AYA in the USA. International Perspectives on AYAO, Part 5

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Within the past decade, the discipline of adolescent and young adult (AYA) oncology has taken root in the United States. It arose from the observation that survival improvements for 15–39-year-olds have lagged behind those of both children and older adults. Rapid progress in this new area has resulted from energetic work by researchers, clinicians, and non-profit organizations focusing on AYA-aged cancer patients and survivors. The term “AYA” is now well recognized within both pediatric and medical oncology, and AYA-specific aims are increasingly included in clinical trials and also basic and translational oncology research. The AYA oncology movement in the United States was spearheaded by the LIVESTRONG Young Adult Alliance (the Alliance), a coalition of AYA-focused non-profit organizations and academic institutions that has recently transitioned into a successor organization—Critical Mass: The Young Adult Cancer Alliance, composed of individual AYAO professionals. The work of groups such as the Alliance/Critical Mass and key collaborators—including the National Cancer Institute, National Comprehensive Cancer Network, Children’s Oncology Group, and advocacy organizations—provides a useful platform for the discussion of progress in AYA oncology in the United States, including advances in (1) research and tool development; (2) public and professional education; (3) advocacy and patient support; (4) awareness; and (5) service delivery. AYA oncology programs are now burgeoning dramatically throughout the United States, and many well-established U.S. programs share distinctive features in clinical programming. The United States is now entering an era of larger-scale coordinated efforts in research, advocacy, and clinical care for AYAs with cancer.

Keywords: carcinoma, mortality, pediatric, social support, supportive care, survivorship

THE ADOLESCENT AND YOUNG ADULT (AYA) oncology movement in the United States began simultaneously on multiple fronts. In 2006, the grassroots advocacy efforts of young adult cancer survivors led to the formation of the Young Adult Alliance (the Alliance) of the Lance Armstrong Foundation (LAF—since renamed LIVESTRONG), and that same year the U.S. National Cancer Institute (NCI) published the monograph “Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age including SEER incidence and Survival: 1975–2000.”¹ This publication highlighted the lack of survival improvement of AYA cancer patients between 15 and 29 years of age. As stakeholders in AYA oncology, LAF and NCI partnered to hold an AYA oncology progress review group (the AYAO PRG) that concluded in 2006.² The LAF tasked the newly formed Alliance with the work of organizing and implementing the 5-year plan outlined in the PRG recommendations,³ in partnership

with the NCI and later the Children’s Oncology Group (COG) and the National Comprehensive Cancer Network (NCCN). The PRG strategic plan included recommendations to: (1) identify the characteristics that distinguish the unique cancer burden in the AYA cancer 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 (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life); and (5) strengthen and promote advocacy and support of the AYA cancer patient.^{2,3}

These recommendations laid the foundation for subsequent progress in the United States in five key areas: (1) research and tool development; (2) public and professional education; (3) advocacy and patient support; (4) awareness; and (5) service delivery (Table 1). This article reviews both the

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important accomplishments to date in each of these domains and potential future directions. With the successful 2011 conclusion of the PRG's 5-year implementation plan, the Alliance transitioned from a program of the LAF into an independent non-profit organization for AYA oncology professionals. The infrastructure of AYA oncology in the United States has expanded and matured in recent years and can now support national coordination of research, advocacy, and clinical care, which will stimulate further rapid progress in the discipline.

Research and Tool Development

The PRG noted a lack of data on the differences in tumor and host biology between AYAs and other age groups. It proposed that such data were needed to validate AYA oncology as a distinct clinical entity that was separate from either pediatric or adult oncology.² Through the Alliance's Research Task Force, LIVESTRONG funded retrospective studies on the biological basis of nine common AYA cancers: breast cancer, colorectal cancer, melanoma, Hodgkin lymphoma, non-Hodgkin lymphoma, germ cell tumors, sarcoma (Ewing sarcoma and osteosarcoma), acute myeloid leukemia (AML), and acute lymphoblastic leukemia (ALL).⁴ These studies revealed age- and protocol-specific patterns of incidence, survival and treatment-related toxicity in cancers such as breast cancer,⁵ colorectal cancer,⁶ AML,⁷ and thyroid cancer.⁸ To highlight progress in the field, the Alliance and NCI partnered to host a 2009 workshop focusing on the biology of cancer arising in AYAs, with specific attention to ALL, breast cancer, and colon cancer,⁹ and reconvened at a scientific update meeting in September 2013 to review recent progress and define priorities for future research.

