



Packed workshop and great panel discussion! From left to right: Lauren Spiker, Sabrina Gauer, Kristin Opett, Alex Vogelwede, and Dr. David Korones

insights

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

Learning From the Experts

Healthcare providers, caregivers and cancer survivors come together

On a snowy morning in January, the Al Sigl community conference center was full. Healthcare providers, caregivers, and cancer survivors came to our clinician workshop to learn more about adolescents and young adults (AYAs) with cancer.

The diverse group represented multiple disciplines including oncology, nursing, social work, music therapy, physical therapy, home health and hospice care, and hospital administration, some traveling from as far away as Syracuse.

Though highly skilled in their respective areas of expertise, many of the attendees confessed they were less confident in their ability to understand and communicate with teens and young adults. Each came

with a common goal: to share and learn from each other and the experts on the panel.

"We know," said Executive Director, Lauren Spiker, "that it's sometimes difficult to 'connect' with teens and young adults. Their cancer experience is very different from children and older adults."

Because our AYAs don't fit neatly into either of our existing healthcare systems - pediatric and adult medicine - their needs have long been underserved and misunderstood.

The half-day workshop, made possible by generous grants from the Genesee Valley Medical Foundation and the Polissen Foundation, was designed to change that.

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SAVE THE DATES!

Bandana Bolt 5K

July 8, 2018

Journeys

October 13, 2018

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 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,

As I write, the view from my window is obscured with falling snow. Not the weather we'd like but it is March in Rochester! It's unkind and troublesome, for sure, but also beautiful if we reframe the inconvenience. I think this thought is appropriate today for we all awoke to hear that the visionary physicist, Stephen Hawking, had died.

His brilliant observations of the universe and its origin are surpassed only by his uncanny ability to transform adversity into unquenchable curiosity. Expected to live only two years after a devastating diagnosis, Hawking defied the odds. For more than 50 years, despite losing abilities most of us take for granted, he never stopped asking questions and seeking answers. His profound insights will inspire generations to come and new mysteries will be unlocked because he persevered.

"Remember to look at the stars and not down at your feet. Try to make sense of what you see. And however difficult life may seem, there is always something you can do and succeed at. It matters that you don't just give up." (Stephen Hawking)

In our business, it's sometimes necessary to look down as we place one unsteady foot in front of the other. Sometimes, that's as far as we can see. Looking up is difficult some days. Our vision of the future is often clouded, just like my window today, with doubt and uncertainty. But look to the stars we must. Giving up is not an option. Like Stephen Hawking, we must keep trying to make sense of adolescent and young adult cancer. There is always something we can do.

Today, I ask for your help as we reach for the next bright star. Our goals are bold. Our passion strong. If you are already a 13thirty Champion, thank you from the bottom of my heart. If you haven't yet become a Champion, please choose to cheer for us!

With thanks as always,
 Lauren

13thirty
cancer connect
13thirty.org

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Rochester NY 14620

585.563.6221

What is a 13thirty Champion?
 Our Champions know the importance of connecting teens & young adults with cancer.
 They love to spread our mission.
 They are our teens, young adults, parents, family, friends, community partners & supporters.

Be a 13t Champion

Whole Wellness at 13thirty Cancer Connect

Wellness isn't the absence of illness, but rather a measure of your quality of life. A wellness mindset is important to creating healthy habits, reducing stress, and gaining emotional stability.

But when faced with cancer, our bodies are in a constant state of "fight or flight" leaving us exhausted and in many cases, with physical symptoms brought on by the emotional fatigue. A diagnosis is merely the tip of the iceberg!

The programs we offer for AYAs and their families are based on the concept of "whole wellness" (mind, body, spirit) and help participants better deal with the everyday stress of surviving cancer.

Our wellness programs include yoga, massage by appointment, and a variety of fitness programs with coach and physical therapist, Brianne Young.

We also offer many A.R.T. (**All Relaxing Together**) programs led by artist and cancer mom, Lisa Nichols, writing workshops led by



13thirty Fit



Parent yoga



Fresh cookies!

Charlie Cote, our Board President and bereaved dad, as well as opportunities to cook (and eat!) together!

When cancer strikes, self-care is probably the furthest thing on your mind. But making time is one of the most healing and helpful things you can do for yourself!

At 13thirty, you are surrounded by a community of people who "get it". You'll learn to better manage stress, relax and unwind, and give yourself permission to be present.

The mission of 13thirty Cancer Connect is to help teens and young adults with cancer live their very best lives - TODAY!

SO, WHAT ARE YOU WAITING FOR?

For more information, contact our Program Director, Steve Esposito, at (585) 563-6221 or by email - stephen@13thirty.org

STAYING HEALTHY WITH SABRINA!

