The In-Betweeners:

A Focus on Young Adults with Cancer

BY KRISTIN S. DONAHUE, MSN, RN, OCN,
AND ANNE MARIE FRALEY RAINEY, MSN, RN, CHC

At the 2016 Association of Community Cancer Centers (ACCC) National Oncology Conference, staff from Clearview Cancer Institute attended Suleika Jaouad's keynote session "Life, Interrupted," where the young journalist shared her experience and journey with lymphoma. After this empowering talk, our team of young adult administrators quietly agreed that we were not doing all that we could for our young adult cancer patients. This session was our call to action. When we returned to our program, our team pledged do more for this often forgotten about patient population—the In-Betweeners.

Our Program At-a-Glance

Since 1985 Clearview Cancer Institute has served adult hematology and oncology patients in north Alabama. We are a private, physician-owned, community practice with six full-service locations, two of which are in Huntsville, with others in surrounding areas, including Decatur, Florence, Cullman, and Jasper. We also have three satellite clinics in Athens, Madison, and Scottsboro that are available to serve patients for office visits on select days of the week. Our practice is home to 17 physicians and 18 advanced practice providers. Our mission statement is "Clearview is committed to providing cutting-edge, quality, compassionate, comprehensive care." These words align perfectly with Suleika Jaouad's charge that cancer programs need services tailored specifically for their adolescent and young adult (AYA) patients. Education was the first step in our journey.

Identifying Our AYA Patient Population

In 2017 we conducted an analysis of our patient population to determine how many patients could benefit from a formal AYA program. Because Clearview Cancer Institute only treats patients aged 18 and older, we adopted the criteria of patients aged 18 to 39, which is consistent with national guidelines for adolescents and young adults with cancer.[1] In terms of diagnoses, we used the criteria of either an active cancer diagnosis or a history of a cancer diagnosis for patients who were seen at any of our clinics during 2016. After reviewing data from our practice management system and electronic health record, we identified approximately 250 patients across our facilities who may benefit from a formal AYA program.

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Understanding the Needs of AYA Cancer Patients

Next we conducted literature reviews to determine the needs of this special patient population.

Globally, 350,000 patients between the ages of 15 and 29 and 650,000 patients between the ages of 30 to 39 are newly diagnosed with cancer each year.[1] Approximately 70,000 AYAs (individuals aged 15 to 39) are diagnosed with cancer in the United States each year.[2] Cancer kills more 20- to 30-year-olds than any other disease except depression.[3] Several factors play into cancer being so deadly for this age group. For example, many healthcare professionals may not consider the possibility of cancer when discussing a symptom profile or working up this age group, sometimes impeding or delaying a diagnosis and impacting outcomes.[3] In addition to this barrier, many in this age group lack access to healthcare services or may not have insurance coverage at all.[3] Often AYAs ignore signs of health issues because they do not consider the possibility of a life-threatening illness at this stage in their lives. Infrequent routine medical care—for example, a lack of annual wellness visits—may further delay diagnosis.

The age at diagnosis can significantly affect how individuals cope with cancer. In 2011 Zebrack categorized five areas of disruptions that may occur across all life stages:[4]

- Altered interpersonal relationships
- Issues of dependence and independence
- Achievement of life goals
- Concerns of body and sexual image and integrity
- Existential issues.

AYAs are already going through a transformational period from dependence as a child to independence as a young adult. These individuals are also facing body image and sexuality changes. Add a new cancer diagnosis into the mix and it is evident how coping can be extremely challenging for these patients.

There is very little published information regarding the needs of AYAs in relation to their understanding of medical care, side effect management, emotional challenges, and maintaining a sense of normalcy following a cancer diagnosis.[5] The limited studies published to date have shown that AYAs with a current or previous cancer diagnosis are more likely to suffer from quality of life issues and poor mental health and social functioning, reporting 2.5 times more fatigue than their peers who have not been diagnosed with cancer.[6]

A 2006 survey conducted by Zebrack and colleagues highlighted the many needs of AYAs. Of those surveyed, over 50 percent stated that their needs were unmet in the following areas:[7]

- Sexuality and intimacy
- Family counseling
- Camps and retreats
- Infertility treatments
- Adoption services
- Childcare
- Transportation assistance
- Alcohol and drug abuse counseling.

