

THE 2024 SPRING/SUMMER UPDATE

# 13THIRTY INSIGHTS

ON HOW WE ARE HELPING ADOLESCENTS AND YOUNG ADULTS LIVE THEIR BEST LIVES - TODAY!

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**13thirty**  
cancer connect

1000 ELMWOOD AVE., ROCHESTER, NY 14620 • 1035 7TH N ST., LIVERPOOL, NY 13088

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## THANKS TO OUR PRINT SPONSOR:



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

13thirty Cancer Connect is a registered IRS 501 (c) (3) tax exempt organization.

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## A Message from Lauren Spiker

Founder & Executive Director

Hello Friends,

So, how do you like the new look of *Insights*? We thought it was time for a little design change and hope you like it!

But don't worry, the important things have not changed. Our mission, our team, our vision remain the same - clear, focused, and unwavering. Every day, Melissa's challenge "to make a difference, to make things better" inspires us to do just a little more to help our AYAs live their best lives - today!

But there are some changes afoot that are troubling in the world of AYA cancer. The incidence of cancer in young people has been growing at an alarming rate over the last ten years and, as reported in a recent 2023 study, cancer in young adults is growing by the largest percentage, nearly 20%.

The increasing cancer burden among adolescents and young adults, referred to as the "early-onset cancer epidemic" in a 2022 report, caused the National Cancer Institute to consider this issue a research priority. Projections indicate that, globally, **the incidence of early-onset cancer would increase by 31% in 2030.**

The good news - survival for AYAs is improving a little bit. That's to be celebrated, for sure. But we also know that survivorship often comes with a high price. Increased risk of recurrence or secondary cancers. Complicated late effects of treatment and multiple health-related quality of life challenges. We can't stop now! There is too much at risk and we need to do more.

And with your help, we will do more. We'll continue keeping the promise I made to Melissa 24 years ago, just days before she died. Together, we will get it done!

With thanks as always,

**Lauren**



### Metzler Yard Jam Summer Concert - 6:00 pm

Friday, August 9, 2024 | 12 Foxboro Lane, Fairport, NY 14450

Join us for a summer evening of music and picnic food hosted by the Metzler family to benefit 13thirty Cancer Connect and the Hannah Metzler Memorial Fund.



### The 20-Day Challenge: Help us Raise \$100,000 in 20 Days

Monday, July 22, 2024 - Saturday, August 10, 2024

We're embarking on a challenge to raise \$100,000 in just 20 days. The growing incidence of AYA cancer is alarming. We need your help to support our mission. Can we count on you?



### Journeys, 24th Annual Celebration of Living

Saturday, November 3, 2024 | Temple B'rith Kodesh | Rochester

Don't miss our special annual gala, Journeys - a night to honor and celebrate our teens and young adults with cancer. This year's theme: *The Golden Butterfly Awards!*



# TURNING CANCER INTO COMEDY

*Cancer.* If that word elicits feelings of fear, anxiety, and shock in you, you're not alone. 13thirty Cancer Connect decided to change the narrative using stand-up comedy as the tool.

On April 19th, nine of our AYAs from Rochester and Syracuse laughed in the face of cancer with 320 other people at a sold-out performance of *Sometimes You Just Gotta Laugh!*™ With original sets derived from their own cancer experience, they reframed some of their darkest moments with humor.

The show "gave people permission to uncomfortably laugh with me," said Meesh Hopkins, Rochester member and ovarian cancer survivor. "Laughing is always a better response than feeling sorry for someone."

It all started when Todd Youngman, a local comedian, approached Lauren in 2022 with the idea of featuring our AYAs doing stand-up comedy at our annual gala, *Journeys*.

Skeptical at first, Lauren was happily surprised as four 13thirty members performed at the caliber of professional comedians on stage at Comedy @The Carlson in Rochester. Our guests were given a new - and hilarious - look at something not at all funny, AYA cancer.

Jake Tower, a member of that first show, summed up the experience. "It was really empowering to turn one of my most terrible experiences into joy for others and myself. It's healing. It creates a close-knit bond of friends".

