"We are honored to mark the beginning of AYA Cancer Awareness Month and to thank 13thirty Cancer Connect for all they do for the young people who call our region home, here, across the country, and across the world."

These words from Monroe County Executive Adam Bello helped kick off a month-long awareness campaign at a press conference held on April 4th at the Rochester City Hall.

In addition to the County Executive, the Rochester Deputy Mayor, physicians from UR Medical Center and Rochester Regional Health, and 13thirty member Brittany McNair, joined Lauren at the podium. All spoke of the need to heighten awareness of the unique needs facing our teens and young adults.

No longer children but not yet fully independent adults, our AYAs do not fit neatly into either of our two existing healthcare systems - pediatric and adult medicine. Their age-specific challenges have long been unrecognized and thus, underserved.

Several years ago, AYA cancer groups designated a week in April as AYA Cancer Awareness Week. But we, at 13thirty Cancer Connect, didn’t think one week was enough, so we shine a light on our AYAs for the entire month!
Hello friends,

Recently, my family celebrated a cousin’s wedding, a long-awaited, happy occasion postponed twice due to COVID. Hailing from a large Italian family, it was a joy to see long-distance cousins, some of whom traveled thousands of miles to be together.

But it was a busy weekend. Like many, it seemed there wasn’t time to do all that needed doing. Gardening, work catch-up, grocery shopping. And the kitchen floor really needed mopping! So many projects unfinished.

I hesitated to invite out-of-town family to visit, worried about not having the garden perfectly landscaped and my kitchen floor definitely not clean enough to eat off. But what the heck, I finally said. They’re family! I called my cousins and prefaced an invitation with, “I hope you won’t mind a lot of unfinished projects.” Unfortunately, I had waited too long. They already had plans but my cousin, Jeff, wisely responded,

“Life is a series of unfinished projects.”

His words resonated and gave me pause. How many opportunities have I missed because of unfinished projects? At what cost have I put off the most important, while finishing the less important? What does it really mean to be finished anyway? Isn’t the finish line just the start of a new line?

I like my cousin’s notion of life as an unfinished project, more than just a straight-line passage through time with a beginning and end. For our AYAs, cancer has a beginning but it definitely does not have an end. It’s never really finished. For survivors, a new phase beckons with things to learn and challenges to conquer, all colored by cancer. For too many others, unfinished projects or legacies, are carried forward by those left behind.

I think our lives are works in progress, never perfect, always unfinished. There’s always something more to do, to experience, to love. Here’s to the something more’s of life!

With deep thanks, as always,

Lauren
It’s often said that if you look hard enough, there is a silver lining behind every cloud. As the world emerges from the cloud of COVID, finding a sliver of silver is difficult, but when all in-person programs were canceled for nearly 18 months, Steve and his program team managed to find it.

“Transitioning to virtual programs helped us learn better ways to use technology to reach our AYAs,” Steve reflects. Not only were local members able to participate but members who have moved to other parts of the country were able to reconnect.

This led to the development of our new mobile wellness app – 13thirty To Go!

This new resource will house a library of on-demand fitness and nutrition programs available to all AYAs wherever and whenever they want. New fitness and nutrition tips will be constantly added to help them turn healthy choices into healing habits.

As always, we sought feedback from our members to ensure this tool was relevant and met their needs. Feedback from two focus groups and many informal conversations highlighted one important priority – it must feature young people just like them. No stock photos of body-building, buffed, and bronzed athletic types. What our members wanted were practical, doable, manageable tips on how to return to the level of well-being they enjoyed before cancer. We listened.

13thirty To Go! features 13thirty AYAs and parents in all videos led by Kim Leonard, a functional nutritional therapy practitioner and 3-time survivor of young adult cancer (read more about Kim on p. 7) and our awesome fitness coach and physical therapist, Brianne Young.

“For many years now, I’ve seen 13thirty members build strength and confidence through 13thirty Fit!, our 8-week fitness program,” says Brianne. “It’s wonderful to know that AYAs around the world will now also have a tool for functional fitness.”