The Adolescent and Young Adult Oncology Progress Review Group was started in 2005 to evaluate the unique needs of AYAs and prompt further research into their unmet needs.[2] Composed of prominent members of the scientific, medical, and advocacy communities, the group is a public-private partnership between the National Cancer Institute and the LIVESTRONG Young Adult Alliance. Its purpose: to develop a national agenda for AYA oncology. *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer* is a recommendation report that reflects the opinions of the approximately 100 individuals who participated in the AYA Oncology Progress Review Group.[8] In 2012 the National Cancer Institute established working groups to help identify and solve issues related to AYAs. One group, the Health-Related Quality of Life and Symptoms Group, was tasked with evaluating AYA needs related to physical, psychological, social, and spiritual well-being.[2] While recognizing that spiritual well-being is a core component of patient-centered care, our team at Clearview Cancer Institute has focused on the physical, psychological, and social needs of our AYA cancer patient population.

The CAYAC group participates in a "Share Your Story" event with the local Oncology Nursing Society chapter.

Physical Considerations for AYAs with Cancer

The physical changes following a cancer diagnosis may be difficult for AYAs to deal with for various reasons. A 2013 study conducted by Kumar and Schapira revealed that both men and women struggled with the physical changes that accompanied a cancer diagnosis.[9] The loss of hair, weight gain or weight loss, and the loss of body parts can all have a negative impact on an AYA with cancer. AYAs aged 20 to 29 were significantly more likely to report that they had unmet needs around infertility, diet and nutrition, and general cancer information.[5] In a 2012 study, AYA cancer survivors were much more likely to be obese and were more likely not to engage in physical activity than individuals in the same age group with no cancer diagnosis.[10]

AYAs not only have the burden of working through physical symptoms related to their disease during and immediately following cancer treatment but may also experience long- and late-term side effects related to their diagnosis. AYA cancer survivors have a greater incidence of health issues than those who have never had cancer, including:[10]

- Cardiovascular disease (14 percent vs. 7 percent)
- Asthma (15 percent vs. 8 percent)
- Diabetes (12 percent vs. 9 percent)
- Hypertension (35 percent vs. 29 percent)
- Disability (36 percent vs. 18 percent).

AYAs are also at greater risk of recurrence and/or secondary cancers, which may bring increased burden or worries to this patient population and result in greater unmet needs related to long-term side effects and/or inadequate follow-up cancer care.[11]

AYAs who have completed cancer treatment have different needs than both the general AYA population and the pediatric and geriatric cancer patient populations. For example, fertility can be a major area of concern for AYA cancer survivors who have not yet started to consider options related to family planning. Many AYAs have limited knowledge about their reproductive health and the impact that their cancer treatment may have on future family planning. In fact, fertility information is cited as one of the biggest unmet needs for AYAs.[6] It is interesting to note that one study found that individuals in their 20s and 30s who had been treated in an adult oncology clinic were less likely to report the use of fertility information than teens who were treated in a pediatric oncology setting.[5] In addition, sexuality can be impacted during and following cancer treatment. Physical changes such as hair loss, weight changes, and loss of body parts may negatively impact sexuality.[9] One study that followed patients with breast cancer found that 52 percent of breast cancer survivors reported having a small problem in two or more areas of sexual functioning.[6]

It is important to note that physical symptoms may contribute to higher levels of distress in AYAs.[5] A 2013 study conducted by Zebrack and colleagues suggested that as treatment-related symptoms increased, AYAs reported more unmet needs for mental health services.[5] In another 2013 study, between 25 and 50 percent of respondents identified unmet needs related to physical activity and diet, meeting other AYAs, financial support, and fertility concerns, among other issues.[12]