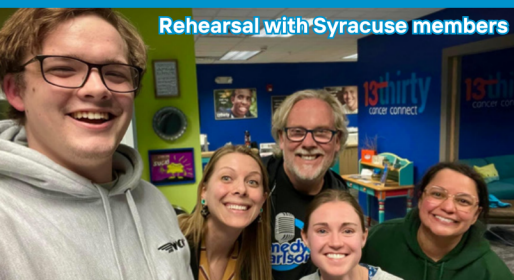
Since 2022, our AYA comedy show has become the highlight of April's Adolescent and Young Adult Cancer Awareness Month events. After another successful show (and an audience hungry for more!) we are excited to announce that *Sometimes You Just Gotta Laugh!*™ will be a two-night event in 2025!

**EXCITING NEWS: Save the date for TWO SHOWS in 2025 at Comedy @ The Carlson on April 25th and 26th!**



Thank you, Mark Ippolito and Comedy @ The Carlson!

**"Laughing is always a better response than feeling sorry for someone."**



Rehearsal with Syracuse members



2024 Wrap Party at the Syracuse Center



Channel 13 Spotlight

# Snapshots



## New Year, Same Mission

Family and friends gathered at our Syracuse center to kick-off the New Year with brunch and mocktails, some friendly competition, and new goals for 2024!



## Pioneering Progress, Together

Elected officials and medical professionals from Wilmot Cancer Institute and Rochester Regional Health announced our joint community-wide AYA health study.



## Finding Light In the Darkness

Rochester and Syracuse members were in the spotlight for an eclipse-themed photoshoot! AYAs shared how they found light in the darkest of times.



## Bigger Than Beauty

13thirty was chosen as a Thrive Causemetics "Bigger Than Beauty Giving Partner" and received a generous donation of beauty products to share with our members.



## Smash Room Shenanigans

Rochester AYAs reflected on times when they felt angry, thanks to cancer, and were given an opportunity to let it all out! It was a 'smashing' success!



## Goin' Bald for Bucks

For one of our longest running school fundraisers, Letchworth Schools K-12, raised \$7,288 to support our programs and research at Roswell Cancer Institute.



### Identity Beyond Cancer

Syracuse members tie-dyed 13thirty tees, while discussing the many “colors” of their identities and how cancer impacted, not defined who they are.



### Some Heroes Wear Scrubs

Our appreciation for the oncology nurses at Golisano Children’s Hospital is beyond words. We stopped by with treats to fuel their important work.



### Empowered Educators

On Fridays in May, Byron-Bergen staff and students wore 13thirty tees in support of our mission and Brain Tumor Awareness Month. Thanks to Pam Johnson!



### Comfort Food with Friends

Food can be ‘healthy’ and ‘helpful!’ Members reflected on how sharing a meal can be comforting and a way to learn about other cultures. We made Empanadas!



### The Perfect Launch to April

We kicked-off AYA Cancer Awareness Month at Three Heads Brewing with a concert from Head to the Roots and live painting by Miss Casey of Muck Duck Studio.



### State Recognition

Lauren and Steve headed to Albany for the passing of a resolution recognizing April as AYA Cancer Awareness Month in NYS. Thanks to Assemblyman Josh Jensen!

# VIRTUAL TO HYBRID PROGRAMS



## Breaking Barriers to Connect Our AYAs

Four years after the restrictions imposed by COVID kept us separated, most of us would like to see social distancing become a distant memory. But what if this challenge sparked new ideas? In true 13thirty fashion, we saw an opportunity and ran with it!

Knowing how vital peer connections are to our members, we pivoted to virtual programming when we couldn't meet in person. "Virtual programs gave our current members a way to stay connected and offered new opportunities to past members who had moved out of the area," said Steve Esposito, Associate Director. While not the same as in-person programs, we learned how to use technology to help offset the isolation that often comes with cancer. When the restrictions were lifted, we asked ourselves, "Now what?"

Take the best of both, was the answer. Continue delivering in-person programs led by Clare in Rochester and Michaela in Syracuse, and connect both groups virtually via Zoom! Voila! A new hybrid program model was born. The first pilot program was 13thirty Fit!, our 6-week fitness program led by Brianne Young, fitness coach and physical therapist.