COG conducted a number of retrospective analyses on survival disparities and treatment toxicities in AYAs compared to children. One study found that among osteosarcoma patients on COG treatment protocols, patients in the AYA age range had inferior outcomes compared with pediatric patients.¹⁰ However, no discrepancy in outcome was found between AYA and pediatric patients treated on COG protocols for either Hodgkin lymphoma¹¹ or AML.¹² COG's retrospective studies also found distinctive patterns of treatment-related toxicity in AYAs treated with COG protocols for AML,¹² ALL,^{13,14} rhabdomyosarcoma,¹⁵ and Wilms tumor.¹⁶ COG has also obtained sponsorship for young investigator and cancer biology grants to promote new scholarship in medical and psychosocial AYA outcomes research.¹⁷

The PRG noted that the research infrastructure and tools that existed in 2006 did not adequately support the study of either medical or psychosocial issues in AYA oncology. AYAs have a disproportionately low number of biospecimens stored in tumor banks for basic science and translational research, in large part due to low clinical trial enrollment for this age group.² The Alliance's Research Task Force documented the paucity of clinical trials available to older adolescents ages 15–17 with leukemia and lymphoma in North America.¹⁸ As a preliminary step to the creation of a collaborative national network of tissue banks in Alliance institutions, LIVESTRONG supported a retrospective study cataloging tissue samples from six Alliance-member medical centers.⁴

In psychosocial research, the majority of patient-reported outcome instruments have been validated either for chil-

dren <18 years of age or for adults 18 years of age or older; very few span both age groups, although research to address this deficit is ongoing.^{19,20} As initial steps toward the goal of collecting prospective psychosocial data on AYAs, LIVESTRONG supported two initiatives: (1) NCI's Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study, a population-based analysis that determined best practices for medical record collection, validated the feasibility of assessing psychosocial outcomes in recent survivors of AYA cancer,^{21–23} and reported on the social information and service needs, health-related quality of life, work disparities, and educational disparities of AYAs with cancer^{24–26} and (2) the Alliance's AYA cohort study, a prospective, multi-institutional study testing the feasibility of collecting AYAs' clinical, psychosocial, and health-related quality of life data at several time points during the first year of cancer therapy.⁴

The Alliance made strides toward coordinating the research and clinical efforts of the pediatric and adult branches of NCI-designated cancer centers through the formation and coordination of the Cancer Centers Working Group (CCWG). "Champions" from each center were charged with (1) raising awareness of AYA oncology within their institutions, and (2) promoting collaborative AYA-specific research within and between institutions. The Alliance developed an institutional review board toolkit to help cancer centers promote the participation of AYAs in clinical trials and to implement AYA-specific trials.

NCI optimized its Cancer Trials Support Unit (CTSU; www.ctsu.org/public/) for use with AYA-focused clinical trials in order to improve access to age-appropriate protocols regardless of the location of patient care. For example, through CTSU a medical oncologist can independently enroll a young adult on a COG pediatric phase III Ewing sarcoma protocol, without the medical oncologist's institution needing to be a participant in the trial. Another mechanism to promote AYA-focused clinical trials is direct collaboration between COG and adult clinical trials groups. This strategy was previously used successfully with C10403, when the Cancer and Leukemia Group B worked with the Southwest Oncology Group, the Eastern Cooperative Oncology Group, and the NCI's Cancer Therapy Evaluation Program to create a pediatric-type protocol for AYAs with ALL.²⁷

Future directions for research and tool development

Critical Mass: The Young Adult Cancer Alliance (the successor organization to the Alliance) aims to create a collaborative environment for AYA cancer researchers in order to improve medical and psychosocial outcomes and decrease barriers for this population.²⁸ Possible future directions include a multi-institution, prospectively collected database of AYA cancer biospecimens and psychosocial outcome data, extending through cancer treatment into survivorship, which would provide a powerful resource for AYA oncology researchers worldwide.