Easy Fettuccine with Tomato Cream Sauce and Asparagus



Eating "in season" is healthy for your body AND your wallet.

Here's a great plant-based recipe perfect for any day of the week!

Ingredients:

- 6 to 8 oz cooked fettuccine pasta
- 1 tsp extra virgin olive oil
- 1/3 lb asparagus
- 3 cloves of garlic minced, divided
- 1/2 cup finely chopped onion
- 2 tsp extra virgin olive oil
- 22 to 24 oz pasta sauce
- 1 tbsp wheat flour or other flour
- 1/2 tsp dried thyme
- salt and pepper to taste
- 1/2 to 3/4 cup non-dairy milk or creamer
- Optional: Fresh basil, nutritional yeast or vegan parm for garnish (Add some chickpea chorizo or smoked coconut for variation!)

- Heat 1 tsp oil in skillet over medium heat, add asparagus and 1 clove of minced garlic or 1/2 tsp garlic powder. Cook until lightly brown, 4 to 5 mins. Stir occasionally.
- Remove asparagus from the skillet, set aside.
- Add onions, 2 cloves of garlic and 2 tsp olive oil. Cook until translucent (4 mins.)
- Add flour and cook for 1 minute.
- Add sauce, salt, a good dash of black pepper and thyme, mix. Cook for 10 minutes until boiling. Adjust for taste.
- Add non-dairy milk or creamer, asparagus, cooked fettuccine. Mix well, cook for 2 minutes or until heated through. Take off heat and let sit for a minute.
- Optional: Serve with nutritional yeast or vegan parm and/or fresh basil. YUM!

SNAPSHOTS!

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

1. Our recent staff photoshoot! Local photographer Monika Gauer (Monika Leeza Photography) captured moments around our office, including laughter and a hot beverage together! From left to right: Lauren, Steve, Sabrina & Christina!

2. Bald For Bucks
Students at Rush-Henrietta High School (Melissa's alma mater) shaved their heads and cut their hair to raise money for 13thirty and Roswell Park! Great job everyone!

3. AYA Bowling Night
Our teens and young adults bonded over a fun night of bowling, friendly competition, and laughter!

4. 13thirty Olympians!
Our 8-week fitness participants are getting FIT together with exercises specially designed for strength and conditioning by physical therapist Brienne Young!

5. Traveling Many Miles
Charlie and his mom, Lynda, come all the way from Syracuse, NY for programs (or to participate via FaceTime when the weather's bad)! They are hoping for a 13thirty center one day in their hometown!





6. Goin' Bald at St. John Fisher! Teachers at World of Inquiry School No. 58 are in a band called "Saturday Morning Detention" – and invited students on stage for a rousing rendition of "All I Need" by Sam Smith!

7. Bald Alumni
Lauren snagged a quick pic with Kristen Burgmaster and her father, Richard, who have been "Goin' Bald for Bucks" over the past few years in honor of Kristen's mom!

8. Christmas in February!
Special thanks to Nicole Zobel and the team at Rochester Progressive Insurance for donating this awesome box of goodies for the office!

9. Parent A.R.T. (All Relaxing Together!)
Our parents have been gathering on Wednesday nights with fellow cancer parent and artist, Lisa Nichols, for our painting program! Their canvases are incredible!

10. Now You Are "In the Know"
Steve and Sabrina host "In the Know" every Friday afternoon on our social media platforms – keeping you up-to-date on the latest news at 13thirty!



Happy Spring!

Clinician Workshop - cont. from page 1

All participants were encouraged to watch a series of brief videos on the 13thirty website called *Cancer 101 - Straight Talk from Teens*. This early project features teens with cancer openly sharing the impact of illness on their lives.

These candid interviews set the stage for viewing the award-winning documentary, "Until 20." The resilience and courage of AYA patient James Ragan inspired this powerful film made in collaboration with MD Anderson Cancer Center. Watching the film helped participants frame their questions for the panel following the film.



Alex and Dr. Korones share a laugh

"Although James and his story are mind-blowingly inspiring, he gives voice to the compelling stories of so many teenagers and young adults," said David Korones, hematologist-oncologist and Director of the Pediatric Palliative Care Program at Golisano Children's Hospital. "I know because I have met many James's in my career."

Other panel members, including Kristin Opett, RN, Chief Nursing Officer at Rochester General Hospital and AYA survivor; Sabrina Gauer,



Kristin describes her own AYA story

AYA survivor and 13thirty Communications Coordinator; Alex Vogelwede, 13thirty teen survivor and Lauren Spiker, founder of 13thirty, shared similar insights. "You need to connect with your patients, and know them as a person, not their cancer," said Kristin.