Psychological Considerations for AYAs with Cancer

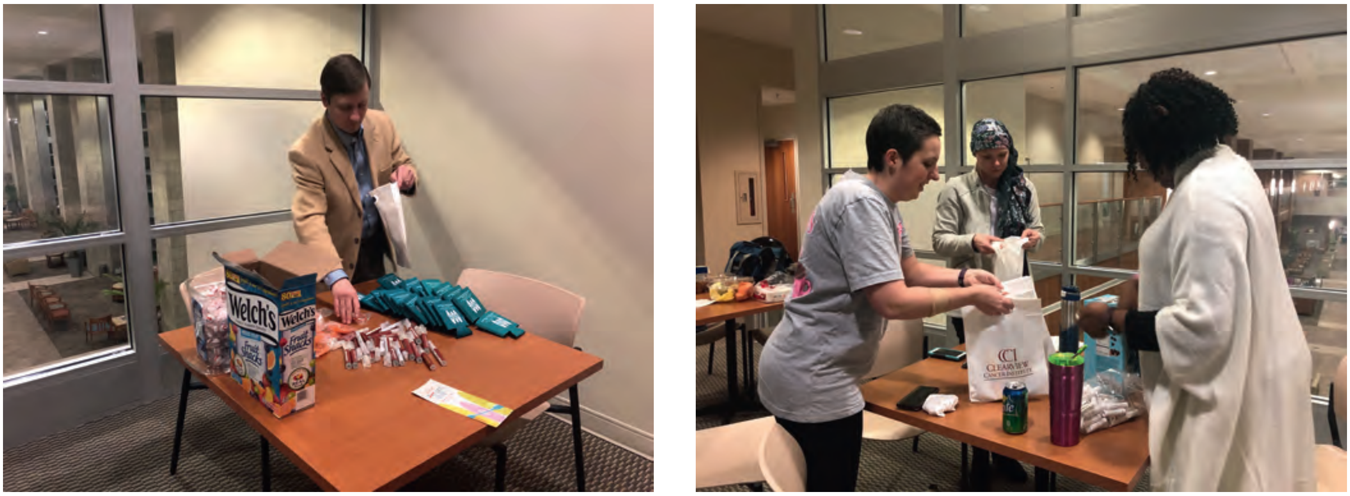
Though the psychological effects related to a cancer diagnosis can have the most impact on AYAs, they are often the most difficult to identify. Unlike physical changes that are often visible for all to see and recognize, psychological changes can be masked. These changes may be hidden and only revealed after a long period of time or may never be revealed at all but still have a significant impact on the overall well-being of an AYA. In one study, about one-third of AYA respondents indicated a need for referral to a mental health professional.[12]

> A 2006 study demonstrated that AYAs place a higher value on meeting other survivors than healthcare professionals perceived; this same study also showed that AYAs placed a greater value on meeting other peer survivors over social support from family and friends.

The financial impact of a cancer diagnosis can be devastating. One study notes that AYA patients with cancer and survivors are more likely to report overall non-adherence to medications and are more likely to report cost-related barriers to care, forgo preventive or follow-up care, and engage in unhealthy behaviors.[13] One study found that because healthcare costs became so expensive with a cancer diagnosis, many of the study participants would forego psychological care entirely.[14] In the 2013 study conducted by Zebrack and colleagues, almost half of AYAs surveyed reported a need for mental health counseling, with individuals treated in an adult oncology setting reporting more unmet mental health needs than those treated in a pediatric setting.[5] For many cancer programs, limited resources and lack of knowledge regarding the care of AYAs may play a role in psychological needs remaining underaddressed or entirely unmet.

