



**Getting Stronger Together!**

## Building Healthy, Healing Habits

### Year-long wellness program gives care to the caregivers

“Your child has cancer.” When a parent hears these words, the reaction is immediate. Gripping fear quickly turns to action. “What do I need to do?”

Sadly, there is often nothing to do except worry but life must go on. Meals need to be prepared, work needs to be managed, younger children need care, and bills must still be paid.

Life becomes one endless day after another in the hospital. Beeping IV pumps and early morning rounds conspire with fretful dreams to deny sleep. Coffee and candy bars keep us going but the fear never goes away.

No matter the costs – emotional, physical, financial, psychological - parents do whatever is necessary to help their child get well. “Taking care of Melissa became my

full-time job,” recalls Lauren Spiker, our Executive Director.

The costs to parents, however, are very high. The demands of caregiving coupled with normal parental responsibilities often cause parents to neglect their own health.

Getting enough rest, eating nutritiously and exercising are not priorities. Constant worry about disease recurrence coupled with the financial burden often associated with diagnosis make it difficult to resume healthy habits long after treatment is over.

“So much was out of my control,” says parent Kiersten Kunick. “The one thing I could control was eating, so I stress ate for sure. That’s one reason why I joined this group. I’d like to get healthier and lose the weight.”

— cont. on page 6

# insights

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

## In this Issue - Summer '17

A Message from Lauren Spiker	2
New Scholarship Opportunity	3
Snapshots	4
13thirty A.R.T.	6
Spotlight on Sabrina Gauer	7

## Save the Date!

Journeys, 16th Annual Celebration of Living Saturday, Nov. 4, 2017

**13thirty**  
cancer connect

Teens and Young Adults  
Get it Together!



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### insights

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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 and their families will have the opportunity for life-affirming experiences throughout all stages of their cancer.

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



## A Message from Lauren Spiker Founder and Executive Director

Hello Friends,

Today is the Summer Solstice, the longest day of the year. The roses in my garden are in bloom. Daisies and coneflowers will soon follow and though the geraniums haven't liked the recent torrential rains, our grass is lush and green. Chirping birds wake with the sun.

Ahhh, summer. I wait all year to drink my coffee on our front porch and watch the day begin. As I collect the morning paper thrown on our driveway long before sunrise, I often pick a few weeds still wet with dew. Today, as I sat in the early morning light, I thought about our 8-week parent fitness program that you will read about in this issue. A quote by Voltaire, the 18<sup>th</sup> century French writer and philosopher came to mind.

*"We must cultivate our own garden."*

Being a parent and gardening are very similar. Both involve patience, nurturing and the willingness to sometimes overlook pesky, unsightly weeds - or children, in the case of parenting! To do both jobs well, one must have the courage to envision and hope for the future. Neither happen overnight and shortcuts never work.

But perhaps the greatest similarity is that both parenting and gardening are difficult, exhausting tasks leaving one bone-weary and often disappointed. In my role, I meet loving, hard-working parents willing to do anything humanly possible to take care of their children. It's physically, emotionally, and psychologically draining with little respite.

One of our jobs is to help parents heed Voltaire's advice - to cultivate their "own garden." To take care of themselves. To recharge in order to take care of their kids. That's what our new parent wellness program is all about. Parents taking care of themselves in the company of others who understand. I guess you might say, we're building our own little community garden here at 13thirty Cancer Connect!

Happy Gardening,  
 Lauren






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# 2017 Brittany Arnold "Spirit of Life" Award

When Jeff Carlton first heard Brittany's story, he was immediately inspired. He asked her to share her experience with his employees at Excellus BlueCross BlueShield where Brittany's mom, Jennifer, is a supervisor on Jeff's team.

Moved by her presentation, Jeff decided to learn more about the organization that had supported Brittany throughout her cancer experience - 13thirty Cancer Connect. He ran in the Bandana Bolt 5K and bought a reserved table at Journeys that year.

"And if that didn't sell me," Jeff said, "I read Melissa's story and decided that's why I want to bring this proposal forward."

The proposal Jeff offered was to fund an annual scholarship for an active member of 13thirty Cancer Connect enrolled in an accredited, undergraduate college degree program.

Appreciating how important his own education was, Jeff hopes the Brittany Arnold "Spirit of Life" Award will serve as a "beacon

of hope for striving for one's dreams. You find yourself through education," he says.



Jeff and Brittany

*"I've been blessed, so I see it as my obligation to pay it forward and cascade this goodwill to others."*

Applications for this year's extremely generous \$2,000 award are currently being reviewed by Jeff and Brittany. The lucky recipient will be notified in August, just in time for the start of the school year.

Graduating high school seniors, enrolled college undergraduates and non-traditional students entering college for the first time were invited to apply.

