



With special guests, NYS Senator Robach, U.S. Congressman Morelle, Monroe County Human Services Commissioner Crossdale, NYS Senator Funke

insights

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

20 Years of Making a Difference!

A Promise Made. A Promise Kept.

Twenty years is a long time in the cancer world - new therapies are introduced, early screening tools are developed, and new resources become available. But when Melissa Sengbusch was diagnosed in 1998, very little was available for teens like her.

For two years, Melissa did her best to navigate the dual healthcare systems in which she was treated - pediatric and adult medicine. Like nearly 82,000 other teens and young adults diagnosed each year in the United States, Melissa was no longer a child but not yet a fully independent adult.

Though she received excellent medical care from caring, compassionate providers, the happy, frolicking animal characters on the walls of the children's

hospital stood in stark contrast to the bare walls of the adult cancer center where she spent many lonely hours.

Despite the void, Melissa managed to live an extraordinary life. "Not able to go to the university she had planned, Melissa attended a local university part-time," said her mother, Lauren.

A former high-school athlete, she asked for an exercise bike in her hospital room, joined the YMCA shortly after her bone marrow transplant, and began a pottery class even when she knew she was going to die. Despite it all, she always knew who she was and what she needed.

She also knew her mom and trusted that she would keep a promise, her last request which would become her lasting legacy.

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ON YOUR MARK. GET SET. GO!



8th Annual
Bandana Bolt 5K
June 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.

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A Message from Lauren Spiker Founder and Executive Director

Hello friends,

How we perceive time is a function of many things – our emotions, the number of things happening in a certain period, the normalcy or abnormality of it all, how much we care about what is happening. All these factors, I'm sure, have influenced my perception of time these past twenty years. Some days it feels like Melissa has been gone forever; others, like she died just this morning.

How can it be twenty years, I often ask myself?

Twenty years ago, just three nights before Melissa died, I made her a promise. "Yes, I will do something," I said. *Something to make a difference, to make things better.* Since then, I'm proud to say, many things I care deeply about have happened and time has flown. Emotions, however, still color everything because the death of a child is anything but normal, making time feel like it's standing still.

During our first years, we were anxious to get started. We knew the problems facing teens with cancer and had lots of good ideas but the rest of the world did not yet share our sense of urgency. It would take 8 years before adolescent and young adult oncology began receiving widespread attention. But when it did, we were ready to run and haven't stopped since.

You will read more about our 20-year history in this issue. Many of you have been an integral part of it since the beginning and I am forever grateful. As we look ahead to our next 20 years, we will keep running pace with all that's happening in the world of AYA cancer.

But every now and then, I will try to remind us to slow down. To reflect on how and why we got started, to refresh and renew winter-weary spirits, and to welcome Spring with new energy and purpose. How will you use this time?

With deep thanks as always,

Lauren



Building on Success

For the past twenty years, our mission has been to help adolescents and young adults (AYAs) with cancer live their very best lives. Because treatment takes its toll physically, emotionally, and psychologically, our wellness programs have strong focus on physical fitness, nutrition, and effective coping strategies.

13thirty Fit, one of our wellness programs since 2011, is designed for survivors who have completed treatment and want to get back to their pre-cancer activity level.



Brianne leading Rochester class

Pre/post data, collected from this 8-week program over the last 9 years, demonstrate the program's effectiveness - increased strength, greater endurance, and improved self-confidence.

This successful program was introduced at our new Syracuse center this past fall. Michelle Dougan, our Syracuse trainer, immediately recognized one of the program's many benefits. "The beauty of *13thirty Fit!* is that every exercise can be transferred from the group class to your living room. It's challenging and adaptable."

Building on the success of this long-running program, Michelle is helping to develop a new program: *13, Thirty-Second Exercises* - for AYAs still in treatment. With a goal

of helping maintain physical strength, flexibility, and balance during treatment, the program will include easy to follow instructions and on-line video demonstrations making it easy to exercise from home or the hospital.



Michelle & Connor in Syracuse

A self-assessment and check-in system with Michelle and other AYAs will help keep members accountable to their personal goals.

Meesh, a Rochester survivor, knows how important goals are to staying motivated. "Gathering each week to work out and share our successes and failures, as a group, helps me with my goals."

13thirty Fit is one of the many ways we help AYAs live their very best lives. Healthy habits developed during and after treatment become life-long habits.

Like all programs at 13thirty Cancer Connect, our fitness programs are also offered to our parents. Wellness at 13thirty is a family affair!



Meesh & Alex resting!

For more on our SYR trainer, Michelle, see page 7!

Community Partners - Working Together



Everyone loves Wegmans and so do we! For many years, Wegmans has been a 13thirty Champion and we've been grateful for their support. This year, 13thirty Cancer Connect is very proud to be partnering with the Wegmans Leadership Group in a number of important initiatives.



