



Together Apart!

Image by Junwei Ren

In the midst of crisis, the 13thirty team adapts and stays connected.

This year began with high hopes and great expectations. Plans celebrating our 20th year of making a difference for teens and young adults were ambitious as we set the stage for our next 20 years.

As you read in our last issue, we kicked off the celebrations with great fanfare at our annual pancake breakfast. We looked back with pride at what has been accomplished since Melissa issued her mom a challenge that brought us to today.

"If you've learned anything from me through all of this," Melissa said to her mom, our Executive Director, Lauren, "do something with it."

Something to make a difference, to make things better."

And for 20 years, we've done just that. With the help of many, we've grown from a small, grassroots effort to a nationally recognized leader in the field of adolescent and young adult oncology.

After opening our Syracuse center last summer, we were on the move! And then, coronavirus entered the picture and our plans, like those of many, changed.

Our first concern, of course, was for our AYAs. Recognizing the threat this virus presented to them, we canceled all face-to-face programs even before New York State mandated closures.

— cont. page 6

insights

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

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SAVE THE DATE Virtually!

Journeys
the 19th Annual
Celebration of Living
November 7, 2020



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.

13thirty Cancer Connect is a registered IRS 501 (c) (3) tax exempt organization. United Way donor choice agency #2383. Tax ID# 47-4493013



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

Hello Friends,

If there were one word that defines the teens and young adults I know, it would be resilience, the ability to recover from or adjust to misfortune or change. Time and time again, I watch with admiration as these young people absorb the shock of cancer, integrate the experience into their life, and emerge stronger and with greater purpose. How do they do it, I often wonder? What can I learn about resilience from them?

Learning to be resilient seems especially important today as the world grapples with the impact of COVID-19 and widespread social unrest. How do communities recover? How do we adjust appropriately and adequately? I once heard that resilience is not like being on a trampoline. Suddenly up, and then down, and immediately up again. "Bouncing back" takes time, determination and all the inner strength we can muster. Sometimes, and I think now is one of those times, we need to call on others to help. Others who can give what we may not have - perspective, knowledge, wisdom, shared experience.

As you'll read, 13thirty Cancer Connect has been impacted during this difficult time but I'm proud of the way our team has adjusted. In some very significant ways, we are better than we were - more creative, more closely connected, even more focused on our mission. We are grateful for the sustaining support of many also impacted by this crisis.

In her book, The Desert Warrior, M. B. Dallochi, poignantly writes of her experience returning home from the Iraq war. Her words strike a chord today:

"Adversity has the remarkable ability of introducing the real you to yourself."

May our **real** selves be our **best** selves as we adjust to these challenging times.

With deep thanks, as always,

Lauren

THANK YOU TO OUR 2020 CORPORATE SPONSORS

Staying Connected - Virtually!

Where there's a will, there's a way! And we are finding many ways to stay connected while still keeping our AYAs safe during the COVID-19 crisis. Zoom has become our new friend while we offer a variety of virtual programs for all our members, including our parents.

While we've missed our face-to-face programs at both our Rochester and Syracuse centers, we've taken the opportunity to be creative and reach out in new ways.

Through virtual programming, our AYAs are able to meet even more AYAs who 'get it'. Our Rochester and Syracuse AYAs have been able to meet without traveling the NYS Thruway and some of our veteran 13thirty members who have moved out of state have also been able to join us.

We have continued offering programs in our usual categories: wellness, expressive arts, and just-for-fun social activities. Recently, Steve led a lesson on no-bake, nutritious energy

balls, Megan has become our resident card-making expert, and together, Steve and Megan have facilitated some fiercely competitive and fun virtual game nights.

We've been staying fit thanks to our Rochester and Syracuse fitness trainers, Brianne and Michelle, who have kept us working hard even from our living rooms!

Even our parents are taking advantage of our virtual programs through Parent Happy Hours and monthly fitness programs. It's been great to see all our members support one another and be committed to staying connected.

We look forward to when we can be back in our centers and host face-to-face programs once again.



No-Bake Nutrition Night

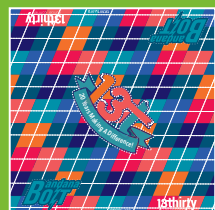


13thirty Fit!



Parent Happy Hour

In the meantime, we will continue our mission of helping teens and young adults live their very best lives - even virtually!



