



Understanding Disparities for AYAs with Cancer

FACT:

90,000 adolescents and young adults are diagnosed with cancer each year in the United States.

FACT:

Every six minutes, somewhere in this country, a young person hears the words, "You have cancer."

FACT:

Nearly 700,000 AYAs in the United States have a history of cancer, some from the time they were children.

If these facts surprise you, you're not alone. For AYAs with cancer, being overlooked and underserved has been the norm for too many years and the unique age-related challenges facing this group of cancer patients and survivors have long been unrecognized.

Adolescence and young adulthood is a difficult time even for healthy young people. It's a time of important development transitions. A time of emerging independence and self-identity. A time to find one's place in the world, explore options, and plan for the future.

Cancer, however, disrupts these normal milestones and complicates the process in ways that are not yet completely understood. Fortunately, though, the the landscape of care for AYAs with cancer is changing.

More attention is being paid to AYAs with cancer, a significant improvement since we began our work twenty-one years ago. But much more needs to be done.

- cont. page 6

insights

On How
We're
Helping
Teens &
Young Adults
Live With
Cancer

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November 4, 2023

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cancer connect

Teens and Young Adults
Get it Together!



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Our mission is to help teens and young adults with cancer live their very best lives by providing a comprehensive continuum of care throughout all stages of their cancer experience.

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A Message from Lauren Spiker Founder and Executive Director

Hello Friends,

I'm not sure when cancer awareness months began, but the earliest reference I could find was 1985. Former First Lady Betty Ford, diagnosed with breast cancer during her husband's presidency in 1974, kicked off a one-week awareness event sponsored by the American Cancer Society and a pharmaceutical company. In 1992, Estée Lauder cosmetics introduced the now ubiquitous pink ribbon, and October was officially dubbed Breast Cancer awareness month. Since then, just about every cancer has a colored ribbon and awareness month. Childhood cancer, as a whole, is recognized with a gold ribbon in September and dedicated to the many devastating cancers afflicting little ones.

But what about Adolescent and Young Adult cancer? Well, it doesn't have a colored ribbon and only recently, has the first week in April been declared AYA Cancer Awareness Week. Well, we don't think one week is enough to recognize the 90,000 teens and young adults diagnosed each year in the United States so, we celebrate the entire month of April as Adolescent and Young Adult Cancer Month! We have an array of great community events scheduled this month in their honor and we hope you will join us! (see page 3)

Our goal in April is to heighten awareness of the unique, age-related challenges facing our AYAs, reminding me of the song sung by Kermit the Frog, the first Muppet designed by Jim Henson. In *It's Not Easy Being Green*, Kermit laments feeling passed over, overlooked, just "blending in with so many other ordinary things." Our members can relate. It's not easy being an AYA with cancer. No longer children but not yet fully independent adults, our AYAs have been passed over, and for far too long, overlooked. Like Kermit, they just need others to understand who they are and what they need.

We're here to do just that and invite you to help!

With deep thanks as always,

Lauren



April is AYA Cancer Awareness Month!