"It's such an honor to have this award named for me," said Brittany. "13thirty has been a very important part of my life both during my cancer and still today, as a survivor." In the spirit of the scholarship named after her, Brittany continues to give back to 13thirty as the newest member of our Board of Directors.

Thank you, Jeff, for believing in our mission. You are helping to keep Melissa's legacy alive and definitely *"making a difference and making things better!"*

## Congratulations to our 13thirty Cancer Connect graduates!

### The sky's the limit! Fly high and strong!

Catherine Gawronski - SUNY Buffalo School of Pharmacy

Katya Mailloux-Kuz - SUNY Potsdam

Bryn Mugnolo - Ithaca College

Emily Wurzel - SUNY Brockport

Greg Heinrich - Miami University

Adam Turner - Greece Olympia High School

Micaela Allen - SUNY Geneseo

Jason Ryan - Kendall High School

Devin Hoffer - SUNY Brockport

AJ Plyter - Williamson High School

Michaela Deeg - SUNY Brockport

Nigel Brown - Greece Olympia High School

# SNAPSHOTS!

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

## 1. Too Many Cooks in the Kitchen!

Our "Home Cooked Meals to Help Hearts Heal" program continued at the Ronald McDonald House where 13thirty members, friends and family cooked for others in need.



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## 2. Opa!

13thirty was the featured charity at the Greek Festival hosted by the Annunciation Greek Orthodox Church. Lauren and staff were on hand to accept the generous \$3,000 donation!



## 3. Lilac Festival

A few of our young adults made their way over to the Lilac Festival for a night out for some good tunes and great food!



## 4. Magnificent Mel

A very big thank you to Mel, our awesome Spring intern. She quickly became an integral part of our team and will be missed. Congrats on graduating from SUNY Brockport!



## 5. Until 20 at FLCC

We were proud to host a screening of the film *Until 20* during Finger Lakes Community College's spring Activity Day. We gathered all the nursing professors and students for a picture afterward!



6. 13thirty Feud!

Kathy Morris (RN, MSN) and Chrisanne Mansfield (RN, MSN), from Golisano Children's Hospital, surprised our teens and young adults for an unforgettable night of fun and laughter!

7. Color Run Crazies

The Henrietta Youth Asset Group volunteered at the Color Run in May! Under the direction of Mary Beth Recore, they are always there for 13thirty and we can't thank them enough!

8. Healthy AND Delicious!

Our 8-week, 13thirty Fit! program was capped off with an amazing potluck! Special thanks to Brianne and Sabrina for keeping the group on track with their fitness and nutrition goals!

9. Allendale Columbia Visit

Kelsey Lesi and her students from Allendale Columbia High School visited to discuss the importance of 13thirty and learn about the challenges their peers face with AYA cancer.

10. FORE!

Douglas Spiker (left) and Board President, Charlie Cote (center), pose for a picture with Mike Zaffuts (right) and his wife Jen at the 7th Annual Flower City Invitational Golf Tournament. The tournament, established by the Zaffuts, was a "hole-in-one!"

Happy  
Summer!



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## Healthy Habits - cont. from page 1

To help combat the stress of caregiving and knowing the benefits of peer support, we developed a 12-month program called *Building Healthy, Healing Habits* for parents.

Always looking for ways to leverage community resources, we asked Holly Dutcher, Executive Director of CURE Childhood Cancer Association, if she'd like to collaborate and offer the program to CURE parents. She readily got on board.

"I think collaboration is important because we cannot be all things to all people," said Holly. "This program encourages parents to care for themselves which makes the care they give their children even better since they are recharged and healthy."

With CURE as our partner, we extended the program to parents of children with cancer as well as chronic blood disorders such as sickle cell and aplastic anemia. This multi-faceted program consists of three essential elements of wellness:

- Physical Activity
- Nutrition
- Stress Management

Led by fitness coach and licensed physical therapist, Brianne Young, twelve moms recently finished the first 8-week program. Focused on improving functional fitness, all workouts are



designed to be done at home after the program. As an example, empty milk jugs filled with water serve as weights for strength building.

Data from pre- and post-program assessments are tracked to measure

improvement. A second 8-week session will be held in the winter and quarterly *QuickFit* sessions will keep us active throughout the year.

Sabrina Gauer, one of our young adult survivors and soon-to-be certified Health Coach (learn more about Sabrina on P.7), follows each fitness session with a Nutrition lesson, offering healthy eating tips and nutritious snacks complete with easy-to-make recipes.

Starting in the summer, gentle yoga will be offered monthly by our yoga instructor, Jen Zaffuts, who incorporates mindfulness - and lavender-infused towels - into each session. Lastly, massage will be offered two evenings per month. Emily Shortt, Licensed Massage Therapist, will begin taking appointments in August.