A Virtual Race to the Finish Line

The Bandana Bolt 5K has grown over the past 8 years, and we were excited for our biggest race yet in 2020. But as COVID-19 restrictions grew, we knew we were going to have to change the race this year. Canceling was simply not an option, so our team quickly adjusted to create our first ever virtual race!



Dallas TX

The Bandana Bolt, one of our signature events, is a time for our community to come together to support our teens and young adults. A fun, family environment marks the day, so creating that same feeling virtually was a top priority. Over 160 participants received a Race Packet in the mail with their 2020 Bandana and a digital race bib. Fun Race Day videos included "13 Ways to Wear Your Bandana" and a virtual view of the Seneca Park course. Participants could even log their race times online to compare their time with other runners!



Atlanta, GA



Washington, DC



New York City

Going virtual allowed people from around the country to join local runners. We loved seeing pictures from coast to coast flooding social media. The entire 13thirty staff was live on Facebook and Instagram throughout the day, starting at what is normally the starting line in Rochester, and closing at Green Lakes State Park in Fayetteville - the site of the 1st Bandana Bolt 5K in Syracuse, scheduled for the weekend of Oct. 3 - Oct. 4, 2020.



San Francisco, CA

Mark your calendar and cross your fingers - we will go virtual again if necessary!

For more Fun Facts on the Bandana Bolt 5K, visit 13thirty.org/a-great-day-for-the-bandana-bolt

SNAPSHOTS!

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

1. 2020 Virtual Bandana Bolt

How appropriate that the 8th annual Bandana Bolt 5K and National Cancer Survivors Day were both celebrated on June 7! Thanks to all our 13thirty Champions who helped us cross the virtual finish line together!

2. 13thirty Cancer Connect Board

Even the 13thirty Board of Directors has adapted to new ways of connecting! Their commitment is never-ending!

3. Virtual Open Mic Night

Our community Open Mic Night has gone virtual! Join us every second Monday of the month on Zoom or share your video on social media. Thanks to Bob Lewis for all his help!

4. Renovations in Rochester

When 13thirty Cancer Connect re-opens, the Rochester center will look a little different! Our expanded kitchenette will be the perfect place for upcoming nutrition programs.

5. Syracuse One Year Anniversary

We have officially been in Syracuse for a whole year! We are thankful for all the support in the past year and cannot wait to see what the future holds!



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6. Women of Excellence Honoree
Our fearless leader, Lauren Spiker, was named a 2020 Rochester Business Journal Women of Excellence Honoree - a perfect way to honor Lauren and her daughter's legacy as 13thirty celebrates 20 years in 2020.



7. 'Cuse Camp Donation
A big thank you to Liverpool 'Cuse Camp for collecting art supplies, snacks, and games for our programs!



8. Save the Date
The 13thirty Cancer Connect Bandana Bolt 5K is coming to Syracuse at Green Lakes State Park this coming fall!



9. New Merch for Exciting Milestones
Here's a sneak peek of our 20th year t-shirt design to celebrate 20 years of making a difference. Coming soon!



10. Summer Golf Giving Program
We cannot host our annual Flower City Invitational this year, but next time you're social-distance golfing, consider giving \$10 to support our mission and be entered into the Giving Greens Golf Raffle!



Enjoy the
Summer!

COVID-19 - cont. from page 1

Our program team, Steve and Megan, immediately pivoted to virtual programs, while Christina and Katie swiftly transitioned to a virtual plan for the 8th Annual Bandana Bolt in Rochester (see page 3). For Caroline, our new Communications Coordinator, there was barely time to get settled at the Center before working from home became our 'new normal.'

But cancer doesn't stop, even for a pandemic. We needed to find a way to keep our doors open after all events and our Go in' Bald for Bucks program were canceled. So, Lauren, with the help of her husband, Doug, became well-versed in all the economic stimulus opportunities available to non-profits.



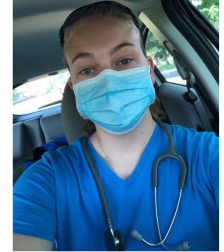
The Spiker's also offered a match up to \$20,000 as we launched our \$20K/

20 Day Challenge in May. Thanks to Doug and Lauren, and hundreds of loyal, dedicated supporters, we exceeded our goal and raised \$44,000 in just 20 days!

While 13thirty was coping with many changes, our friends on the front-line of healthcare were facing even more serious challenges. "It's been very stressful," said Michelle (Meesh)

Hopkins, RN, a case manager for URM Home Care and one of our 13thirty Cancer Connect young adult survivors.