Proudly supported by Wesley Clark & Peshkin, LLP



<p>April Initiatives</p> <p>Upstate Bottle Return: Cans for Cancer - Save your bottles and cans!</p> <ul style="list-style-type: none"> • 13thirty Center Drive: April 15 (9:00 - 3:00 p.m.) • 13thirty Center Drive: April 28 (noon - 6:00 p.m.) • Schedule a pick-up with 13thirty staff. Call (585) 563-6221. • Bring your bags to the 13thirty Rochester Center (9:00 - 5:00 p.m., M-F) <p>BeeKind Syracuse: Healing Himalayan candle fundraiser (purchase at 13thirty.org)</p>
<p>April 1 Noon - 4:00 p.m.</p> <p>Heroes Brewing "My Best Life" Beer Release Event \$1 of every 4-pack benefits 13thirty Food, live music & beer</p>
<p>April 11 1:00 - 6:00 p.m.</p> <p>13thirty x Al Sigl Blood Drive Schedule donation at 13thirty.org Chance to win a #BillsMafia basket</p>
<p>April 12 - Zoom 6:00 p.m.</p> <p>Passions in Action: Breast Cancer Confidence Speaker Series Michaela Raes (cancer survivor, founder of BCC)</p>
<p>April 19 6:00 p.m.</p> <p>13thirty x Game Night Rochester Raffles + Cocktails @ 6:00 p.m. Twisted Trivia @ 7:30 p.m.</p>
<p>April 21 7:00 p.m.</p> <p>"Sometimes, You Just Gotta Laugh!" Part II A night of comedy to benefit 13thirty Hosted by comedian Todd Youngman, Starring comedian Sky Sands Stand-up comedy performances by 13thirty members</p>
<p>April 27 5:00 p.m.</p> <p>Sip & Shop: Figgy Studio & Shop x Statement Boutique Sip wine, shop local, & support local AYAs Visit both Park Ave shops</p>
<p>April 29 9:00 a.m. - noon</p> <p>13thirty Fit! Fest at Three Heads Brewing Sessions from ROC Strong Club, The Reformatory, Zumba & Yoga+ Register at 13thirty.org</p>

Goin' Bald for Bucks - Fund and Fun-Raising!

As each strand of hair fell to the floor, the noise grew at Letchworth Central School's *Goin' Bald for Bucks* event, a collaborative initiative of 13thirty Cancer Connect and Roswell Park Comprehensive Cancer Center.

The atmosphere was electric as students cut or shaved their hair to raise awareness and funds for peer support programs at 13thirty and cancer research at Roswell.

Kara Bonn, the school's *Leadership in Action* teacher, presented *Bald for Bucks* to her students in 2017 as an opportunity for a hands-on leadership experience.

"Our event is 100% student run through our *Leadership in Action* class," said Kara. "Giving ownership to the students creates a bigger buy-in from their peers."



"I love that it includes all grades, K-12," exclaimed Ella, a junior in Kara's leadership class.

"The assembly allows all levels to participate in games, and learn about cancer, while supporting their classmates."

Twenty-three participants raised over \$8,000 for their event bringing Letchworth's six-year total to nearly \$60,000!

Kara's already looking forward to next year and challenges other schools to get involved.

"Go for it," she says, "I promise it will be worth it once you see how

big of an impact your project has on your students and so many people in the community."

Create a buzz at your school and go Bald for Bucks!
Contact Clare for all the details - clare@13thirty.org

SNAPSHOTS!

What's been happening with -
and for - teens and young
adults with cancer!

1. Syracuse Wine Club

The Cirque d'Vin Wine Club in Syracuse chose 13thirty for their monthly wine tasting. Club members raised \$1,521 for 13thirty, their highest charity donation to date.

2. Crayon Connections Program

During this March program, members made butterflies out of melted crayons to represent the changes to one's relationships as a result of treatment.

3. Holiday Treats for the Nurses

Our Rochester Program Manager, Clare, spread some holiday spirit in December by bringing treats to our amazing oncology nurses at Galisano Children's Hospital!

4. Volunteers at The Center for Youth

13thirty members spent an evening giving back. Using our organization and folding skills, we helped sort clothing donations used to support local youth.

5. Family Feud Night

Competition was high as 13thirty members tried their hand at Family Feud! Clare will not be adding Game Show Host to her resume!



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6. Yoga with Audrey

Audrey Dunn, a dedicated associate board member and founder of Yoga+, spent a night using yoga to help 13thirty members stretch, relax, and zen out. Namaste!

7. Thank you, Alice!

Special shoutout to our volunteer, Alice, a senior at Bishop Kearney High School. Every Tuesday, she helps with a variety of tasks and program preparation. Thanks, Alice!

8. Protein packed brownies!

Syracuse members turned up the heat baking spiced protein brownies, after learning about the importance of protein in their diet from our wellness app, 13thirty To Go!

