



insights

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

Board member, Tad Mack, is ready to color the community with AYA Month lawn signs!

Neighborhoods in the Rochester and Syracuse area were recently dotted with lawn signs promoting April as Adolescent & Young Adult (AYA) Cancer Awareness Month!

This was just one of the many ways 13thirty Cancer Connect hoped to heighten awareness of AYA cancer and engage the community in our efforts to support teens and young adults with cancer.

“Twenty years ago,” said Lauren Spiker, “few people were thinking about the challenges facing our AYAs. Today, the acronym AYA is common vernacular in the oncology community - and now we have lawn signs! That’s progress!”

Lawn signs, however, are not progress enough and much greater attention is still needed to meet the unique needs of our teens and young adults. No longer children but not yet fully independent adults, AYAs face serious medical and psychosocial challenges.

While much remains unknown, one known cause of poor outcomes for AYAs is delayed diagnosis. Because cancer is relatively rare in this age group, early signs are often mistaken for more common adolescent or young adult ailments. Higher uninsured rates may also contribute to cancer being diagnosed at a late, more difficult to treat, stage.

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SAVE THE DATE!

Journeys
November 13, 2021
Stay tuned!

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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,

As we near the Summer Solstice, the longest day of the year and the official start of summer, the Beatles song, "Here Comes the Sun", rings in my ear. The lyrics seem fitting after the past 16 months of social isolation.

*Little darling, the smiles returning to the faces.
 Little darling, it feels like years since it's been here.*

*Here comes the sun, do, do, do. Here comes the sun.
 And I say, it's all right.*

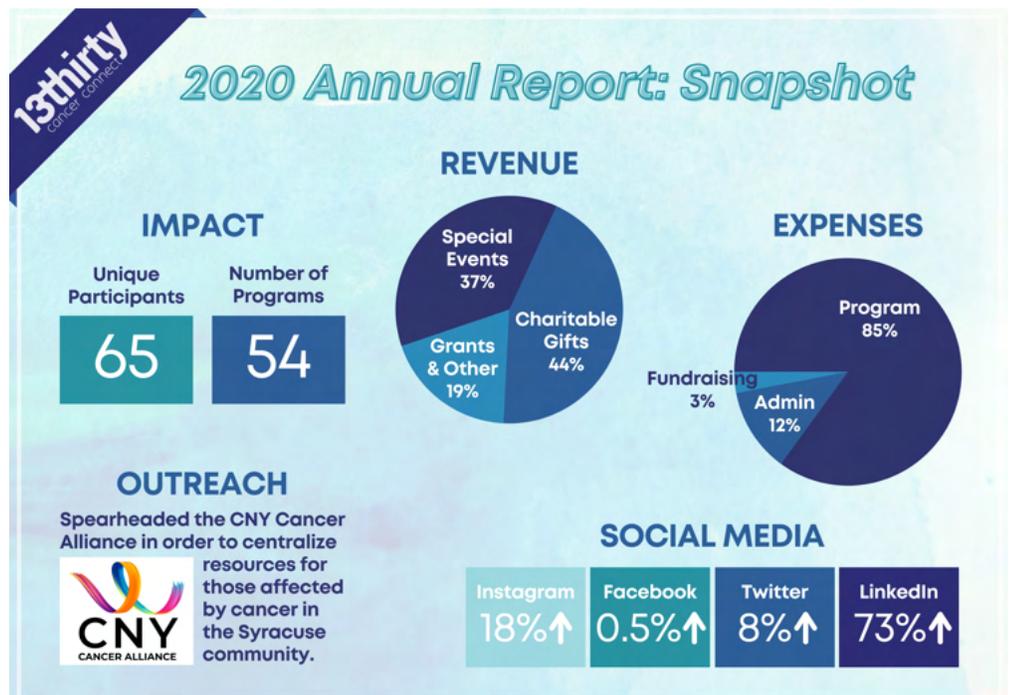
Even though the risk of COVID is not completely gone, the long, cold, lonely winter is melting with a hint of 'normal' and it feels so good. We are slowly returning to in-person programs at our Centers and we happily held our first, live major event, the 2021 Bandana Bolt 5K, this past weekend. Here comes the sun, indeed!