"There is a lot of fear about this virus," says Meesh who understands the anxiety. "It's my goal to make sure my patients don't feel like a number, that they feel heard and cared for."



Meesh on her way to see a patient!

Though we miss seeing our AYAs in person, we've stayed in touch via Zoom, texts, and social media.

We've used this time for over-due projects like website maintenance, file organization, data base updates, and photo library clean-up. All new marketing materials have a fresh look and new content so, when it's safe to be back in the community, we'll be ready!

Despite the hardships, we've discovered new strengths and tapped into new fonts of creativity. More than anything, we've harnessed the power of teamwork and common vision.

Together, we'll keep "making a difference!"

13thirty Takes the Lead

13thirty Cancer Connect has initiated a collaboration of nonprofit cancer organizations in the Central New York region. The overarching mission of the new CNY Cancer Alliance is to facilitate access to available community resources for all impacted by cancer in the area.

A number of organizations providing direct support to patients and caregivers were invited to an initial meeting to assess interest. Next, a core working group was created to draft a plan for moving forward.

Two short term objectives were set:

- Create a centralized directory of cancer support resources.
- Develop a comprehensive calendar of events and programs benefitting cancer patients, caregivers, and others who support them.

The goals of both projects are to direct patients and caretakers to relevant resources in the area, provide timely information about cancer concerns and issues, and raise awareness of the support offered by local organizations.



The Alliance's Facebook page will be live soon with a calendar of local events and programs. Plans will be underway soon to create a comprehensive, digital directory of local resources.

We are hopeful this effort will help spread the word about 13thirty Cancer Connect in Central New York and are grateful to the following organizations for their active involvement in helping to get the Alliance started: CancerConnects, Hope for Heather, and Upstate Medical University Hospital.

Look for the CNY Cancer Alliance on Facebook soon!

Spotlight On



Paige Strassner, RN
Asst. Mgr. Medical ICU

"I understand the fear of many of these patients as they face their own unknown."

Tell our readers a little about you.

I am a 11-year survivor of Acute Myeloid Leukemia and my husband Will and I have two beautiful daughters, Hanna and Juliet. I work at Strong Memorial Hospital in Rochester, NY where I am the assistant nurse manager in the medical ICU.

What's it been like being on the COVID-19 front line?

I chose to work specifically in the COVID ICU, caring for critically ill patients. This has been one of the most rewarding, exhausting and challenging experiences of my life. Every day has been a huge learning experience but there are still so many unknowns that I continue to learn about, and face along with my co-workers.

I have really enjoyed being a nurse to patients in their time of greatest need. It is amazing to watch someone so critically ill get better. I absolutely love what I do and have met other nurses from different services which has fostered great relationships and more perspective on other areas of nursing.

How does being a cancer survivor impact your perspective of COVID-19?

Being a cancer survivor, as well as a nurse, gives me a very different perspective on COVID and being a nurse. I feel like I

understand patients much better as a nurse in general, having been a patient myself.

I understand the fear of many of these patients as they face their own unknown in the weeks to come after initial diagnosis. I have a greater understanding for family members who are not able to see their loved ones who are hospitalized. I remember having limited interaction with many of my family members and friends due to risk for infection.

I can also really relate to the seniors in high school who have been unable to finish their senior years due to schools being closed. I was diagnosed with cancer in April of my senior year and was not able to return to school. I can certainly identify with my patients, students across the country, and people in general in regards to quarantine as I became a professional "quarantiner" when I had cancer!

Lastly, I chose to work directly with COVID-19 patients due to my lasting lung issues and other chronic conditions related to my cancer. It may sound crazy, but I feel I am best protected working with COVID patients. I wear full PPE for every patient I come across which I believe is protective for me.

*We are so proud of you, Paige!
We are very grateful to you and all front-line workers who risk everything to keep us safe!*

KEEPING EVERYONE SAFE AT 13THIRTY!

- Appropriate social distance and face covering guidelines will be followed.
- All shared hard-surfaces will be wiped with disinfectant before and after each use.
- Temperature and wellness checks will be required daily for staff and offered to visitors.



- Visitor logs will be maintained should there be a need for contact tracing.
- Frequent hand washing and use of hand sanitizer will continued to be encouraged.
- Before resuming contact with 13thirty members, staff will be tested and show negative results.



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**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
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