

THE 2025 SPRING UPDATE

13THIRTY INSIGHTS

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

INFO@13THIRTY.ORG • 13THIRTY.ORG • (585) 563-6221 • TOGO.13THIRTY.ORG



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

BOARD OF DIRECTORS

Charlie Coté
Nada Debbaghi, Co-Treasurer
Christina Gilligan
Ericka Elliott, Past Chair
Linda Palmeri Jacobson, Secretary
Brannan Karg
Kimberly Koetter
Amina Mecca
Mary Beth Morelle
Esther Neal
Chris Piedici, Treasurer
Jacquie Platt
George Poulos, Chair
Rachel Rockwell
Lauren Spiker

CHIEF MEDICAL ADVISORS

Archie Bleyer, MD
St. Charles Medical Center | Bend, OR
David Korones, MD
Golisano Children's Hospital | Rochester, NY
O.J. Sahler, MD
Golisano Children's Hospital | Rochester, NY
Sue Ogle, MSN
Children's Hospital of Philadelphia, PA
Louis S. Constine, MD
Univ. of Rochester Med. Ctr. | Rochester, NY

STAFF

Michaela Deeg
Program Manager
Steve Esposito
Associate Director
Katelyn MacDougall, MSW, LCSW
Program Director
Caroline Miller
Communications Director
Lauren Spiker
Founder & Executive Director

THANKS TO OUR PRINT SPONSOR:

Perinton Publishing

Our mission is to help teens and young adults diagnosed with cancer meet their unique challenges through a coordinated, continuum of essential resources and public advocacy efforts.

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

United Way Donor Choice #2383
Tax ID# 47-4493013

13thirty
cancer connect



A Message from **Lauren Spiker** Founder & Executive Director

Hello Friends,

Love it or hate it, daylight saving time has started! Time to change our clocks, re-adjust to longer daylight hours, and, for some, lose an hour of sleep!

Why do we go through this ritual twice a year? How did it all get started? Some accounts point to Benjamin Franklin first proposing the idea, although he didn't suggest changing the clocks. He just thought people should get out of bed earlier to be more productive and use fewer expensive, smoky candles!

Other sources say DST started in Germany during World War I as a way to conserve fuel. Some say it restarted during World War II for the same reason, but it wasn't until 1966 when the Uniform Time Act standardized time in the United States. However it began, some like it. Some do not!

Despite the controversy, each March, we spring forward, and fall back again in Autumn. If you are one who would rather not switch, maybe think of it like this.

*It isn't just a time change.
It's a time **of** change!*

When we set our clocks ahead one hour in the Spring, the trees are beginning to bloom and the crocus re-awakens. We trade winter coats for umbrellas and enjoy driving home from work with the sun still shining. In the Fall, we re-adjust to woolen sweaters and dinner after sunset. And so it goes.

But change isn't always easy. We are creatures of habit and it's often easier to stay the same. To color inside the lines and not stray beyond what we know to be safe and comfortable. To not risk the unknown.

As Spring unfolds in all its glory, the circle of life, so poignantly illustrated in Disney's *The Lion King*, reminds us that endings are also new beginnings. So, happy Spring! Besides the time on your microwave, what else will you change?

With thanks, as always,
Lauren

Melissa Sengbusch

INSPIRATION SCHOLARSHIP



The Melissa Sengbusch Inspiration Scholarship (\$2,000) supports a 13thirty Cancer Connect member (cancer survivor or patient undergoing treatment) who is pursuing a career in healthcare.

- **NOW OPEN! Application deadline: Wednesday, May 14, 2025**
 - Apply here: <https://13thirty.org/13thirty-resources/>
- **Finalist interviews begin: Monday, May 19, 2025**
- Must be enrolled/accepted in an accredited, post-secondary institution
- Healthcare related fields: medicine, nursing, pharmacy, chiropractic medicine
- The recipient of the scholarship will be announced on June 22, 2025 and awarded on August 1, 2025

This scholarship, funded by RoseAnn Bovenzi, RN, serves as a tribute to Melissa's legacy that continues to inspire and uplift individuals as they embark on their journey towards a career in healthcare. RoseAnn compassionately took care of Melissa, but also helped nurture her dream of one day becoming a nurse.

Questions? Please contact Steve Esposito, Associate Director - stephen@13thirty.org.

April is AYA Cancer Awareness Month



For 24 years, 13thirty Cancer Connect (originally named Melissa's Living Legacy Teen Cancer Foundation) has been making a difference for adolescents and young adults (AYAs) with cancer. April is their month to be recognized!

