



13thirty young adults lead the way to our future.

# insights

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

## Happy First Birthday, 13thirty Cancer Connect

A new name and expanded mission are the next steps in our evolution.

The American Heritage Dictionary defines evolution as a gradual process in which something changes into a different and usually more complex or better form.

This aptly describes our last 15 years. Started as a small, grassroots effort in Lauren's dining room, Melissa's Living Legacy Teen Cancer Foundation was a way to keep a promise and find purpose in her daughter's all too short life.

For the first seven years, we held fast to our mission - to enhance the quality of life for teens with cancer. Despite little to no broad recognition of the unique challenges facing teens like Melissa, Lauren's voice and passion were strong.

She reached out to teens in our community, listened to what they wanted and created the Teens Living with Cancer (TLC) peer support program along with the pioneering website, [teenslivingwithcancer.org](http://teenslivingwithcancer.org).

Our resources were distributed to hospitals nationwide and in 2009, we moved into a home of our own within the AI Sigl Community of Agencies. The pancake breakfasts, holiday party and annual picnic, however, stayed at Lauren and Doug's home!

Just like all natural organisms who survive and thrive, our organization adapted over the years to the changing landscape of teen and young adult cancer.

— cont. on page 6

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## Save The Date!

Journeys, 15th Annual  
Celebration of Living  
Saturday, Oct. 15, 2016

**13thirty**  
cancer connect

Teens and Young Adults Get it Together!



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**Thanks to Our Sponsor**

We are grateful to Lifetime Care Home Health Care and Hospice who generously print this publication.

Our mission is to provide resources that enhance the quality of life for teens and young adults living with cancer. We envision that all teens and young adults with cancer will have the opportunity for life-affirming experiences throughout all stages of disease and treatment.

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,

This month marks an important milestone in our history. 13thirty Cancer Connect is celebrating its first birthday! It's been a full year since we changed our name and expanded our mission to include young adults as well as teens with cancer. And what a year it has been! Admittedly, it's been a bit hectic with some speed bumps along the way but our roots as Melissa's Living Legacy Teen Cancer Foundation kept us grounded, our values a strong anchor. Our vision to see all teens and young adults with cancer live their very best lives remained crystal clear.

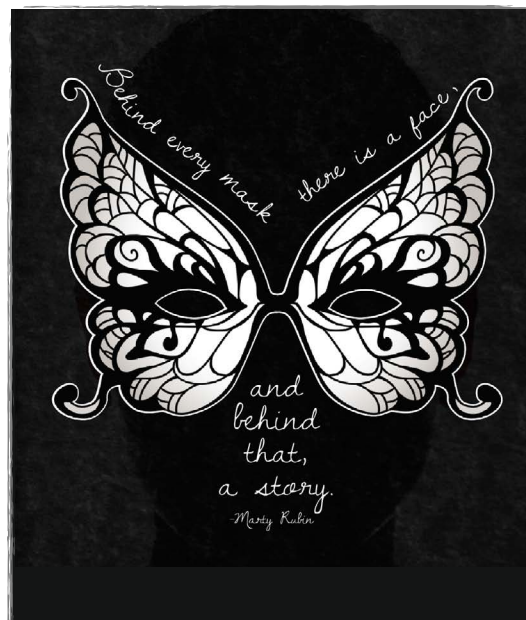
As you will read in this issue, each full-time member of our team - Josh, Steve and myself - came on board at different points in our organizational history. We each have a unique perspective on where we've been, where we're going, and how we'll get there. It makes me think of a prism, a three-sided, transparent object that refracts a beam of light and separates it into a rainbow of colors.

I think that beautifully describes our team as we celebrate the first year with our new name. We each bring individual experience and insight to our work yielding a rich spectrum of creative ideas and composite energy.

Some bemoan the passing of each year. "Oh, don't remind me." "Let's just forget my birthday this year." I have the opposite reaction. I love birthdays, especially my own! I always tell people who complain about getting old that it sure beats the alternative. I've known too many wonderful young people, including my own daughter, who didn't have the chance to celebrate enough birthdays.

So, whenever I get the chance, I'm ready to celebrate another year. How about you? Please visit our Center and tell us how you're living - and loving - life!

With thanks as always,  
*Lauren*



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## The COR of 13thirty Cancer Connect

Early in the spring, we pitched an idea to some young adult survivors who were long-time members of 13thirty Cancer Connect. How about forming an alumni and friends group to help expand our outreach? They loved the idea!

With everyone on board, the group met in June. Their mission was pretty clear from the start - community outreach, awareness of adolescent and young adult cancer, and giving back to 13thirty Cancer Connect.