The team, including Gerad Levey, Joe Fitzsimons, Joe Alosio, Brook Soechtig, Brian Morton, Jeremy Becker, Dave Degan, Laura Berkley, and Justine Farina, will help the 13thirty team develop a solid business plan, an effective marketing strategy, and a new nutrition curriculum complete with a cookbook of healthy recipes geared to the life styles of teens and young adults with cancer.

As part of this project, our Rochester center will be renovated to provide room for monthly cooking demonstrations of the healthy, budget-friendly, easy to prepare meals developed by the Wegmans team.

Wegmans Leadership Group

Thank you, Wegmans, for your commitment to our community. Our AYAs and families will be healthier - and happier - because of it!

SNAPSHOTS!

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

1. Journeys Celebration of Living
In November, 13thirty members
performed original poetry at
*Journeys, the 18th Annual
Celebration of Living*. This year's
theme was "What's Behind the
Closed Doors?"

2. Rochester Locust Club Beards
The Rochester Police Locust Club
supported "Beards for Bucks" for
the 3rd year in a row last
November. Thank you to all the
officers who participated!

3. LPD Beards for Bucks

The Liverpool Police Department
also shaved their beards for
"Beards for Bucks" in Syracuse!
Thanks to The Liverpool Barber
Shop, owned by Paul Macri, for
your support!

4. Holiday Party 2019

We enjoyed an afternoon filled
with laughs, stories, and lots of
holiday treats- in spite of the cold!

5. Thankful for Friends in Syracuse

The 13thirty Syracuse Center
celebrated friendship with great
food, friends, and games at the
first Friendsgiving dinner!





13t



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6. Confluence Benefit Concert

In February, Mother-daughter duo, Nadine Dyskant-Miller and Barbara Dyskant, performed at Lovin' Cup in Rochester. Nadine and Barbara have been part of 13thirty since Nadine's diagnosis in 2009. Brava!

7. Open Mic Night in Syracuse

The 13thirty - Syracuse fitness room transforms from workout space to talent stage each month for Open Mic Night, an evening of comedy, music, poetry, and more!

8. Letchworth Legends

Over 30 students from the Letchworth Central School District went "Bald for Bucks" again this February and raised more than \$12,700! This makes their total from the last few years over \$38,700!

9. Rush-Henrietta Rotary Gives Back

Many thanks to R-H Rotary and member Steve Synesael for their generous gift again this year. Your continued support right from the start has truly "made a difference!"

10. Welcome to Club 13thirty

Like, share, comment! Caroline, our new Communications Coordinator, joined Club 13thirty in January. She brings her passion for storytelling to the Rochester center and makes sure all our social platforms are up to date and on trend.

Happy
Spring!

20 Years - cont. from page 1

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



1st Pancake Breakfast at Lauren's house

20 YEARS



Melissa
1981-2000



Pancake Breakfast 2020

Melissa asked her mom, our Executive Director, Lauren Spiker, to use what she had learned, to *make a difference, to make things better*. "We started as a small grassroots effort around my dining room table," Lauren recalls. "I began by simply asking other teens how it could "be better." Within just a few months, Melissa's Living Legacy Teen Cancer Foundation was born.

"I was one of the first kids to meet with Lauren," said Diane Farrell, now a healthy mother of 3. "It was just great to meet other kids who knew what I was going through because there was nothing else like this for teens like us."

Lauren was determined to find a way to meet the very unique challenges facing teens like Melissa. Jon Ozimek, another early teen, lived with cancer for 9 years before he sadly died at 23 in 2006. He summed it up perfectly. "It would be nice to have something to read that was between Highlights for Children and Time."



Jon & the new website

The early years were a slow climb into uncharted territory as the challenges of AYA cancer were not yet widely recognized. Lauren soon forged an important national partnership and the innovative Teens Living with Cancer website launched in 2002.



Opening the 1st Center

Like all new ideas, it took time for the medical community at large to embrace AYA oncology as a new discipline. During that time, we refined our peer support model and, in 2009, opened our first Center in Rochester, a warm, welcoming space that felt like "home." In 2013, that space was expanded for our new parent programs.

Relative to the first years, we were now moving at warp speed. In 2015, we expanded our mission to include young adults, changed our name to better reflect our new age group, and moved into a larger space to accommodate more members and new programs. In 2019, we proudly opened our second center in Syracuse!



Syracuse Grand Opening!

And just like that - 20 years! We hope this is what Melissa had in mind!
Where will the next 20 years take us?