We recently exhibited at CancerCon, an AYA conference in Minneapolis to beta test the app with over 200 AYAs. Before launching it to the world, we wanted our subject matter experts to take another look. After navigating the app, one conference attendee said, “Wow, this is actually geared to me.”

One of our 13thirty Syracuse members, Lucas, was also there. “I’m really excited to know that other AYAs anywhere in the world can have what I have right in my own backyard!”

Check it out - ToGo.13thirty.org
SNAPSHOTS!
What’s been happening with - and for - teens and young adults with cancer!

1. Tie-Dye Night
Syracuse AYAs got creative while tie-dyeing socks for local athletes to wear during AYA Month! Even Lauren made a pair!

2. ROC Lights Up for AYAs
The Rochester skyline was beautifully lit up blue and green to support AYA month. The Rochester airport, Butler/Till and Strong Memorial Hospital joined in as well!

3. Support from the Newlyweds
Big thanks and best wishes to Christina and Dom Coleprete for making a donation in lieu of wedding favors. Congratulations!

4. Annual Lilac Fest Concert
Rochester YAs gathered for some sun, music, and friends at the annual Rochester Lilac Festival! Not pictured - the mountain of kettle corn that we ate!

5. Spotless Center
First American Equipment Finance spent their Impact Day helping Rochester staff with spring cleaning! We are so grateful for their donation of cleaning supplies, too!
6. Milestone Race
We were very excited to be back in-person together at Seneca Park for our 10th Annual Bandana Bolt 5K & Team Relay. It was a beautiful day to honor National Cancer Survivors Day!

7. The Art of Pizza Tossing
Syracuse AYAs got to toss some dough with Sergeant Jon Seeber of the Onondaga County Sheriff’s Office. The final pizzas were much prettier than our tossing skills!

8. Greek Fest
Lauren gratefully accepted a $1,000 grant from the Annunciation Greek Orthodox Church of Rochester, at their annual Greek Fest. Thanks for making a difference in our community!

9. Cookout at the Center
Our Father’s Day cookout was a ton of fun, especially with so many different loved ones of our Rochester AYAs! Steve and Clare are still undefeated in cornhole...for now!

10. Flower City Invitational
Over 100 golfers participated in the 11th annual tournament held at Irondequoit Country Club. Special thanks to 13thirty Champion, Derek Pino, for coordinating this event!

Happy Summer!
Dr. Michael Stolton, a radiation oncologist at Rochester Regional Health, understands the challenges of AYA cancer better than most. Diagnosed at 23 with a primary malignant brain tumor, his approach as a physician is holistic and patient-centered but he recognizes the gap.

“There is a lot we can do,” he says, “but part of it is spreading the message and letting people know there are a lot of shortfalls.”

To help spread that message, we reached out to the community. Throughout the month, many businesses and schools responded with a variety of fundraising and awareness events.

Hundreds of signs with our AYAs’ pictures graced front lawns, and local sports teams came to the Rochester Center to tie-dye socks worn in support of our AYAs. Several donations-based fitness classes were conducted, including a sunset yoga class at the Cobbs Hill Reservoir.

Restaurants and boutique businesses returned a percentage of sales, bottles and cans were returned, and the city of Rochester, including the airport, was awash in blue and green lights. Kudos to all who helped amplify our mission - to help teens and young adults with cancer live their very best lives.

But awareness is only the first step in bridging the gap into which our AYAs fall. As Dr. Jeff Andolina said at the press conference, “Many young adult cancer patients merely want to live their lives and not be defined by their illness.”

We often hear our members say, “I’m not my cancer. I’m still me.” Our new wellness app - 13thirty To Go! - was designed to help AYAs with cancer be just that - themselves, their very best selves (see p. 3 for more about the app).

Perhaps the best evidence of how well we do that is the longevity of our members’ involvement. Brittany McNair, now a proud 13thirty Board member and mother of two beautiful children, reflects on the 16 years she has been a part of the organization.

“13thirty has changed my life in so many ways. I know I am a better person, a stronger person, a more confident person. I’m grateful to have had them as a resource when I was sick and to continue having them as I am moving on with my life and enjoying survivorship.”

