigation Flow Chart	CCWG	COG/Alliance Collaboration	College Health Care Provider Survey	Environmental Scan	NCI/LIVESTRONG AYA HOPE Study	IRB Toolkit	LIVESTRONG CME (Focus under Forty / NDEP/Nurse.com)	LIVESTRONG College Student Survey	Missed Video	NCI AYA Portal	NCI/LIVESTRONG Biology Workshop	NCI CTSU Utilization for AYA	NYACAW	Peer-to-Peer Support Programs	Research Task Force Advancing CT	Research Task Force Disease Studies	SEER Cancer Statistics Review	Standards Task Force Position Statements	Standards Task Force/LIVESTRONG Literature Search	Supportive Care Service Use and Unmet Need	YAP@DFCI		
Rec 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.																														
Strategy 1: Establish a strong scientific foundation for the biology of AYA cancers		•	•	•	•			•				•						•	•				•							
Strategy 2: Publish a summary of this meeting																														
Strategy 3: Encourage NCI to develop and solicit a program announcement (PA)																														
Strategy 4: Encourage completed, ongoing, and new clinical trials			•					•	•			•							•											
Rec 2: Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.																														
Strategy 1: Bring together experts with experience in AYA programs to prepare a white paper that lays out a blueprint for the professional development of AYA cancer providers. Based on the white paper, prepare a position statement that lays the foundation for creating nationally accepted criteria and standards of care for practice, ultimately leading to the development of formal, certified training programs for AYAO healthcare practitioners																										•				
Strategy 2: Evaluate and help improve existing sources of information and support	•			•				•								•	•				•									
Strategy 3: Increase healthcare providers' early recognition of AYA cancers and referrals								•	•	•						•														
Strategy 4: Penetrate the consciousness of the public and frontline providers						•				•					•	•														
Rec 3: Create the tools to study the AYA cancer problem																														
Strategy 1: Create tools to enhance clinical trial activity in AYA cancer patients			•					•				•							•					•						
Rec 4: Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).																														
Strategy 1: Develop standards-of-care (SOC) guidelines for AYAO programs and patients																							•							
Strategy 2: Develop tools for capturing and measuring quality-of-care data																										•				
Strategy 3: Analyze existing models of care																														
Strategy 4: Develop and disseminate evidence-or consensus-based treatment and follow-up guidelines																							•							
Strategy 5: Educate current and future health care professionals								•				•													•					
Rec 5: Strengthen and promote advocacy and support of the AYA cancer patient.																														
Strategy 1: Evaluate and catalog existing peer-to-peer support programs and patient navigator programs											•																			
Strategy 2: Facilitate the development of peer-to-peer networks and access to these networks																														
Strategy 3: Facilitate development of AYA standards for patient navigation or health coaching programs																														
Strategy 4: Identify indicators of success for programs that offer supportive services			•				•																				•	•		
Strategy 5: Provide opportunities for peer-to-peer support and awareness							•	•									•				•								•	

Figure 5. LIVESTRONG Alliance Member Projects.



CONCLUSION

A significant amount of work has been accomplished since the AYAO PRG Report was published in August 2006. The Alliance's expansion to include NCI-designated cancer centers, cooperative groups and larger cancer-treatment-related organizations has helped to promote awareness and AYA-tailored treatment for AYAs diagnosed with cancer. The programs and initiatives highlighted in this report are only a representative sampling of the resources that now exist for AYAs with cancer, their loved ones and the health care professionals serving this age group.

The AYAO PRG Report provided a framework for a national agenda to improve cancer prevention, detection, diagnosis, treatment, and outcomes for AYAs diagnosed with cancer. The LIVESTRONG Young Adult Alliance was the vehicle for the implementation of that framework.

The young age of the field brought forth some challenges; some strategies will not be realized until there is more data available from studies to provide evidence of outcomes. The strength of the Alliance lies in its diversity and collaborative nature among member institutions. Numerous examples of Alliance-inspired work provide evidence of the growth of the AYAO movement over the past five years. There also have been several funding announcements, published articles on AYA-specific cancer (see Figure 6, "AYA-Related Publications") and endowed faculty positions.