A recent development in the United States is the restructuring of the adult cooperative clinical trial groups into the NCI Clinical Trials Network.²⁹ COG will be a member of this new organization,³⁰ which is slated to be operational by March 2014.³¹ AYA-related clinical trials and aims will serve as a logical ground for collaborative studies between COG and the adult oncology groups within NCTN. In November 2013

Critical Mass sponsored a meeting between the COG AYA committee and representatives from three of the newly formed adult cooperative groups to discuss strategies for collaboration. Future clinical trials can incorporate a wide variety of AYA-specific aims, including those related to outcomes, treatment adherence, clinical trial participation, psychosocial adjustment, outcomes, and late effects such as infertility and delayed achievement of developmental milestones. This high-level coordination of working groups and clinical trials will allow the entire AYA age spectrum to be analyzed as a group and should facilitate rapid improvement in medical and psychosocial outcomes for AYAs with cancer.

Public and Professional Education

Because the large majority of patients and caregivers in the United States now use the internet to obtain information about healthcare,³¹ the Alliance focused on developing internet-based educational resources for patients and caregivers. The LIVESTRONG website offers age-specific resources for AYA oncology patients, including the video “MISSED,” and NCI has developed a comprehensive AYA webpage (www.cancer.gov/cancertopics/aya). This website is updated periodically and contains evidence-based educational material on specific cancers, treatment, clinical trials, and survivorship. Numerous non-profit organizations such as Stupid Cancer and the Leukemia and Lymphoma Society offer educational sessions aimed at AYA patients. In 2012, the NCCN created a set of evidence- and consensus-based clinical practice guidelines for AYA oncology for use by medical professionals (http://www.nccn.org/professionals/physician_gls/pdf/aya.pdf). NCCN and LIVESTRONG then partnered to develop a set of care guidelines for AYA patients and their caregivers, which was published in 2013 (<http://www.nccn.org/patients/guidelines/aya/index.html>). These publications are updated annually. The Critical Mass website provides a list of partner organizations—both in the non-profit sector and within medical institutions in the United States—which provide specialized medical care and psychosocial support to AYAs coping with cancer and its aftermath. The Critical Mass website also links to multimedia resources created specifically for AYA patients and seminal articles of interest to AYA professionals.

Efforts to provide certified curricula to educate healthcare professionals about AYA oncology have also been primarily internet based. LIVESTRONG collaborated with the American Society of Clinical Oncology to create a set of 11 internet-based continuing medical education (CME) modules (<http://university.asco.org/focus-under-forty>). LIVESTRONG also collaborated with the Nurse Oncology Education Program to create an online continuing nursing education module “At the Crossroads: Cancer in Ages 15–39” (www.noep.org/nursing-cne/preview/40-at-the-crossroads-cancer-in-ages-15-39).

Within AYA cancer programs throughout the United States, the CCWG encouraged clinicians who focus on AYA oncology to become involved in local and regional outreach. Many CCWG institutions gave presentations at grand rounds or other CME programs that focused on the distinctive needs of AYA cancer patients. Institutions with AYA programs may also offer additional educational outreach programs to members of the community in order to raise awareness.

As AYA oncology continues to develop into a recognized area of expertise, the PRG envisioned the future need for

certified training programs for healthcare professionals serving AYAs. In 2010, the Alliance’s Standards Task Force published a position statement in the *Journal of Clinical Oncology* specifying the key elements of professional training for healthcare providers in AYA oncology.³³ At least two institutions in the United States currently offer specialized training in AYA oncology for medical students and/or fellows.^{34,35} Finally, professional education in AYA oncology has been greatly facilitated by the development of both a journal specific to this area, the *Journal of Adolescent and Young Adult Oncology*, and by the creation of regional and national annual meetings to report on new developments in the field and provide continuing education to medical professionals. Annual meetings of this type include Critical Mass, the Society for Adolescent and Young Adult Oncology, and the Texas AYA Oncology conference. A recent one-time meeting of note was an Institute of Medicine workshop in July 2013 that focused on identifying and disseminating evidence-based strategies to address clinical needs of AYAs with cancer.³⁶