Coming up with a name, on the other hand, was tougher. Consensus was finally reached and COR became official. COR - pronounced, core, stands for Cancer Outreach of Rochester.

Brothers John and Ryan Fox joined COR, not as survivors, but as friends. Their cousin, Louis D'Amanda was a member of 13thirty Cancer Connect before he died in December, 2015.

They wanted to get involved in his honor because of all that 13thirty had meant to Louis and his family.

"This group was the perfect opportunity," Ryan says. John joked that agreeing on

### FAIRPORT MUSIC FESTIVAL



Newlyweds Brittany and Scot with sister Lexie, Lauren & Steve

COR's name took a while. "It took us a few meetings but I think it's spot on."

Cat Gawronski, one of three co-presidents, talked about COR's importance. "We wanted to give back for everything that 13thirty did for us. COR allows me to be a part of raising awareness and letting others know the benefits of 13thirty."

Cat, along with Brittany McNair and Michelle Hopkins, the other co-presidents, will keep 13thirty's Board of Directors updated about COR's plans and how they align with 13thirty Cancer Connect's overall mission.

COR has already helped raise AYA cancer awareness with a table at the Fairport Music Festival last month.

The group has plans to attend other community events, organize their own fundraisers, and be mentors to younger teens diagnosed with cancer.

Paige Strassner, another COR member, speaks about COR's future. "I'm hoping to eventually have our own annual fundraiser. I see big things down the road for COR and for 13thirty."



John, Steve, Ryan & Cat and the 13thirty prize wheel. Step right up!

## 13thirty Cancer Connect Survivors - The Healing Power of Music

Lovin' Cup Bistro was filled with the sound of music on June 29 when two of our talented survivors took the stage.



Sabrina Gauer, Singer/Songwriter

Sabrina was first to play. Diagnosed just a year ago with Stage IV oral cancer, Sabrina had to re-learn how to talk and needed extensive therapy to regain use of her arm after skin and muscle were grafted to reconstruct her tongue.

Nadine was diagnosed in 2009 with leukemia as a teen. Throughout treatment, Nadine continued playing flute and has since earned a degree in music composition. Interested in organic farming, Nadine also travels the country with her band, Ensoleil.



Nadine Dyskant-Miller (left) and Ensoleil

**WE ARE VERY PROUD OF YOU!**

# SNAPSHOTS!

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

## 1. Wedding Bells will Ring

For the third straight year, we celebrated upcoming weddings at our Annual Picnic. Scot & Brittany (middle, right) got married in August and Steve will be tying the knot in October!

## 2. Lasertron

The excitement, fun and laughs were never ending at Lasertron this July. Both our teens and young adults got to experience the action and it sure was a "blast!" Special thanks to Jeffrey Carlton for making it happen.

## 3. The Maker's Ministry

These amazing women from His Place Church paid a visit to the center. "The Maker's Ministry," as they call themselves, stopped in to donate some beautiful, hand-made afghans for 13thirty families!

## 4. Survivor Night

It was a special night at Frontier Field for all of 13thirty and other Rochester cancer survivors. Michelle (aka, Meesh) and several others held the American flag and were honored during the pre-game ceremonies.

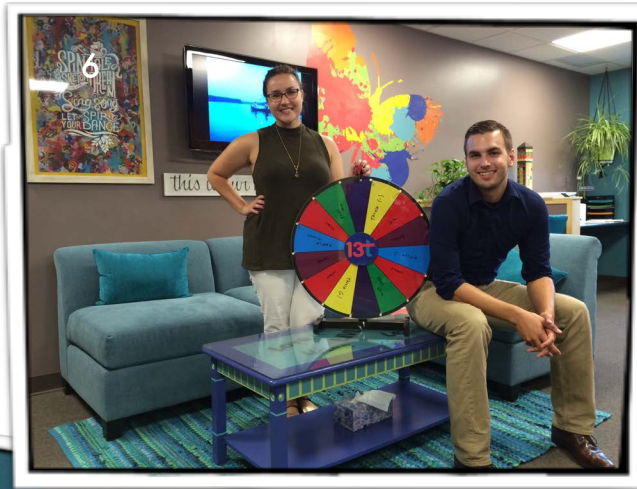
## 5. Moonlight Canoe

Once again, we joined forces with legendary Rick French of Pack, Paddle, Ski for a moonlight canoe trip and special dinner on Canadice Lake. Big thanks to Larry D'Angelo for his support!