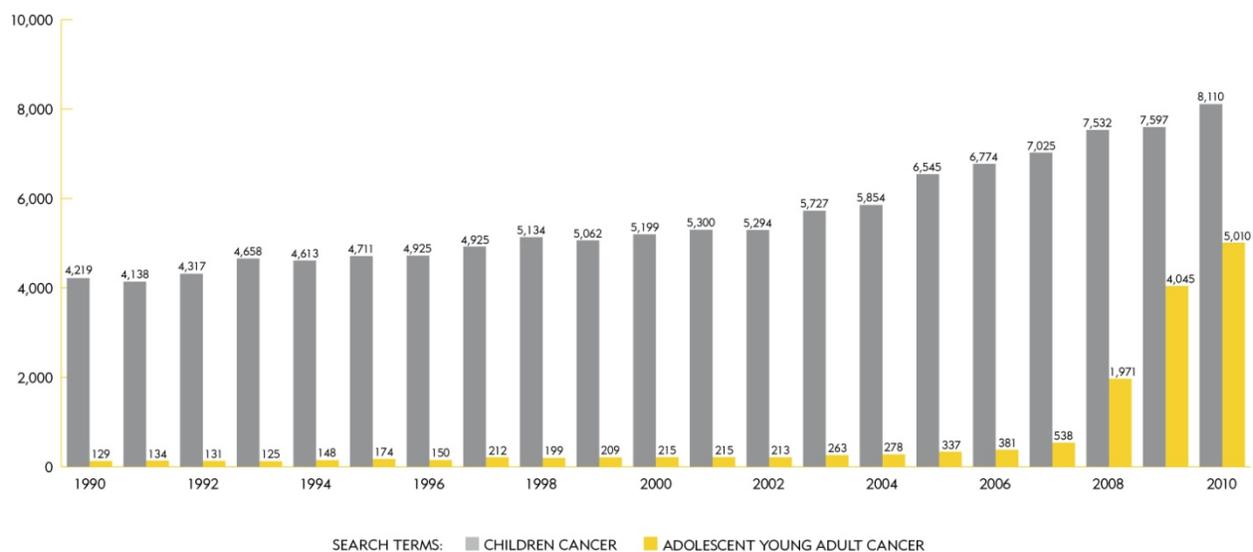


Figure 6. AYA-Related Publications

Moving Forward.....A New Alliance is Formed

The growth in the AYA movement prompted the LIVESTRONG Foundation and the Alliance Steering Committee to consider next best steps for the Alliance and its place within the AYA movement. They conducted a feasibility study and held discussions to address the following questions:

- What is needed to continue the growth of the Alliance?
- How can the LIVESTRONG Foundation best support the Alliance moving forward? and
- What is needed to carry the AYA movement forward?

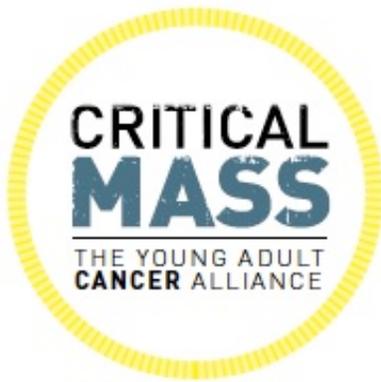
Ultimately, the decision was made to create a new alliance separate from the LIVESTRONG Foundation. The vision was that the new alliance will continue to focus on serving AYAs diagnosed with cancer by increasing survival rates and quality of life and ensuring access to the best medical and psychosocial resources. To help the new entity become established financially, the LIVESTRONG Foundation granted seed money to the entity in 2012 and hired an interim executive director to lead the charge. The LIVESTRONG Foundation also pledges

continued support through the end of 2014. In addition to its support of the new alliance, the LIVESTRONG Foundation will continue to invest internally in AYAO-related work.

As of the writing of this report, the new entity has been formed, CRITICAL MASS: The Young Adult Cancer Alliance, and has filed and received approval for its Articles of Incorporation. It has also applied for 501(c)3 status and is awaiting approval. Fayruz Benyousef, CFRE, is the interim executive director and six members of the former Alliance Steering Committee are serving as interim board members: Brandon Hayes-Lattin, MD, chair; Rebecca Johnson, MD, vice chair; Stu Siegel, MD, secretary; Brock Yetso, treasurer; and Anna Cluxton and Stuart Kaplan, MD, 2012 Annual Conference Planning Committee co-chairs.

The interim executive director and board of directors have created the following statements in support of the new entity:

Our Vision



Adolescents and Young Adults diagnosed with cancer face issues fundamentally different from children or the elderly. We highlight the unique features of the AYA cancer experience with the goal of improving treatments and outcomes. We envision a world where AYAs with cancer have every resource necessary to survive and thrive.

Our Mission

Our mission focuses on serving AYAs diagnosed with cancer by:

1. Increasing survival rates and quality of life and
2. Ensuring access to the best medical and psychosocial resources.

Our Goals

1. Serve as the unified voice for the AYA cancer movement.
2. Establish AYA cancer programs in U.S. medical institutions.
3. Organize and provide access to comprehensive data on AYA cancer.
4. Create a collaborative environment for AYA cancer researchers, health care professionals and advocates.

The **LIVESTRONG** Foundation is proud of the work completed by the **LIVESTRONG** Young Adult Alliance, the steering committee, task forces, working groups and member organizations and is confident that we will see continued growth in the field of AYAO.

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