AYAs are at a stage in their lives when they are more susceptible to stress,[6] which can contribute to the increased difficulty they often experience coping with their new diagnosis.[15] A cancer diagnosis may be the first dramatic life change or experience for some AYAs, and many have not fully developed the coping skills needed to face such a challenging life event.[15]

Findings from several studies imply that AYAs have higher levels of fear of recurrence than older adults.[6] AYAs also experience more depression compared to survivors in other age groups. For example, one study showed that 16 percent of AYA cancer survivors met the clinical requirements for a depression diagnosis.[6] Increased risk of suicide, anxiety, and post-traumatic stress disorder were also found to be more frequent in this population, with



Group members make welcome bags for new AYA patients that receive treatment at Clearview Cancer Institute.

suicide rates 2.6 times higher than those of their peers without a cancer diagnosis, and the risk of post-traumatic stress disorder was four to five times higher when compared with siblings.[6]

Social Considerations for AYAs with Cancer

Adolescence and young adulthood usher in many life changes. Evidence suggests that when AYAs are diagnosed with cancer they are more likely to deal with physical and emotional challenges that are associated with the transition from childhood to adulthood.[9] Identity formation occurs during adolescence and young adulthood.[4] During this time, it is important for AYAs to form relationships with their peers. These relationships help to shape identity. Unfortunately, many AYA cancer survivors report feelings of isolation and alienation from their peers.[16] They are unsure when to tell their peers about their diagnosis or how they will be perceived by their peers. Some AYAs choose not to disclose their cancer diagnosis at all.[4]

Because peer relationships shape identity, AYAs place high importance on friendships and social life.[17] AYAs also place great importance on sense of control, because it reinforces feelings of normalcy and maintenance of relationships.[16] When a life event, such as a cancer diagnosis, disrupts or pulls AYAs from their social lives, it can cause a great deal of distress. It is important for young adults to maintain their relationships after diagnosis, throughout treatment, and once treatment has been completed. Similarly, minimal disruptions to school and work schedules may also assist in maximizing normalcy.[17] AYAs who believe that they have support from their family and peers tend to have higher levels of empowerment and are better able to cope with their diagnosis than their peers with a cancer diagnosis who do not have a social support network.[15]

It is important for AYAs to be knowledgeable of their workplace rights; they should not be fearful of losing their job as a result of disclosing their cancer diagnosis. One HOPE study reports that one in three AYAs believed that their cancer diagnosis negatively affected their employment plans.[2] As such, it is important that AYAs reintegrate into society during or following their cancer diagnosis. AYAs with the ability to return to work or school following a cancer diagnosis report an overall improvement in their quality of life.[18] Individuals who are not able to return to work or school are more likely to have increased feelings of distress and isolation. These individuals also may experience long-term consequences in relation to career opportunities and earning potential.[18] Finally, AYA cancer survivors returning to work may face "stigma and misperceptions" related to job tasks and abilities.[19] As they return to the workforce, it is important for AYAs to be educated about the accommodations and community resources available to them.[19]

Making the Case for Support Groups

Support groups can play a critical role in meeting the unique needs of AYAs. A 2006 study demonstrated that AYAs place a higher value on meeting other survivors than healthcare professionals perceived; this same study also showed that AYAs placed a greater value on meeting other peer survivors over social support from family and friends.[7] In this study, 50 percent of AYAs undergoing treatment ranked support from friends and family as a top five need and 100 percent of AYAs ranked interaction with peer survivors as a top five need. Even after completion of treatment, AYAs rank peer survivor interactions higher than support from family and friends.[7] Another study demonstrated that the further into the cancer journey the AYA was, the more likely the individual valued meeting other AYAs with cancer.[16]

Yet in a 2009 survey, three out of four AYAs stated that they had yet to be able to participate in a peer support group.[14] And, according to a 2013 study, 25 percent of teens and 40 to 45 percent of adults in their 20s and 30s reported unmet needs in regards to retreats and camps for young adults, demonstrating a need for connection with other young adults in similar life situations or scenarios.[5]

Peer support groups allow AYAs to share their unique experiences with each other and provide an opportunity to commiserate with others on their disease journey. AYAs can share their experiences and concerns without the fear of being judged. These peer support groups are different from other social networks in that they can provide information, affiliation, coping skills, and hope.[20]