Future directions for public and professional education

With time, more training programs may offer joint training in medical and pediatric oncology, and AYA oncology could eventually become an accredited medical specialty. In addition, medical and pediatric oncology fellows could have a period of AYA-focused “cross-training” in the alternate discipline, giving trainees disease-specific education in all areas of AYA cancer while teaching skills such as treatment protocol selection and fostering both ongoing communication and appropriate referrals between medical and pediatric oncologists caring for AYAs. A model program for this strategy has been the Aflac Young Investigator Award in Adolescent and Young Adult Oncology, which requires mentorship across departmental lines (e.g., pediatric oncology mentors for medical oncologists) and has successfully promoted AYA oncology collaboration at numerous recipient institutions.¹⁷

Advocacy and Patient Support

The PRG recommended research into factors affecting psychosocial functioning during and after cancer treatment,² along with the enhancement of existing programs and the development of new interventions to offer psychosocial support to AYA-aged cancer patients and survivors. To provide peer-to-peer support for this population, LIVESTRONG operates the Planet Cancer website (<http://myplanet.planetcancer.org/>), an online discussion forum. The Critical Mass website and the NCI webpage (www.cancer.gov/cancertopics/aya) both list numerous non-profit organizations that provide patient support for AYA cancer patients and survivors through mechanisms such as online written information, interactive websites, patient navigation, peer-to-peer support, social media interactions, podcasts, face-to-face meetings, camps, workshops, and adventure travel.

The PRG challenged medical institutions in the United States to extend the capacity of existing resources, evaluate their efficacy, and develop evidence-based interventions for psychosocial support of AYA cancer patients.² Cancer centers with AYA programs often develop partnerships with local non-profit organizations serving AYAs to provide outpatient programming for AYA oncology patients and survivors. For

TABLE 1. MAJOR AYA ONCOLOGY INITIATIVES IN THE UNITED STATES, 2006–2013

<p>AYA cancer epidemiology and outcomes monograph (NCI/LIVESTRONG; 2006¹)</p> <p>AYA Progress Review Group (NCI/LIVESTRONG; completed in 2006)</p> <p>Implementation by Alliance (completed in 2011)</p>			
Topic	Alliance/NCI/COG ↔ Clinical programs		Future directions
<p>Research and tool development</p> <p>PRG Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYA/O patient</p> <p>PRG Recommendation 3: Create the tools to study the AYA cancer problem</p>	<p>1. Disease-specific studies: outcome and treatment toxicity</p> <p>2. Psychosocial outcome studies</p> <p>3. Tissue bank study</p> <p>4. AYA cancer biology symposium</p> <p>5. Young investigator and AYA biology research grants</p>	<p>Pediatric/medical oncology collaboration:</p> <p>1. NCI-designated Cancer Centers Working Group (CCWG)</p> <p>2. Clinical trials:</p> <p>a. Cancer Trials Support Unit (CTSU)</p> <p>b. C10403 ALL trial</p>	<p>1. Multi-institution, prospective AYA database (medical, psychosocial)</p> <p>2. Coordinated AYA aims in pediatric and adult cooperative group studies (outcome, toxicity, fertility, psychosocial adjustment, adherence)</p> <p>3. AYA-specific patient-reported outcome instruments</p>
<p>Public/professional education</p> <p>PRG Recommendation 2: Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs</p>	<p>1. AYA/O websites</p> <p>2. Continuing education programs (medical/nursing)</p> <p>3. AYA training manuscript³³</p>	<p>1. Local/regional/national symposia (NCI) and annual conferences by AYA experts (TAYA, SAYAO)</p> <p>2. AYA oncology journal (JAYAO)</p>	<p>1. Accredited AYA professional training programs</p> <p>2. AYA cross-training for pediatric and medical oncology fellows</p>
<p>Advocacy and patient support</p> <p>PRG Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient</p>	<p>1. Peer-to-peer support such as Planet Cancer. This is the focus of many AYA non-profit organizations in the United States.</p>	<p>Partnerships between non-profits and cancer centers to offer camps, retreats, and workshops</p>	<p>1. Critical Mass facilitates advocacy and professional collaboration</p> <p>2. Widespread availability and utilization of patient support services</p> <p>3. Insurance coverage for fertility preservation</p>
<p>Awareness</p> <p>PRG Recommendation 2 (as above) and</p> <p>PRG Recommendation 5 (as above)</p>	<p>1. Social media campaigns such as “Break Cancer”</p> <p>2. Publically available internet content posted by non-profit, government, and academic organizations</p>	<p>Local/regional outreach by AYA experts at cancer centers</p>	<p>Increased government and philanthropic funding for AYA initiatives</p>
<p>Service delivery</p> <p>PRG Recommendation 4: Ensure excellence in service delivery across the cancer control continuum</p>	<p>1. Standards of care manuscript¹⁹</p> <p>2. NCCN AYA guidelines for patients and providers</p>	<p>Change it Back “Centers of Excellence” program</p>	<p>Increased number of designated and accredited AYA oncology facilities in both academic centers and the community, aided by Teen Cancer America and Change it Back</p>