Like many, 13thirty Cancer Connect was severely impacted by the pandemic but not even a global crisis could stop us. Working together, we weathered the storm and proudly met our pandemic goals: to keep our doors open, to keep our team engaged and intact, and most importantly, to keep supporting our AYAs. As you'll see in the graphic below, decreased grant funding was offset by an increase of 17% in charitable gifts from our dedicated and loyal supporters to whom we are very grateful.

We are looking forward to life after COVID. Despite the challenges, there were silver linings and we are energized by what we have learned. We feel more creative, act more decisively, and love more deeply. Here comes the sun, friends, and I say, it's all right!

With deep thanks, as always,

Lauren



Wait for it

Beginning with this issue, we'll share good news and updates about our 13thirty Cancer Connect community. Please join us in celebrating!

New Board Members



Alexis Arnold is part of the *Good Day Rochester* team on 13WHAM ABC and FOX Rochester. Her years of experience help increase awareness of AYA Cancer.



Keith Poole is our first Syracuse Board member. Keith and Lynda's son, Charlie, who died in 2018, helped inspire the establishment of our Syracuse center.

The Graduates



Zechariah
Byron - Bergen
High School



Liz
Webster Thomas
High School



Taylor
Albany College
of Pharmacy



Mia
Cornell
University

New Additions



Joey, son of Erica & Steve Esposito
(13thirty Program Director)



Greyson, son of Scot & Brittany McNair
(13thirty survivor & Board member)

It's Official



Valii, adopted by John & Nicole Zobel
(13thirty survivor)



Hannah & Juliet, adopted by Bill & Paige Strassner (13thirty survivor)

2021

9th Annual

Bandana Bolt

The Race Was On and It Was Great!

For the first time in 16 months, we met in person for a 13thirty Cancer Connect event - the 9th Annual Bandana Bolt 5K Race & Fitness Walk at Seneca Park in Rochester on Sunday, June 6th! Dozens of 13thirty Champions participated virtually from as far away as San Francisco, Dallas, Tampa, and Washington, D.C.



When planning for this year's race began, many COVID restrictions were still in place limiting the number of people who could gather outdoors. Another virtual event, we thought.

Fortunately, though, with the vaccination roll-out and decreased incidence of COVID in New York State, restrictions were lifted and the in-person race was on! Because of the early uncertainty, the Bandana Bolt was not officially timed but over 150 people ran and walked at their own pace, enjoying a beautiful sunny day together! Big thanks to all who joined us either in person or from afar.



Thanks for helping our teens and young adults cross their own finish line!

SAVE THE DATE!
Syracuse - Bandana Bolt 5K
Green Lakes State Park - Oct. 1-3, 2021

SNAPSHOTS!

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

1. Relationships & Cancer

This February program addressed the unique challenges AYAs face in their love lives. Members shared experiences and learned new ways to strengthen their relationships.

2. PRIMA

13thirty is collaborating with the Prima Group at St. John Fisher College on a 13thirty - Brand Ambassador Program on campus. We look forward to this exciting new partnership!

3. 'Goin Bald for a Cause

13thirty Champion, Steve Synesael, shaved his head to raise money and awareness for AYA cancer. Steve joined Good Day Rochester before and after shaving his head to explain why. Thanks, Steve!