Support groups can be supplemented by online communities, which have been shown to improve knowledge, problem-solving skills, and efficacy while also reducing feelings of isolation.[15] In one survey, as many as 30 percent of AYA respondents stated that there was an unmet need for age-appropriate sites on the Internet.[17]

ACCC recognizes this knowledge gap and is working to address this issue with provider resources on fertility preservation discussions for male AYA patients with cancer, developing an oncofertility program, implementing a medical oncology home for AYAs, and more at accc-cancer.org/AYA-resources.

Networking with Key Stakeholders

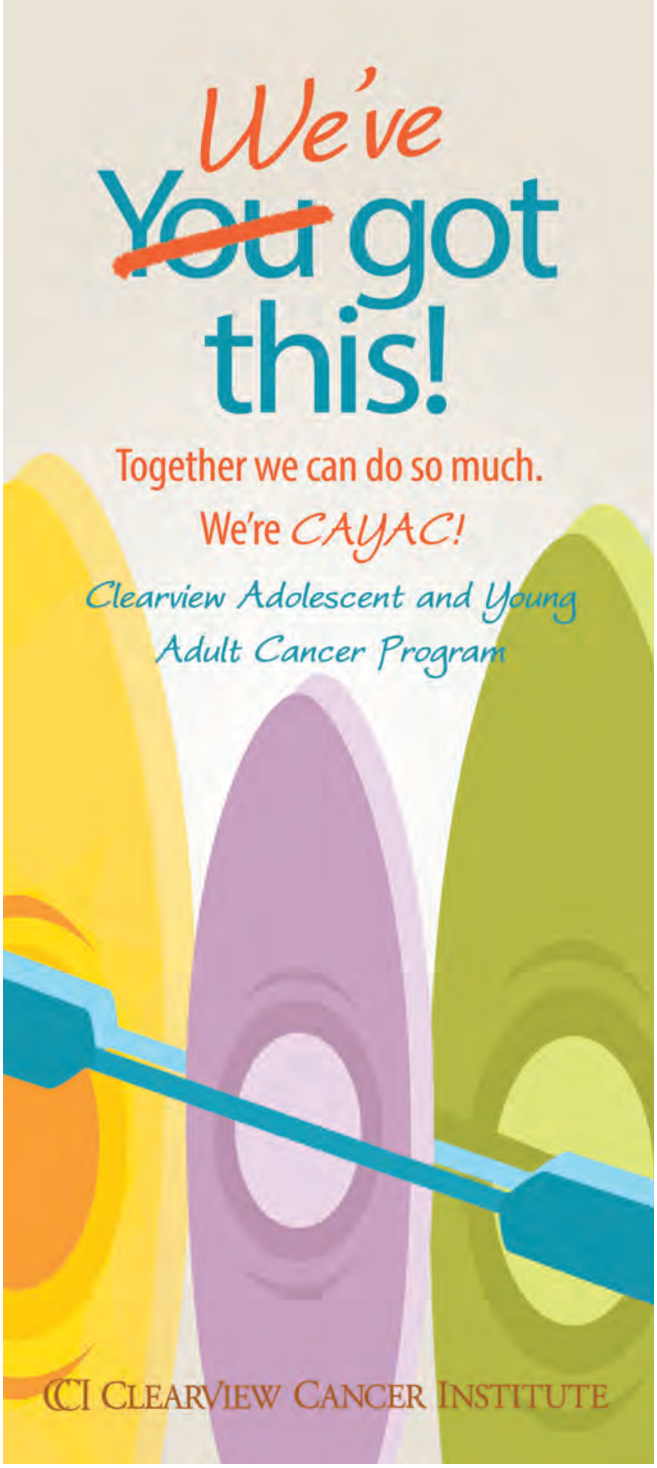
Armed with a better understanding of the unique needs of AYAs with cancer, our next step was to reach out to cancer programs that provide services to this patient population. We researched AYA programs and spoke to stakeholders from other cancer centers with similar programming in place. For example, we contacted program leaders at ACCC Member Program, the Robert H. Lurie Comprehensive Cancer Center at Northwestern Medicine, to gain more insight about its AYA program and services.