In addition to discussing the film, the panel explored many topics including the importance of honesty, not letting your disease define you, the reality of survivor's guilt, and letting your voice be heard as an AYA patient. Attendees left with a better understanding of the challenges of AYA cancer, improved confidence in their ability to communicate with their AYA patients, and greater comfort with end-of-life discussions and support. They were also much more informed about the services and resources provided by 13thirty Cancer Connect, ending the day with a tour of the awesome 13thirty Cancer Connect Center!

"Being able to express some of our thoughts about what nurses have done for us and bringing awareness to the other side (as a patient) of treatment is really important," Alex reflected after the panel. "It was awesome to give back, to help them understand how they could better help us." Alex will soon have the opportunity to put these words into action as he will be attending nursing school in the fall. *Best of luck Alex. We're proud of you!*



Now Accepting Applications!

2018

Brittany Arnold "Spirit of Life" Award

This \$2000 award is given annually to a 13thirty Cancer Connect member who embodies the qualities that its funder, Mr. Jeffrey Carlton, found so inspiring in Brittany Arnold McNair for whom the award is named.

To be eligible, candidates must be enrolled in an accredited, undergraduate college degree program and commit to helping 13thirty Cancer Connect continue its mission of helping teens and young adults with cancer live their very best lives.

Applicants may be graduating high school seniors, enrolled college undergraduates, and non-traditional students entering college for the first time. We hope this scholarship will ignite a desire in recipients to search for their life purpose and find meaning in each day.

As 13thirty Champions, recipients will "pay it forward" and continue the cascade of goodwill that Jeff has begun. Thank you Jeff for your continued generous support as a member of Melissa's Legacy Circle!

If you or someone you know may be eligible, review the application which can be found at <http://roc.13thirty.org/scholarships>. Applications will be accepted until May 15. For more information, call 13thirty Cancer Connect (585) 563-6221 and speak with Lauren Spiker.



Kristin Opett, RN, MSHA

Chief Nursing Officer
Rochester General Hospital &
13thirty Cancer Connect,
Board of Directors

“Organizations like 13thirty help our kids to be kids and not a diagnosis.”

Tell us a bit about yourself.

I grew up in the Finger Lakes and have called Rochester home since 1992. Clinically, my background is in oncology nursing. I have worked in general medical oncology, bone marrow transplant, and breast oncology. I’ve been with RGH for 15 years in a variety of nursing and quality leadership roles.

This year, I am celebrating my 17th wedding anniversary to Andy. He is a Physical Therapy Professor at Nazareth College. We have an amazing little boy, Drew, who is turning seven in April! When I am not with my family or working, I love to spend time at Keuka Lake. It is absolutely my happy place!

What brought you to 13thirty? How does our organization resonate with you?

I was told a local organization was looking for a board member who was a clinician. My colleague thought I’d be the perfect choice from our organization because of my ties to oncology and AYA cancers.

But what she didn’t know is that I have known Lauren since Melissa was a patient on the Bone Marrow Transplant unit at Strong! I was one of the nurses on BMT while Melissa was a patient. Like Melissa, I had recently had a Bone Marrow Transplant to treat AML, an aggressive form of leukemia. We had a connection because of some of our similarities.

During my journey, I decided to pursue a career in healthcare and went on to become a nurse. Now, as a proud Board member, it is an honor to support other teens and young adults through what’s arguably the toughest times in their lives.

Why is AYA Cancer so important to you?

From my vantage as a clinician – and as a survivor – AYAs are a group that “doesn’t fit” the research of pediatric and adult cancers. There has been too little focus. Not only is research for AYA cancers so important but issues of survivorship need far greater attention.

I believe organizations like 13thirty help our kids be kids and not just a diagnosis. The work 13thirty does is crucial in helping our kids and families weave through a forever life-changing journey.

Any advice you have for us today?

Be present and in the moment. If you’re a clinician, find a connection with your patient. Know them as a person, not just a diagnosis. Customize your approach to individualize your care. Each patient needs something different from the next. Our work as clinicians is truly a great privilege as we walk with someone during their most vulnerable times.

A huge thank you to Kristin and all of our clinicians and providers who work with our teens, young adults, and families. We appreciate YOU!

Be a **13th** Champion
and help us reach our CrowdRise goal!

- Help us qualify for a \$100K grant from "A Community Thrives/ USA Today Network" so 13thirty can expand into a second community!
- "Fan Favorites" receive an additional \$25K!
- Participate in weekly fundraising challenges from March 19 - May 11. Share with family & friends!

www.crowdrise.com/13thirtycancerconnect



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live their very best lives...TODAY!

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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**