Making a Difference

13thirty

cancer connect

Getting Started

- 2002, YEAR OF FIRSTS**
Held 1st informal peer program at Lauren's house; 1st teen cancer website; 1st important partnership with CCG

2000 - 2001, OUR INSPIRATION
Melissa died on June 22, 2000. Established Melissa's Living Legacy Teen Cancer Foundation as a 501 (c) 3
- 2006, GROWING INFLUENCE**
Became charter member of 1st international AYA coalition; recognized by *Wall St. Journal*

2004 - 2005, RESOURCE DEVELOPMENT
Recognized by National Cancer Institute; distributed resources nationwide

Program Growth

- 2011, NEW PROGRAMS**
Developed new fitness, nutrition, and expressive arts programs; began community advocacy

2009, A HOME OF OUR OWN
Opened first center in Rochester, NY. Teens with cancer have a safe, welcoming space to connect with others
- 2013, NEW INITIATIVES**
Expanded ROC center for parent programs; started *Goat/Bird for Bucks in ROC*; 1st Bandana Built 5K

2012, BEYOND ROCHESTER
Co-sponsored teen program in Buffalo in partnership with Roswell Park for five years

New Horizons

- 2017, BROADER ADVOCACY**
Began outreach to local school and colleges; started *Bands for Bucks* with local law enforcement

2015, EXPANDED MISSION & NEW NAME
Began supporting young adults as well as teens with cancer; changed name to reflect age group 13-30; moved into larger ROC space
- 2020, TWENTY YEAR CELEBRATION**
Looking forward to making more history...

2019, ON THE MOVE
Opened second center in Syracuse, NY; established Young Professionals Associate Board



Spotlight On



Michelle Dougan
Cancer Survivor
Syracuse Fitness Trainer

**If you don't give up,
you can do anything!**

Tell us a little about yourself.

I am a mother, a grandmother, a three-time cancer survivor and a fitness professional for the last 25 years - and I forgot to mention, a World Champion Arm Wrestler!

What is your role at 13thirty Cancer Connect - Syracuse?

I am a fitness consultant for 13thirty members and their parents. Working out does so much for your mental and physical health. I try to put workouts together that are fun and a little different every time. While working out, we discuss things that might be bothering them, or things that have made it a great day!

What led you to become involved in our fitness programs?

13thirty reached out to the gym where I work, Elevate Fitness, asking for recommendations for a fitness professional in Syracuse, and I was lucky enough to be referred.

I immediately wanted to be involved. I wanted to help the kids that were going through a life-changing event know that they are not alone. I felt very alone when I was going through my cancers. I did have a lot of support from my family but it would have helped if I had

known someone that went through it, too. Working with 13thirty is unique because I get to work with teens and young adults.

I love that they also have programs for parents because they are going through a life-changing event, too. I can't even imagine. It's definitely different and a little challenging. I do love a challenge!

How do you think your own cancer experience plays a role in working with 13thirty members?

I think I am a living reminder that you can overcome any obstacle. Sure, there will be good days and bad but if you don't give up, you can do anything!

What would you like others to know about 13thirty Cancer Connect?

It's a family atmosphere with several programs that make it a lot of fun for the kids to stop by and even just hang out. The staff are there for you and always willing to help!

Thanks, Michelle and Elevate Fitness, for helping us stay strong - together!



April is AYA Cancer Awareness Month!

Support the 13thirty mission!	#30daysof13thirty Events!
 Set up a 13thirty online Facebook fundraiser!	 Donate blood & get bone marrow testing to #GiveBloodtoGiveTime at the 13t SYR Center 4/4
 #Think13thirty & give through United Way #2583!	 Bring friends & family to Three Heads Brewing for the St. John Fisher College WSoP Bald for Bucks Event! 4/7
 Celebrate our 20th year at the 2020 Bandana Bolt!	 Join Club 13thirty for Friday Morning Coffee! 4/10
 Make a difference in April with #30daysof13thirty!	 Share your talent at the 13t SYR Center for Open Mic Night! 4/13



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Bandana Bolt SUNDAY, JUNE 7
8:30AM RACE START
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- Top finisher prizes
- Prize for best team!
- Fundraising incentives
- 2020 Bandana

JOIN US FOR THE 8TH ANNUAL BANDANA BOLT 5K RACE & FITNESS WALK!



REGISTER ONLINE: [RUNSIGNUP.COM/RACE/NY/ROCHESTER/BANDANABOLT5K2020](https://runsignup.com/race/ny/rochester/bandanabolt5k2020)



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Test drive or buy a used vehicle at Balkan Motors to support 13thirty Cancer Connect!

On the **13th & 30th** of every month, Balkan Motors will donate \$10/test drive & \$100/car sold!



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Make the Difference - Donate Today!

I am proud to donate.
I wish to help teens and young adults with cancer live their very best lives...**TODAY!**

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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
1981- 2000

Please make your check payable to:

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YOUR SUPPORT WILL MATTER!