Origin and examples of the National Cancer Institute Adolescent and Young Adult Oncology Progress Review Group implementation by the LIVESTRONG Young Adult Alliance (Alliance) and partner organizations.

AYA, adolescent and young adult; AYA/O, adolescent and young adult oncology; CCWG, Cancer Centers Working Group; COG, Children’s Oncology Group; CTSU, Cancer Trials Support Unit; JAYAO, *Journal of Adolescent and Young Adult Oncology*; NCCN, National Comprehensive Cancer Network; NCI, National Cancer Institute; PRG, Progress Review Group; SAYAO, Society for Adolescent and Young Adult Oncology; TAYA, Texas AYA Oncology conference.

example, camp Mak-A-Dream in Montana (www.campdream.org) offers annual summer programs or weekend retreats for AYAs with cancer from across the United States, as do many regional camps run by non-profit organizations such as Camp Korey in Washington state (<http://campkorey.org/?s=youth+adult>).

Non-profit organizations may also partner with cancer centers to provide programs or workshops for AYA cancer patients. For example, the Seattle Children's AYA program partners with the American Cancer Society on a quarterly basis to sponsor the "Look Good Feel Better for Teens" program (www.cancer.org/treatment/supportprogramsservices/look-good-feel-better-for-teens). In addition to support services originating outside the hospital, many AYA programs also employ a multidisciplinary support staff with specific expertise in the care of this age group, including social workers, psychologists, school teachers, vocational counselors, art therapists, and child life specialists, in order to provide support to AYA cancer patients and survivors.³⁷ Further research is needed to demonstrate the effect of such interventions on psychosocial outcomes in AYAs.

Future directions for advocacy and patient support

As more U.S. cancer centers open AYA programs, Critical Mass will continue to bring together AYA professionals and encourage collaboration between healthcare providers and the non-profit sector. Coordination at the regional and national levels between non-profit organizations and cancer centers serving AYAs has the potential to significantly expand, enhance, and streamline the delivery of patient support services to AYAs in the United States. Successful local services can be offered nationwide.

Insurance coverage for cancer-related services is also an ongoing problem for AYAs. LIVESTRONG is lobbying for the initiation of widespread insurance coverage for fertility preservation, a critical aspect of cancer care for AYAs.³⁸

Awareness

The Alliance launched several initiatives to promote public and professional awareness of AYA cancer, with the long-term goal of increasing national resource allocation for this patient population. LIVESTRONG's "MISSED" video was created to spotlight the medical and psychosocial challenges of AYAs with cancer (www.youtube.com/watch?v=Q3t4LM9zgE). The Alliance's "Break Cancer" campaign was a social media campaign in which people created and documented themselves breaking simple but quirky world records to raise awareness of AYA cancer.³⁹