In addition to conducting research about external AYA programs and resources, we worked internally with our social work department and public relations specialist who oversees support groups to help identify other potential needs and to foster partnerships for moving forward.

Developing Program Goals

Prior to securing funding for our new Clearview Adolescent and Young Adult Cancer (CAYAC) program, we first had to identify overarching and supporting (programmatic) goals. CAYAC's overarching goal was twofold: (1) to create a support group for AYA patients and (2) to develop and integrate programming at Clearview Cancer Institute so that our clinical staff could learn more about AYAs to better identify appropriate treatment plans and improve care. To do so, we identified the following programmatic goals to help us identify and address emergent needs of this patient population:

- Foster connections between AYAs living with cancer
- Provide support during difficult situations
- Discuss effects related to cancer treatment and side effects
- Assist with complex needs of the young adult with cancer, including finances, dating and relationships, sexuality, returning to school or work, and survivorship.



CAYAC logo used for informational pamphlets, advertising, and and other promotional materials.

Through an event at HudsonAlpha Institute for Biotechnology, CAYAC members learn about genetics and genomics and research initiatives.

Securing Funding

In 2017 we developed an initial implementation budget of $4,500 and applied to a local 501(c)(3), the Russel Hill Cancer Foundation, which accepts grant applications each year in the March to April time frame. The Foundation's focus is on distributing grants related to research, education, and patient assistance for programs benefiting cancer patients or survivors. For the 2017-2018 grant year, we received $4,500 in funding to implement the CAYAC program. For subsequent years, we have secured an average of $3,000 annually to continue the CAYAC program, with the ability to request additional funds if needed for special projects.

CAYAC Programming

Once funding was in place, CAYAC's support group held its first meeting in August 2017 and continues to meet monthly. To educate our community about this new support group, Clearview Cancer Institute sent a mass mailing to eligible patients. An active Facebook page provides ongoing information about monthly programming. This information is also available on Clearview Cancer Institute's website on the Support Group page. Finally, we regularly distribute program brochures across our facilities for clinical staff to share with appropriate patients.

The CAYAC support group typically meets on Tuesday nights after 5:00 pm, which allows participants to attend after work or school. Occasionally, the CAYAC support group meets on a weekend for a special event. All meetings include a meal during our time together. These meetings have included traditional support group discussions, educational programs, service projects, and social outings. The more traditional CAYAC support group meetings are open discussion forums. Other CAYAC support group meetings:

- Host representatives from the local YMCA to discuss its Fit to Fight Program.
- Partner with our social work department to present information about local and national resources for AYAs with cancer.
- Visit a local biotechnology company to learn more about genetic and genomic testing and its cancer research initiatives.
- Host a "Share Your Story" night with our local Oncology Nursing Society chapter. At this event CAYAC support group members give a presentation about young adult cancer and breakout groups share their cancer story with infusion nurses and nurse navigators.

Participants support the CAYAC Program at the Survivors' Day Celebration.

- Conduct service projects, such as the creation of a brochure for newly diagnosed AYAs, which highlights questions to ask their provider and outlines resources for their journey; welcome bags for new AYA cancer patients; and "Brews to Benefit" events in which the CAYAC support group partners with a local brewery and a portion of sales for the night is donated to the Russel Hill Cancer Foundation.
- Participate in social outings, like bowling, golfing, an arcade night, annual holiday parties, a formal benefit dinner supporting cancer research, Survivors' Day luncheons, and attending Battle of the Buffalo, a local hot wings festival. These social outings have been the most well-attended events of all of the activities hosted over the last two years. Feedback from AYA patients indicates that they enjoy spending time with people who know what they have been through with cancer—where they can talk about the disease and its effects candidly and comfortably.