Thank you again to our Rochester and Syracuse communities for raising awareness of our AYAs with cancer. Now, let’s transform awareness into purposeful and meaningful action.
**Tell us a bit about yourself.**
I am a 3-time cancer survivor and above-knee amputee and live with my husband, 3 children, 2 dogs, and 1 cat. My favorite things are creating recipes and spending time with my family. As a nutritionist in private practice, I have a Master’s degree in Clinical Nutrition and am working toward board certification. I am passionate about helping others live a full and vibrant life through dietary and lifestyle education and interventions.

**How does our organization resonate with you?**
When I heard about the great support given by 13thirty to a family member whose son was diagnosed, I found it amazing and wanted to learn more. When I was in college, having survived cancer twice at that point, I realized I lacked support through my young adult years. I always thought an organization that addressed that gap was really needed. At the support groups I attended, everyone was older and the support was not meaningful to me. A few years later when I learned about 13thirty, I was thrilled to see exactly what I had envisioned. They reach a population that can be difficult to engage at a time when it is so important.

**What ignited your passion for nutrition?**
My passion for nutrition was first ignited by my children’s health concerns. After doing a ton of reading, I found that nutritional support was much more effective than the prescriptions given for their conditions. I changed their diets and watched them flourish.

I had never thought about it for myself until a doctor told me that as a 3-time survivor of not only cancer but chemotherapy and radiation, I would likely spend the rest of my life in bed on a large number of prescriptions. This was unacceptable, so I started researching how to improve my health. Once again, dietary and lifestyle changes were supported in the research. As I started seeing the changes in myself and my children, I couldn’t wait to help others.

**Why is nutrition so important for AYAs with cancer?**
Proper nutrition can help make the body stronger and decrease the occurrence of lifestyle-related disorders, allowing the body to better fight cancer. Even after remission, properly fueling the body will help fight the residual effects of the disease and treatments. When I changed my diet and lifestyle, I saw the proof.

**Why is our 13thirty To Go! app so important?**
I believe that 13thirty To Go! is very important for AYAs as it highlights big concepts in a quick and easy way. It also provides fabulous recipes and some simple strategies for improving their health through nutrition the right away.

Check out one of Kim’s delicious recipes using healthy carbs - sweet potatoes!

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**Sweet Potato Tostadas**
**Ingredients**
- 4 sweet potatoes, cut into 1/4 inch slices
- 1 Tbsp. olive oil
- 1 Tbsp. sea salt
- 2 (15 oz.) cans of black beans, rinsed & drained
- 1 C water
- 1 medium shallot, peeled
- 1 Tbsp. cumin
- Pinch of cayenne
- 1/2 C shredded pepper jack cheese
- 1 avocado, sliced
- 1 red pepper, sliced
- 1/2 C pickled red onions

**Directions**
1. Preheat oven to 350 degrees.
2. Toss sweet potato slices with 1/2 tsp. sea salt and olive oil.
3. Place on a cookie sheet. Bake in the oven for 30 minutes or until tender.
4. In a small saucepan, over medium heat, add beans, shallot, and 1 cup of water. Bring to a simmer and let simmer until beans are warmed through (about 10 mins.). Remove shallot.
5. Smash bean mix until most are mashed with some whole remaining.
6. Add more water as needed to create a smoother consistency.
7. Mix in cumin and cayenne.
8. Sprinkle cheese on sweet potatoes and bake until cheese is melted (about 5 mins.)
10. Top sweet potatoes with beans, avocado slices, red pepper slices, and pickled onions.
I am proud to donate.
I wish to help teens and young adults with cancer live their very best lives...TODAY!

☐ $100  ☐ $75  ☐ $50  ☐ $25  ☐ Other____
☐ in honor of  ☐ in memory of _______________

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Address:___________________________________
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Please make your check payable to:
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or
Donate online at: 13thirty.org/donate

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

Please consider an online donation during this campaign!

Stay tuned on our social media & help us again earn $25,000 as the 2022 Top Fundraiser!