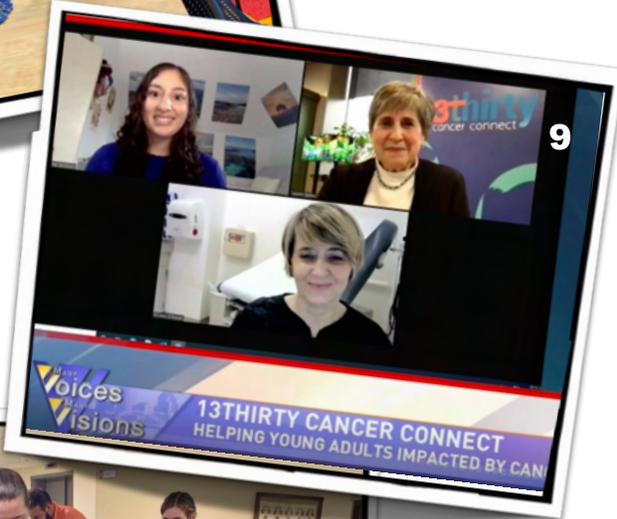
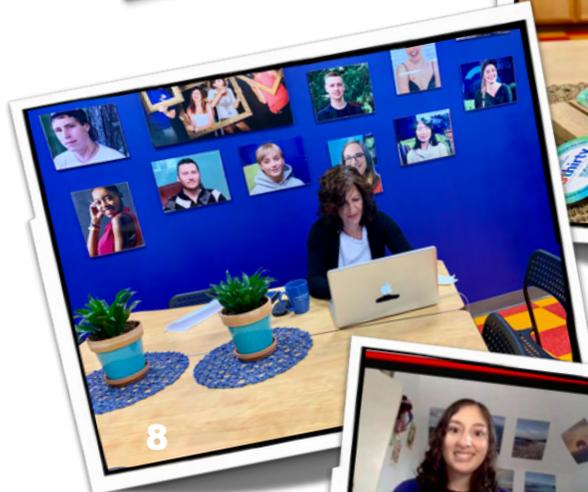
4. Riley's Art Show

Fellow 13thirty Syracuse members visited AYA member, Riley Murray's senior class exhibit art show at Cazenovia College. Such talent! Great job, Riley!

5. Corporate Goodwill

Mindex, a Rochester leader in software development and professional services, has partnered with 13thirty this year. A company-wide pledge of almost \$27,000 brought us all to tears.





6. Best Team Spirit

Sunny skies fueled the enthusiasm of "Team Fireballs" at the 9th Annual Bandana Bolt 5K. Best Team Spirit award goes to this fun group who knows how to celebrate!

7. 13thirty Cancer Connect Candle
BeeKind Candles in Syracuse, NY handcrafted the exclusive Healing Himalayan 13thirty candle. From each purchase, \$5 was donated to support our AYAs. Huge thanks to BeeKind Syracuse!

8. Volunteer Extraordinaire!

Board member and AYA parent, Linda Jacobson, has been busy updating our database, helping with the newsletter, and even organizing our storage closet! You're the best, Linda!

9. Many Voices, Many Visions

Board member, Alexis Arnold interviewed Lauren, AYA survivor Mia Jacobson, and Dr. Kristen O'Dwyer, Wilmot Cancer Center. A great way to highlight AYA cancer and 13thirty Cancer Connect!

10. Tie Dye Program

AYAs met for our first in-person program of 2021 in May to tie-dye their own colorful 13thirty shirts. It was great to see everyone in the Center again!



Enjoy the Summer!

AYA Month - cont. from page 1

AYA patients also have a high risk of long-term, late effects including infertility, cardiac and other major medical issues, as well as secondary cancers, often caused by treatment for their original diagnosis. The social and emotional impact of cancer is also different for AYAs, already in the midst of important early-life transitions.



Mia, 22

"What really affects you is the isolation," says Mia Jacobson, a young adult survivor of Hodgkin's lymphoma. "You're going through something not a lot of people your age can relate to."

That isolation, coupled with the fear of cancer, often leads to other emotional, social, and psychological challenges.

Studies have shown that even mild symptoms of untreated anxiety and depression are linked to poor response to treatment and medications, and may even negatively impact disease progression.

Survivor's guilt, "scanxiety" (anxiety that occurs before routine scans), and fear of recurrence can also be overwhelming. It can be difficult to readjust "back to normal life." Data from 2019 show that nearly 700,000 AYAs in the United States have a history of cancer, some of whom were children when diagnosed but still living with the impact of cancer on their lives.