Many U.S. and several international non-profit organizations serving AYAs with cancer were Alliance members. During the Alliance's 5 years of the PRG implementation plan, many of these organizations had great success increasing public awareness of AYA cancer through website content, social media, face-to-face events, and political lobbying. Medical representatives from Alliance-member AYA cancer centers nationwide participated in local, regional, and national events aimed at raising awareness.⁴ In addition, NCI has increased the visibility of AYA oncology in recent years through funding of the "AYA Oncology" Specific Challenge Topic in the National Institutes of Health's 2009 Stimulus Package, development of the AYA web page, and specific

recognition of the non-profit organization Vital Options' "Young Adult Cancer Awareness Week" on the NCI's AYA website. The reorganization of multiple cancer collaborative research groups into the NCI Clinical Trials Network, a nationwide entity comprising both pediatric and adult clinical trial groups that encourages intergroup collaboration, is already showing potential increase in the visibility of AYA oncology as a research priority.

Future directions for awareness

The goal of active lobbying for AYA concerns is to increase allocation of governmental and philanthropic funds for AYA research and patient support services over the next several years. Critical Mass has recently partnered with the non-profit organization Change it Back to create a "Centers of Excellence" program (<http://hcri.org/programs/change-it-back/>) to recognize cancer treatment facilities that offer high-quality clinical programs in AYA oncology. This formal certification process will raise awareness of AYAO as a distinct clinical entity within oncology, provide a regulatory mechanism to ensure excellence in AYA care delivery across the country, and drive both new patients and physician referrals to treatment facilities that provide the best and most comprehensive care for AYAs with cancer.

Service Delivery

The PRG recommended the formal delineation of standards of care to optimize medical and psychosocial outcomes for AYAs with cancer. In 2010, the Alliance's Standards of Care Task Force published a position statement on this topic in the *Journal of Clinical Oncology*.¹⁹ It enumerated critical elements of care delivery in AYA oncology programs, such as appropriately timed detection, developmentally appropriate psychosocial care, and AYA-specific medical expertise.

The newly created Change it Back "Centers of Excellence" programs formally recognize AYA oncology facilities that deliver high-quality patient care. Criteria for acceptance include an organization's success in providing fertility counseling, health insurance and financial counseling, psychosocial support, and smooth transition from active therapy to survivorship services. AYA Centers of Excellence are also expected to have staff with expertise in the care of this age group and to facilitate clinical trial participation when appropriate. The first two U.S. Change it Back Centers of Excellence were announced at the Fall 2013 Critical Mass meeting, and applications from cancer centers are accepted on an ongoing basis.

Service delivery to AYAs has also been augmented by the recent development of nationally recognized clinical care guidelines for both AYA patients and the healthcare providers who serve this population (www.nccn.org/professionals/physician_gls/pdf/aya.pdf; www.nccn.org/patients/guidelines/aya/index.html).

Delivery of high-quality AYA cancer care in the United States depends upon the number of AYAs who can be served by cancer facilities with dedicated AYA services. Just a few years ago, only a select handful of U.S. comprehensive cancer centers and their affiliated children's hospitals offered designated programs for AYAs with cancer, and none had dedicated treatment facilities for AYAs. Over the past 2 years there has been a swift increase in the number of U.S. cancer

treatment centers that advertise AYA programs, and at least one center now offers a dedicated inpatient unit for AYAs (www.seattlechildrens.org/clinics-programs/cancer/services/cancer-care-unit/). The range of treatment facilities with AYA programs has also broadened considerably, now including not only comprehensive cancer centers but also community hospitals and public hospital systems. Several of the more well-established AYA programs in the United States have common organizational features, including (1) use of a consultative care model to coordinate multidisciplinary services while maintaining disease-specific treatment expertise; (2) emphasis on the provision of fertility preservation prior to start of cancer therapy in compliance with published guidelines;⁴⁰ and (3) professional collaboration/coordination of care between pediatric and adult cancer services to optimize service delivery, selection of care facility, and clinical trial accrual. Programs vary in the age range of patients served and may provide care to all or a subset of patients in the 15-to-39-year age range that is most commonly used to define AYAs in the United States.²