Every week, Rochester and Syracuse members met at their respective centers for a 60-minute session that followed the workouts on our new wellness app, *13thirty To Go!* "I loved having weekly in-person sessions paired with the app. It allowed me to work out whenever and wherever I wanted," said Syracuse member Patrick Corbett.



As is tradition, an in-person potluck dinner was held in Rochester after 13thirty Fit! Members from both centers brought a healthy dish to pass (many inspired by recipes on the app!) and enjoyed meeting face-to-face for the first time. As is often said, necessity is the mother of invention. Little did we know back in 2020 how a nightmare like COVID could lead to innovation. With more hybrid programs, we hope to help even more AYAs with cancer live their best lives - today!

***13thirty To Go! is now bilingual with thanks to translator, Karen Lioy! All the features you know and love, now in Spanish! Check it out at [ToGo.13thirty.org](https://ToGo.13thirty.org)!***



# SPOTLIGHT ON

*Katelyn MacDougall* MSW, LCSW

## Tell us about your work with AYAs and what makes their needs so unique.

I'll never forget one of the first teens I met when working on an adult inpatient oncology unit. She had previously been treated at the children's hospital and missed the services offered there. Eager to help, I'd cross the street to the children's hospital, gather supplies, and ask about best practices for a teen.

I very quickly learned that this was a unique population whose needs were not quite being met and when the opportunity arose, I joined the Young Adult Program team. I have focused on supporting AYAs with cancer ever since.

## How did you find your way to 13thirty?

While living in Boston, I began exploring career options in CNY to be near family and was thrilled when I found 13thirty Cancer Connect. I reached out to Lauren and planted the seed that I might be moving back. Fast forward a few years. When the pandemic sped up our timeline, I again reached out to Lauren. I started working here part-time in 2021 and full-time in 2023!

## What is your role at 13thirty?

As Program Director, I help ensure that our programs are aligned with best practices and current research to best address the unmet psychosocial needs of AYAs. I am also responsible for clinician training to raise awareness of AYA cancer needs and help improve the delivery of care.

## What keeps you busy when not at 13thirty?

One valuable lesson I've learned from my work is the importance of family. So, family fills my time! My partner Luke and I have two children. I'm working on finding more space for baking, hiking, and dancing as I am classically trained in ballet.

**"I very quickly learned that this was a unique population whose needs were not quite being met."**

## Empowering Futures: Navigating Family Building, Intimacy and Choices in Sexual Health for AYAs

Talking about sexual health with your provider is still a difficult topic, especially for AYAs with cancer. Though uncomfortable for many, data show that this is important to AYAs and a subject for which they need support.

One of the reasons this important health issue often goes unaddressed is lack of relevant training for healthcare professionals who treat this group of cancer patients. This often leads to AYAs feeling lost and distressed during a vulnerable stage of sexual development.

To help alleviate this problem, Katelyn, together with Dr. Viktor Clark and Dr. Lauren Ghazal, both researchers at URM, brainstormed how to bridge this gap in service.

A free, half-day workshop offering continuing education credits for oncology providers resulted from this community/academic collaboration and was offered at 13thirty Cancer Connect during AYA Cancer Awareness Month.

Participants heard from three experts on the topic: Dr. Gwendolyn Quinn, from NYU; Dr. Pebble Kranz, Medical Director, Rochester Center for Sexual Wellness; and Susan Wiener, M.D. from URM. Each shared strategies for helping AYAs with this problem. Adding value to the day was a panel of four AYA survivors who shared their personal experiences during and after treatment.

Advocating for improved delivery of care has always been one arm of our mission. Together with our healthcare partners, we look forward to future workshops to heighten awareness of other issues important to the health of our AYAs with cancer.





Upstate New York tennis players served for a cause on Saturday, June 8th at Mendon Racquet Club for our 4th annual team tennis tournament in honor of beloved 13thirty member, Courtney Ferrara Wilhelm. Together, nearly 90 players raised over \$20,330! Special thanks to our Grand Slam Sponsors for making the event possible: Hodgson Russ LLP, Mendon Racquet Club, Safran and Walgreens.



# MAKE A DIFFERENCE - DONATE TODAY!



*Will you help keep the promise?*

**"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

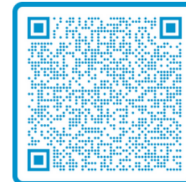
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