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6. Meet the Interns

Where would we be without these two? Matt Phelps and Christina DiBaudo helped us out in any way they could this summer. We are forever grateful for their hard work and dedication to our cause!

7. Mario Kart Madness!

Avoiding the coconuts on DK's Jungle Parkway might not have been successful for some but this inaugural Mario Kart tournament was awesome! Special thanks to The Playhouse for hosting the event!

8. Flaherty's Golf Tournament

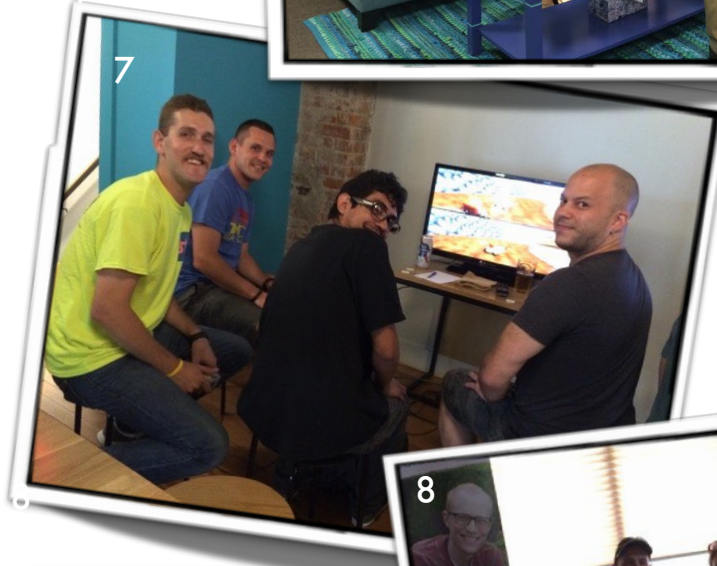
Our friends at Flaherty's Pub in Honeoye Falls hosted a golf tournament in June and 13thirty was the lucky beneficiary of \$5,000! Big thanks to Leah, seen here with Josh, and the entire Flaherty's crew!

9. Here Comes the Bride!

This wonderful picture was taken at the wedding reception of Brittany and Scot McNair on July 29th. Lauren couldn't be prouder of the beautiful bride!

10. The View is "Suite"

Buffalo's TLC group gets together for a Buffalo Bisons baseball game at Coca-Cola Field. The group got to hang out in a box suite for a great time with great friends!



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Celebrate &  
Live Life  
with Joy!

## 1st Birthday – cont. from page 1

Medical data were beginning to highlight the serious issues facing this vulnerable group. The fact that teens and young adults with cancer had seen far less improvement in survival as compared to other age groups triggered a new and growing movement. And we were ready!

Our model of peer support was successful in Rochester and in 2012, we joined forces with Roswell Park Cancer Institute to bring TLC to Buffalo teens. With a second site to manage, we were growing more complex and definitely better.

As we evolved, so did the needs of our former teens. Now young adults, their challenges were changing and they still needed the support of friends who understood. So once again, we drew on our strengths and helped initiate a new adolescent and young adult program at the Wilmot Cancer Institute in Rochester.

In 2015, we took the next big step in our evolution. Adding young adults up to the age of 30 under our wing, we changed our name to reflect our expanded mission, and moved into a larger space.

It was at this point that Josh Symer joined our team. "When I came for my first interview, I went to the wrong place. Having worked for Sigl previously, I knew that Melissa's Living Legacy was at Door 1," laughs Josh. "I had to ask maintenance for directions."

During the interview process, Josh learned about our transition and expansion plans. "I

was excited to hear about all that was happening and felt I could put my mark on the the positive changes ahead."

Hired as Special Events Coordinator, Josh was immediately thrown into the deep-end, our biggest events just weeks away - Goin' Bald for Bucks, the Bandana Bolt 5K and Journeys. On top of that, a community open house to unveil our new name, logo and Center was also scheduled - on Josh's birthday!



Josh, Steve and Lauren with Nadine and Bryn, early TLC'ers!

"There were some growing pains," Josh acknowledges, "but we've grown through that hectic time. We're now primed and ready to roll as 13thirty continues to be a leader in the AYA movement."

Gathering speed as 13thirty Cancer Connect, we were running at full throttle when Steve Esposito became our new Rochester Program Coordinator in June.



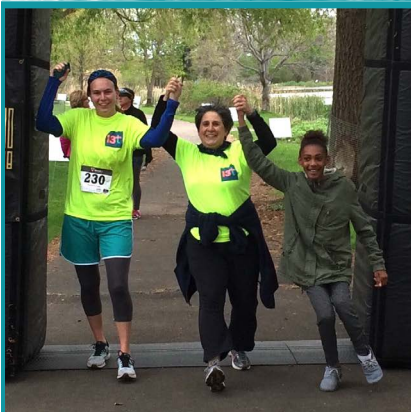
Just a typical day at the Center!