Future directions for service delivery

At most U.S. institutions, AYAs currently comprise a small minority of patients,⁴¹ although percentages may be larger at centers with AYA programs. Clustering AYA care in dedicated units significantly increases the opportunities for peer-to-peer support and psychosocial programming, which allows these activities to become a routine part of daily patient care at AYA centers.⁴²

In addition to the existing AYA inpatient facility, at least two other U.S. hospitals are currently constructing dedicated facilities for AYA inpatient care, and many more are expected to follow. The ambitious new non-profit organization Teen Cancer America (www.teencanceramerica.org) is committed to creating specialized AYA units and services throughout the United States, building on the successes of its well-established partner organization, the Teenage Cancer Trust in Great Britain. These and other new AYA units will serve an increasing percentage of the 70,000 AYAs diagnosed with cancer annually in the United States.² Clinical care will be optimized to meet the needs of AYAs as more cancer centers strive to acquire certification as Change it Back "Centers of Excellence."

Conclusions

In 2006, the AYAO PRG recommended a comprehensive set of research and clinical initiatives to increase understanding of "the AYA cancer problem" and to improve medical and psychosocial outcomes for AYAs with cancer.^{2,3} In recent years, focused collaborative efforts between the Alliance/Critical Mass, NCI, NCCN, COG, adult clinical trial groups, and non-profit organizations have generated substantial knowledge to inform future AYA research and service delivery in the United States and worldwide. The future of AYA oncology in the United States will be characterized by expanding public awareness and increasing national coordination of prospective data collection, clinical trial design, professional training programs, and clinical program accreditation, with coordinated AYA cancer advocacy efforts and professional activities nationally organized through Critical Mass. Focus on AYA as a distinct branch within oncology will ultimately improve medical and psychosocial outcomes.

The number of AYA cancer programs will continue to grow in academic and community cancer facilities, delivering age-appropriate clinical care and high-quality patient support services to AYAs across the United States.

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Commentary from *International Perspectives* on AYA Series Editor Ronald Barr

The birth of adolescent and young adult (AYA) oncology in the United States may be seen as coincident with the 2000 formation of the Children's Oncology Group (COG) by the amalgamation of four antecedent organizations. Dr. Archie Bleyer is widely acknowledged as the parthenogenitor. While the initial efforts to build a home for AYA oncology within the COG met with resistance, Bleyer's wisdom and determination prevailed. The current AYA committee of the COG is testament to his foresight.

Others joined the effort and a Progress Review Group (PRG) was formed by the National Cancer Institute (NCI) in 2005. This PRG was unique in two respects: (1) it had an external partner (the Lance Armstrong Foundation, now LIVESTRONG), and (2) its topic was not a disease but an age group. The PRG produced five main recommendations to move AYA oncology forward. Almost contemporaneously, LIVESTRONG enabled the formation of the Young Adult Cancer Alliance (now Critical Mass) that has been highly effective in promulgating the PRG's recommendations.

Rebecca Johnson has played a leading role in the Alliance and its successor entity, and she has led one of the few AYA cancer programs in the United States that is a physical reality. Most are virtual programs and, while the number is growing rapidly, there are still fewer than in the United Kingdom, which has less than one-fifth the population of the United States. The move to establish Centers of Excellence is a brilliant means of ensuring quality, using the standards proposed by Critical Mass and the clinical practice guidelines developed by the National Comprehensive Cancer Network.

Critical Mass has also augmented public awareness, promoted advocacy, led initiatives in professional education, and addressed a peculiarly American challenge—the inequities of health insurance (the AYA age group is the most under- and uninsured segment of the U.S. population). Perhaps its greatest achievement has been in promoting collaboration between the COG and the realigning adult cooperative clinical trials groups, with the Southwest Oncology Group showing particular interest. In this endeavor, the Cancer Trials Support Unit and the Cancer Therapy Evaluation Program of the NCI have played important roles, somewhat analogous to that of the National Clinical Trials Network in the United Kingdom.

The momentum of AYA oncology has increased progressively over the past 15 years in the United States, with substantial achievements on several fronts. Effective partnerships between government, academic institutions, and philanthropic organizations have been the vehicles for change. All signs point to this momentum continuing to the ultimate benefit of young people with cancer in the United States and beyond.

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