9. Remembering Together

Four bereaved moms shared a meal and memories with Lauren at our Syracuse center recently. Hugs from others who understand help comfort broken hearts.

10. Getting Warmed Up!

Steve led Syracuse members in a warm-up exercise in our fitness room before the planned evening program. Lots of laughing and sharing!

Happy
Spring!



Disparities - cont. from page 1

Achieving equity in healthcare is a topic of great importance today, especially for our population. "For adolescents and young adults with cancer, almost everything is an equity issue," says Dr. David Freyer from the Children's Hospital, Los Angeles.

A wide range of disparities exists among AYAs with cancer, in general. Other socioeconomic, racial and ethnic, and insurance disparities magnifying the problems.

As an example, we've known for many years that survival for AYAs has not improved at the same rate as other age groups (see graph). While the exact cause of this disparity is not known, several factors are known to contribute.

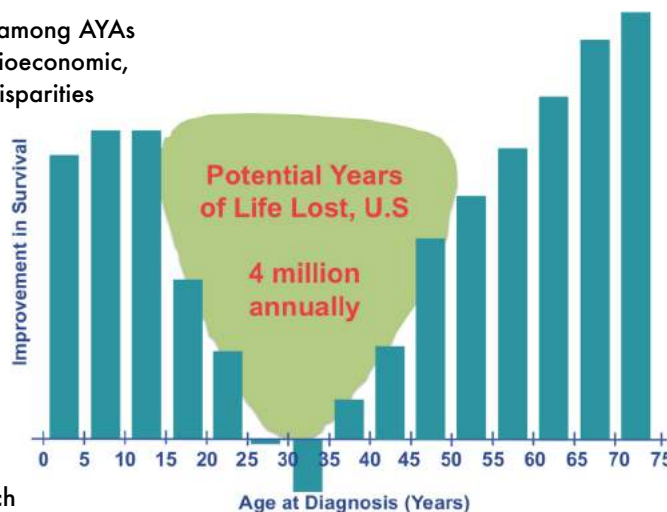
We know that AYAs do not participate in clinical trials as much as children, for whom there has been dramatic improvement in survival over the last forty years.

Only 2% - 5% of AYAs are enrolled in studies as compared to 30% - 60% of children. More research about AYA cancer is imperative.

Delayed diagnoses also impact survival rates. For many teens, early warning signs of cancer are often dismissed as typical adolescent issues like growing pains or sports injuries. For young adults, being uninsured or underinsured may lead to delays in seeking treatment.

Inadequate insurance may also lead to non-adherence to follow-up treatment and surveillance plans, contributing to high rates of recurrence and secondary cancers. For young adults, cancer can be very costly in the short run, especially if underinsured, but also long-term with lifelong earning capacity often severely reduced.

AYA cancer has increased more than 30% in the past forty years in the United States and we need to better understand disparities in this group as compared to other age groups.



90,000
Adolescents and young adults (AYAs) diagnosed each year in the United States
3X
More people are diagnosed in the second 15 years of life than the first

We are excited to be partnering with UR Medical Center and Rochester Regional Health, the two largest healthcare systems in our area, to study this important issue. A study we initiated is underway and expected to be a two-year process. You can read more about the goals of this study on page 7.

Stay tuned!

Getting Fit Together!

Cancer takes its tolls on every aspect of an AYA's life and Ender, 28, wanted to get back in shape after treatment for testicular cancer.



Ender celebrates after a tough workout

"I wanted to improve myself physically and mentally," he said about participating in our 8-week 13thirty Fit! program.

So, he joined six of his 13thirty friends in our gym at the Al Sigl Community of Agencies to work out with Brianne, our fitness coach, who has led our programs since 2014.

After joining 13thirty Cancer Connect, Ender quickly realized the benefit of being with others who understand what it's like to be a teen or young adult with cancer. "I felt that being with other like-minded people would help me achieve my fitness goals," he reflected.

Peers like Meesh and Emily who have attended the program many times over the years.