"It felt like home the first time I walked in. It was great knowing I instantly had support and belonged to a place where people listened and your input was valued."

Like Josh, Steve jumped into his role. "From the first program on my third day, I've been inspired. It's very special." While Steve didn't experience our transition, he feels connected to our past.

"All I've known is 13thirty but I feel its rich history in the beautiful faces and Melissa's butterfly on the wall. It shows that we will never forget our roots and that those roots will always be a part of our future."

## BIG THANKS to all who supported the Inaugural Kick Cancer 15K Race Series!

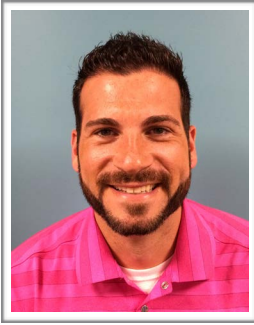


Lauren crosses the finish line with Meesh & Jessica



We were proud to partner with Anna's Wish and Christopher's Challenge to bring the first Cancer Race Series to Rochester. Together with all the runners and walkers who participated, we raised awareness and much needed funding for each organization. STAY TUNED FOR NEXT YEAR!

Spotlight On



Steve Esposito  
ROC Program Coordinator  
13thirty Cancer Connect

*Walking into the Center, my first thought was "this is exactly where I want to work."*

**Q:** What was your first impression of 13thirty?

**S:** Walking into the Center, my first thought was: "This is exactly where I want to work." By the end of my first day, I was looking forward to making an impact!

**Q:** Why were you interested in working at 13thirty?

**S:** Ever since working at the Rochester Museum and Science Center and the ARC of Monroe, I've wanted to return to the non-profit world. 13thirty seemed a great fit where my strengths would excel. My family, like many, has been impacted by cancer. I wanted to give back and make a difference for others going through a similar challenge.

**Q:** What's your favorite thing about working at 13thirty and what have you learned?

**S:** Hands down it is getting to know the people associated with 13thirty, hearing their stories, and being inspired to do more. Also, I've learned more about myself. These teens and young adults have opened my eyes about the things that really matter.

**Q:** Tell us a little bit about yourself.

**S:** I'm the youngest of four boys, born and raised in Rochester. I graduated from Fairport High School and earned my degree from Slippery Rock University where I met my future wife.

Family is everything to me. It is my foundation and my rock through everything. In my free time, I enjoy playing basketball, listening to music, and of course, spending time with my beautiful fiancé.

**Q:** What song is playing on your iPod right now? And while we're at it, what is your favorite song, movie, and TV show?

**S:** On the iPod right now is "The Distance" by Cake. My favorite song is #41 by Dave Matthews Band. Favorite movie is a tie between The Shawshank Redemption and The Godfather Part 2. My favorite TV show is Arrested Development.

**Q:** What's a fun fact about you?

**S:** If you pull up next to me at a red light, I'm usually jamming out singing and dancing.

**Q:** Where do you see 13thirty going in the future?

**S:** In the near future, I see us helping even more teens and young adults in Rochester. Beyond that, I'm excited about replicating our programs. Buffalo has been successful and I can't wait to see 13thirty at all major cancer centers in the U.S.

**Q:** Are you excited for your first Journey's?

**S:** That's a low blow! I'm sad I'm missing it, but I'M GETTING MARRIED!

## Lisa Nichols - 13thirty Cancer Connect Artist-in-Residence

The first time people visit our Center, the response is always the same. "I love the colors! It feels so welcoming in here."

All the credit for that goes to Lisa Nichols - Quin's mom, artist, interior designer, Lauren's thrift-store-shopping partner, and wonderful friend.

Since moving into our first home in 2009, Lisa's keen eye for color, design and composition has made our Center a very cool place to hang out.

She's also helped create a safe, cozy haven where life-long friendships blossom and endure.



Painting Matt's awesome butterfly design.



Where we craft and eat pizza!

Over the years, Lisa has given countless hours of her time and a large measure of her generous heart to our organization.

Thank you, Lisa, for making our space so warm and beautiful.

As is so often true, goodness and light can spring from the darkest places. Had it not been for Quin's diagnosis, our paths may never have crossed.

While we wish cancer had never touched your family, we are blessed to count you as part of ours.

*You have definitely made a difference!*



Where we hang out!



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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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