This is where 13thirty Cancer Connect comes in. Our programs are designed to help AYAs in treatment, as well as survivors,

recover what was lost because of cancer and discover new opportunities and personal strengths. Connecting with others who understand the shared experience makes that much easier - and fun!

We are very grateful to all the local businesses that supported us in April. If you or your company would like to know how you can help, feel free to call us at 585-563-6221.

While we designate April as AYA Cancer Awareness Month, every day is a day to celebrate our AYAs at 13thirty Cancer Connect!

DID YOU KNOW?

89,500 AYAs were diagnosed with cancer in the U.S. last year.

Cancer in AYAs has increased 10% in the last 15 years.



Ashley and Louis

Every 6 minutes, a young person hears the words "you have cancer."

3X more young people are diagnosed in their second 15 years than their first 15 years.

Last year, 9,200 AYAs, ages 15-39, died of cancer.

Thanks to all who supported 13thirty Cancer Connect during AYA Cancer Awareness Month!



Brockport Diner



13thirty Cancer Connect Syracuse & Rochester Associate Boards



Spotlight On



Vicki Ioele
2x Stage IV Survivor
13thirty Blogger



13thirty Cancer Connect is thrilled to introduce our new resident Blogger, Vicki Ioele, a 2x Stage IV Hodgkins Lymphoma thriver. Vicki reached out asking if she could help in some meaningful way. After chatting for just a short time, it was immediately clear that she was the perfect person to share insights with our members.

"It all started on Friday, October 31, 2014," Vicki recalls. The day she heard the words, "You have cancer." What followed for Vicki is much like what our AYAs experience. A chest x-ray, followed by a CT scan led to the diagnosis which as Vicki says, "was not even remotely on my radar."

Multiple surgeries, regular scans, seemingly endless lab work, six months of chemotherapy and 18 rounds of radiation finally led to welcome words for Vicki - no evidence of disease (NED). Her joy, however, was short lived. Eight months later, her cancer was back, again Stage IV, and for the first time, Vicki allowed herself to cry, to feel everything she was feeling, to sit in that moment and "just be."

She asked the universe for clarity and found her way to a clinical trial at Memorial Sloan Kettering in New York City that combined immunotherapy and antibody therapy, followed by

a autologous stem cell transplant. Thankfully, her own stem cells gave her a second chance at life and she was finally in remission in 2016.

Nearly six years after her initial diagnosis, Vicki is proud to say, "I've gone from Stage IV to No More!" Cancer has inspired her to give something back to the world that she almost lost, leading her to start our new blog series, *13thirty Threads*.

Each month, Vicki will reflect on her experience as a cancer survivor, and in an easy conversational style, share her insights and perspective. While each cancer diagnosis and journey is unique, there are some very similar emotions and experiences to which our AYA's can relate and from which we all can learn.

Through her insightful writing, Vicki allows us a raw look at the thoughts, feelings, and emotions that start with diagnosis and continue through treatment, recovery, and life. Check out our website - 13thirty.org - to read Vicki's blog each month.

*Thanks, Vicki, for being willing to share your story!
Your words are inspiring!*



Evan Thomas Valentine
2002-2021

Remembering Evan...

With deep sadness and happy memories, we remember our 13thirty Cancer Connect friend, Evan Valentine, who died of acute myeloid leukemia on February 21 at age 18.

Evan was full of life and laughter. Whether it was dying his hair bright red or learning to play the piano with the hospital music therapist, Evan was willing to tackle anything that came his way, always with a smile and an upbeat attitude. He epitomized his favorite saying, "We got this!"

He faced his cancer with grace and courage, finding beauty in every day. Every person who knew Evan was touched by his positivity. "I left his room every time with a smile on my face," remembers Steve, our Program Director. In honor of Evan, may we all be "Evan Strong!"

"To live in hearts that love is not to die."



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YOUR SUPPORT WILL MATTER!



**Make A Difference for
Teens & Young Adults like Melissa**

*"If you've learned anything from me
through all of this, do something with it
to make a difference, to make things better."*

**Melissa Marie Sengbusch
1981 - 2000**