To remain true to the original goal of the CAYAC program, in 2019 we focused more on wellness, resources, and clinical education. CAYAC support group programs included:

- A Survivors' Day luncheon
- Zumba classes
- An educational program about camps and trips for AYAs with cancer
- A 5K run to support breast cancer research
- A cookie decorating class
- An annual holiday party.

Many of these activities were special requests directly from CAYAC program participants, whose feedback regularly directs our program activities and planning.

In addition to the CAYAC patient support group, we are working to improve internal clinical programming to increase awareness of this patient population. This year, we will be hosting a grand rounds-type program with our advanced practice providers to educate them about AYAs with cancer and National Comprehensive Cancer Network guidelines for this population, including a review of case studies.

Our team is also working with a local reproductive endocrinologist to provide information and resources to new AYA patients at their first clinic visit. We are in the process of adding supportive

Russel Hill Cancer Foundation provides funding for patient research, education, and assistance programs across North Alabama. Here, group leaders advertise for Russel Hill and CAYAC at a fundraising event, Battle of the Buffalo.

care regimens to our electronic health record to help address referral gaps in this area as well. At its nursing conference this year and its advanced practice symposium next year, Clearview Cancer Institute will host a reproductive endocrinologist to discuss implications of treatment, treatment considerations, and family planning options for young adults with cancer.

The Patient and Provider Experience

Since implementing the CAYAC program, Clearview Cancer Institute has distributed more than 1,000 informational brochures. Our CAYAC support group held 24 individual meetings in which we served more than 15 individual AYA patients with cancer and survivors. In addition, some program offerings were extended to the patient's support person, and those individuals were served as well. CAYAC support group participation is consistently in line with—or higher than—the average participation at other Clearview Cancer Institute support groups, demonstrating a continued need for this program. In addition, many CAYAC program participants have become close friends outside of our monthly activities. For staff, it is encouraging to see connections and relationship building growing an additional support system.

The CAYAC program has been an important forum to educate our clinical staff and employees and to raise awareness of the unique needs of the AYA patient population and the necessity of additional outreach to help AYA patients feel supported through their cancer journey. Moreover, the CAYAC program has increased community awareness of the Clearview Cancer Institute and its services within our community.

The Russel Hill Cancer Foundation has also benefited from the CAYAC program because it offers a consistent avenue for the foundation to give back to the community and further impact patient research, education, and assistance programs.

Lessons Learned

For cancer programs looking to develop a similar AYA program, our staff offers these lessons learned:

- The literature and our real-life experience clearly demonstrate that there are many unmet needs in this patient population.
- A support group-type program is an effective way to begin to address some of these needs.
- An AYA support group requires thinking outside the box and going beyond traditional support group type functions. Our experience is that AYAs with cancer do not enjoy structured educational programming or direct sharing of feelings and emotions (the more traditional formats of other support groups). Rather, we have found that social events help this group feel accepted and supported in such a way that they then become willing to share emotions, feelings, and the story of their cancer journey more openly.
- AYAs want to be part of the solution to improving their cancer journey. They put in the time and effort to help those on the cancer care team improve processes. They are willing to tell us what has worked for them and what has not, as well as

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> what processes help and support them and what areas need improvement. Our AYAs have big hearts and are dedicated to improving cancer care for future generations of AYAs.

To positively impact the future of cancer care for AYAs, the cancer community has several responsibilities moving forward. We must continue conducting research and investigating ways to address the needs of this patient population. In addition, we must make a commitment to continue education of our clinical staff regarding standards of care and support of these patients. Lastly, we must advocate for the implementation of programming, like CAYAC, to educate and support our communities. OI

Kristin S. Donahue, MSN, RN, OCN, is director of educational services and Anne Marie Fraley Rainey, MSN, RN, CHC, is compliance and quality control officer, OCM project manager, Clearview Cancer Institute, Huntsville, Ala.

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