Of course, we're proud of all that's been accomplished, but in truth, we'd like to work our way out of a job. Unfortunately, that doesn't seem likely in the near future. Much remains to be done.



Today, approximately 90,000 AYAs are diagnosed each year in the United States and recent data forecast that number to increase dramatically over the next several years.

So, this month, let's look at the current state of AYA cancer as reported by the National Cancer Institute:

GOOD NEWS: Overall, deaths from AYA cancer have been falling on average 0.9% each year from 2013 – 2022.

BAD NEWS: The incidence of AYA cancer is increasing and survivors are at high risk for numerous cancer-related long-term effects.

What's the cause of the growing incidence of cancer in AYAs? Early data are pointing to a triple threat - the vicious cycle of obesity, highly processed foods, and sedentary lifestyles. Other factors likely also play a role.



"This is not a blip," explains Dr. Andrea Cercek from Memorial Sloan Kettering Cancer Center. Increasingly more young people are being diagnosed with colorectal, breast, prostate, uterine, stomach (gastric), and pancreatic cancer. "The more data we gather, the clearer this becomes," said Dr. Cercek.



As always, 13thirty Cancer Connect is staying abreast of these new data and continuing our efforts to help AYAs with cancer live their very best lives - today!

OUR WELLNESS PROGRAMS HELP DEVELOP NEW HEALTHY HABITS

- 13thirty Fit!, now in its 13th year, continues to improve functional fitness for our AYAs (see page 4).
- Our nutrition programs show AYAs that healthy eating can be tasty, inexpensive, and fun to share.
- Off-site programs like rowing, pickle ball, and challenge courses encourage active lifestyles.

Snapshots



Meals That Heal

In December, Syracuse members cooked up a meal of chili and cornbread for the Ronald McDonald House, an organization that has supported many of our members.



Hello 2025

Rochester members and their families came together to welcome in the New Year with brunch, laughter, and a rousing game of trivia hosted by Game Night Roc.



No One Fights Alone

On World Cancer Day, we joined various CNY cancer agencies at the YMCA to raise awareness of resources that can ease the impact of a cancer diagnosis.



Endzone Eats

The Bills may have let us down, but these healthy appetizers sure didn't! Emily from Nourished with Emily taught our member how to cook healthy game-day apps.



A Wish Of Kindness

Local AYA survivor, Will Martins, used his Make-A-Wish to show gratitude by donating funds to the organizations and nurses who played a key role in his cancer journey.



Let's Get Fit!

January kicked-off our traditional 6-week fitness program, 13thirty Fit! Brienne Young led members to a healthier life through weekly workouts and goal setting.



Movin' And Groovin'

Melissa Molongo, dance instructor, had our members dancing the night away as they learned the basics of Salsa. Another great way to stay fit and have fun!



Laughing In The Face Of Cancer

February kicked off rehearsals for our annual comedy show "Sometimes, You Just Gotta Laugh!" Get excited - two shows in Rochester and one in Syracuse this April.



Passionate Peer Support

Our growing group of young professionals kicked off their first Associate Board meeting at Preservation Beer Company, laying the ground work for a purposeful '25.



Pawsitively Purrfect

Rochester members gathered at Pawsitive Cat Cafe to soak up sweet cat snuggles and talk about the fear and uncertainty cancer can bring to an AYA's life.



Duel On The Ice

A night of friendly rivalry as Rochester and Syracuse members came together to watch the SYR Crunch and ROC Americans compete on the ice.



Community Impact Honors

Michaela, Program Manager, was chosen as Amazon's Community Hero, an award given to someone who has had a positive impact on the Upstate NY community.

Best Life 2025



It was a cold, January evening, but inside the Waterstreet Music Hall in downtown Rochester, it was hot! Seven local bands united a crowd of over 200 to raise funds for 13thirty Cancer Connect at **Best Life 2025**. Organized by Charlie Coté and his son Alex, this successful concert brought back all the energy from the first **Best Life** concert in 2018.

Charlie's 18-year old son, Charlie, an early 13thirty member and great musician himself, died in 2005. The event was dedicated to him. We asked Charlie about what the night meant to him.

How did it feel to bring this event back?

Bringing **Best Life 2025** back was deeply emotional and incredibly meaningful. It felt like picking up a conversation that had never truly ended—just paused. The energy, the purpose, the heart behind the event were all still there, waiting for the right time to return.

What was the most inspiring part of the night for you?

It was incredible seeing how the music and the cause resonated with people. How it brought everyone together in a way both celebratory and deeply moving. Watching the performers pour their hearts into their sets, feeling the audience connect, and seeing the ripple effect of support for 13thirty was beyond anything I could have anticipated.