Meesh & Emily take a few laps in the gym

"It always feels good to have Brianne kick our butts again," said Meesh. "It's easy to fall back into old habits."

Since starting the program in 2013, we've seen consistent improvement in participants' endurance, strength, and outlook on life. "It definitely boosted my confidence," said Ender.

At the end of 8 weeks, everyone brings a healthy dish for a potluck dinner when Brianne shares results of their pre- and post-fitness tests and celebrates their progress. Great job, team!

Check out our fitness programs on our new wellness app 13thirty To Go! (ToGo.13thirty.org)



AnnaLynn Williams, Ph.D.
Young adult survivor

UR Medical Center
Asst. Professor, Dept. of Surgery,
Cancer Control

"We have so much to learn about how different social and economic factors and disparities influence needs."

Tell us about your cancer experience as a young adult.

I was diagnosed with Acute Myeloid Leukemia when I was 22. I had just graduated from college and was starting my master's program in epidemiology which had to be delayed 3 years for treatment. I relapsed a year and a half into treatment and underwent a bone marrow transplant. Neither of my siblings were a match, but luckily I had a match in the national donor registry. She was my guardian angel!

Aside from having cancer, what was most difficult?

One thing I struggled with was the passing of time, and watching my friends and family move on with their lives while time stood still for me.

I struggled to find joy for them as they started careers, got married, had families, and completed advanced degrees. I had to do a lot of self-care to give myself permission to just be, and focus what little energy I had on making it through treatment and beating my cancer.

What led you to pursue your current career path?

I knew I wanted to be an epidemiologist. I had a knack for it, and loved the idea of impacting public health. When I was diagnosed, my focus shifted toward cancer epidemiology.

When prepping for bone marrow transplant, one of the steps is total body radiation. The radiation oncologist thoroughly went through the consent form with me, but the section

describing the risk for a subsequent cancer associated with radiation was very vague.

I was shocked that treatment designed to save me, might also cause another cancer. I asked him to describe the risks in more detail but he said the data weren't very specific. They knew from events like Chernobyl that radiation is associated with cancer, but couldn't know what my specific risk was. Right then, I knew I wanted to focus on cancer epidemiology, specifically acute and late effects of cancer and its treatment in children, adolescents, and young adults with cancer.

How does having had cancer impact your research?

My own experience definitely inspires many of my research questions. More importantly, I know how important the patient experience is to our research! Because patients have unique experiences, concerns, and needs, it is important to include them when we are designing studies.

What do you hope will be gained from the project you are working on with 13thirty (see below)?

I am hoping we can learn from AYAs in the greater Rochester area what their medical, psychosocial, and other needs are, so that we can design interventions to help navigate those needs and support them as they go through treatment and transition to life in survivorship.

Thanks, AnnaLynn, for using your experience to "make a difference" for other AYAs with cancer!

UNDERSTANDING DISPARITIES AND ACHIEVING EQUITY IN HEALTHCARE FOR AYAs WITH CANCER IN THE GREATER ROCHESTER AREA

A Multi-Institution and Community-Based Study

We know much more today about the challenges facing AYAs with cancer than we did 20 years ago when we started. But what specific AYA challenges exist in our community and their impact is unclear. This study will attempt to find out.

Project Team

Lauren Spiker, 13thirty Cancer Connect
Dr. Jeff Andolina, UR Medical Center
Dr. AnnaLynn Williams, UR Medical Center
Kelly Palmer-Smith, Rochester Regional Health
Abby Squiciarrini, Rochester Regional Health
Tad Mack, Monroe County Deputy Clerk, 13thirty Board

Study Aims

1. Characterize the number of AYA patients in the Greater Rochester area.
2. Survey the healthcare and psychosocial needs of AYA with cancer in the greater Rochester area.
3. Identify disparities in unmet needs by race/ethnicity income and insurance status, and potential gaps in services, as well as barriers to access.
4. Design interventions to address the unmet needs of AYAs with cancer and achieve greater equity.



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Melissa Marie Sengbusch
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