An additional benefit for parents is free childcare. CURE's Program Coordinator, Sam, keeps little ones busy while their moms enjoy "me" time.



"When I walked into 13thirty, I felt immediately at home," says Devon

Fitzwater, a new 13thirty mom. "The connections between moms who all 'get it' have been wonderful. I feel stronger than ever."

We are grateful to the Greater Rochester Health Foundation and Excellus BlueCross Blue Shield for funding this important program. Big thanks also, to Dr. Kevin Walter who supports the program each year.

**We are getting stronger together!**

For registration information, contact Steve: (585) 563-6221



It's been said that a picture is worth a thousand words.

This idiom proved true for a group of 13thirty moms who used paint to express deep feelings about the impact of cancer on their lives.

Over four dark and cold winter weeks - and a little wine! - spirits were bright and warm



at the 13thirty Center as common experience was shared, often without saying a word.

Lisa Nichols, also one of our moms, expertly led the group.



We explored how color, symbols, and design could be used to reflect the range of emotions felt when our children have cancer.

*Awesome job, ladies!*





**Sabrina Gauer**  
Survivor  
Communications Coordinator/  
Wellness Coach

**“There really is no ‘normal life’ after cancer. It will never be the same but there is a new normal that you will find.”**

**Sabrina Gauer, is a young adult survivor of stage 4 oral cancer and 13thirty’s newest staff member!**

**Tell us a bit about yourself.**

I am a singer/songwriter, love reading and eating a lot of good food! I’m finishing up my certification at the Institution of Integrative Nutrition to be a Certified Health Coach. I’m very passionate about health and wellness and helping people find passion in a well-rounded, healthy lifestyle.

**What brought you to 13thirty?**

I was introduced by a 13thirty Fit program participant who encouraged me to come do the program with her. It was a warm, welcoming, and inviting place and the first thing I did was make an appointment with Lauren to find out more about 13thirty Cancer Connect.

**What was appealing about 13thirty Fit? Tell us more about your new role with the program.**

I was excited about getting together with like-minded young adults with similar experiences. Throughout the cancer healing process, I felt really exhausted and wasn’t ready to just go to a gym. I had gone to Planet Fitness with a friend after surgery and the girl next to me on the treadmill kept looking at my (fresh) scars.

It made me very uncomfortable but at 13thirty Fit, none of that mattered. I’m now doing health coaching and nutrition with 13thirty Fit. It’s fun to share more mind/body/spirit wellness with people and make the connections to each aspect of their daily wellness routines.

**What’s the best advice you can give a young adult facing cancer?**

Definitely that rest is very important and to allow yourself time in the healing process. We get lost in the “being strong” mindset. There really is no “normal life” after cancer. It will never be the same but there is a new normal that you will find. You can’t force the process, it has to be a journey – sometimes it sucks, sometimes it’s great but you have to learn from it and grow with it.

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

I wanted to work here because of the awesome support and community that it offers teens, young adults and their families. 13thirty has been an important part of my healing journey. 13thirty Fit, the moonlight canoeing trip and my new friendships were critical to my journey. Plus, with my focus on health coaching, it’s fun to be a part of other people’s journey. I can be a part of their stories in an impactful way. This is a place they can feel alive again!

**Welcome to 13thirty Cancer Connect, Sabrina!**

**Staying Healthy with Sabrina - Summer Quinoa Salad**



**What is Quinoa?**

Sabrina introduced 13thirty Fit participants to quinoa (pronounced ‘keen-whah’), a nutritious seed, often mistaken for a grain.

Quinoa originated in the Andes Mountains and was dubbed “the gold of the Incas.” It’s a complete protein containing all the essential amino acids our bodies can’t make on their own. It’s also a great source of calcium, lysine, the B vitamins and iron. It’s also gluten-free!

- 2 1/2 cups cooked quinoa
- 1 large cucumber - diced
- 2 red bell peppers - diced
- 1 cup halved cherry tomatoes
- 4 green onions - sliced thin
- 1 clove garlic - minced
- 1 cup chopped spinach
- 2 avocados - sliced
- 2 T white balsamic or apple cider vinegar
- 1 1/2 T olive oil
- sea salt to taste

1. Place all ingredients in a bowl and mix well.
2. This gets better after it sits overnight. The flavors have more time to develop.



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St. John Fisher, Wegmans School of Pharmacy

**Our school is Goin' Bald for Bucks #BaldforBucks**



**Will YOUR school go bald next year? Call Steve NOW for more information! (585) 563-6221**

Gananda High School

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Our Lady of Mercy

SUNY Brockport

Roth Middle School

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**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