Why would this have been important to your son?

Charlie wrote these words in his journal. "Live your best life. Not later. Now." That idea—of embracing life fully in the present, of making meaning out of every moment—was at the heart of **Best Life 2025**. This event was a way of living that truth out loud.



Charlie was the lead vocalist for a local band called Five Star Riot which played regularly at Water Street. His spirit was rocking with the crowd at Best Life 2025!

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



*Makenna Kuhn
2009-2025*



SPOTLIGHT ON

Adam Moran & Collin Doane

Associate Board of Young Professionals Co-Presidents

What inspired you to join our Associate Board?

A: After moving back to the Rochester, NY area from Dallas, TX, I thought it was important to get involved in the local community. When one of my good friends, Caroline Miller, who worked at 13thirty, told me about the Associate Board, it seemed like the perfect fit.

C: Initially, I was looking for a way to give back to the community, and 13thirty's mission sounded like a wonderful cause. Once I heard Lauren tell Melissa's story, which is partially a story about giving back, I was really inspired to take an active role on the Associate Board.

What do you enjoy most about being co-president?

A: Volunteering at the many events that the organization puts on during the year and informing people, who have not heard about the organization, what 13thirty is all about.

C: Knowing that my contributions have a direct, positive impact on folks in my community. For example, seeing 13thirty members participating in and enjoying themselves at an event I helped organize.

How does what you do professionally help you bring value to 13thirty Cancer Connect?

A: I am an Accountant by trade which I believe has helped me better understand the budgeting aspects of the organization in the instances where I have served on the planning committees for both our Cornhole and Tennis tournament fundraisers.

C: One of the main skills I have developed in my career in the legal industry is the ability to communicate effectively. I believe this brings value to the 13thirty team by allowing me to help lead and organize Associate Board events and to raise awareness for the work that 13thirty does.

Whats your favorite way to unwind after a busy week?

A: I love to stay active when I can. I really enjoy playing tennis with friends, board games with my family, and getting outside to hike with my wife and two dogs.

C: Taking my dog Finn for a long walk along the Genesee River Trail while listening to a good podcast or audiobook.

Thanks, Adam and Collin for your support!

In each issue of "Insights", Katelyn MacDougall, MSW, LCSW, 13thirty Program Director, shares how 13thirty addresses the psychosocial needs of AYAs with cancer. Through our peer support programs, clinician workshops, and on-going needs assessments, she helps ensure that our initiatives adhere to best practices by incorporating member feedback and aligning with current research.

Free Webinar: "Meeting the Mental Health Needs of AYAs with Cancer"



Research shows that AYAs with cancer face many unmet supportive care needs, which can lead to lower health-related quality of life and higher levels of psychological distress. Consequently, we are often asked to recommend therapists who specialize in working with AYAs with cancer. The truth is, there is a limited number of providers with this expertise.

To address this need, we hosted a live virtual training program, in partnership with Elephants and Tea and the University of Rochester. This training aimed to equip mental health professionals with the specialized skills and knowledge needed to provide effective, empathetic support to AYAs facing the challenges of a cancer diagnosis. We were amazed by the turnout, 110 attendees including nurses, PAs, NPs, physicians, clinical social workers, licensed mental health clinicians, and psychologists - plus some international attendees! Free continuing education credits were offered.

We're now planning a follow-up, four-session small group series to deepen clinical understanding of AYA challenges, led by Senior Director Kayla Fulginiti, LCSW, OSW-C from Elephants and Tea, and myself. Our ultimate goal is to expand the roster of therapists who truly "get it."

Featuring 13thirty Members

Patrick CORBETT Annabelle LEE-DAVIS Meesh HOPKINS Linda JACOBSON Tim KAISER Valerie LOPEZ Arianna MENDEZ Zechariah MERRELL Liz MYERS Steven NAPOLITANO Tatum O'CONNOR ^{HOST} Justin RABJOHN Hannah TORNES Jake TOWER

SOMETIMES, YOU JUST GOTTA LAUGH!™

Three Nights of Comedy with Original Sets by 13thirty Teens & Young Adults with Cancer



APRIL 25 & 26 • COMEDY @ THE CARLSON | MAY 2 • THE REDHOUSE ARTS CENTER
SHOWTIME 8PM • DOORS OPEN 7PM • TICKETS AT 13THIRTY.ORG



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

Please make checks payable to: 13thirty Cancer Connect
1000 Elmwood Ave., Rochester, NY 14620

DONATE ONLINE!



VENMO US!

