

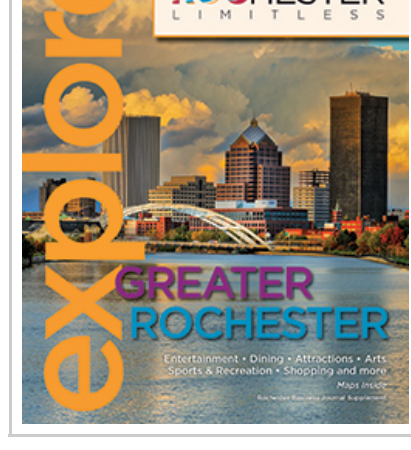
THIS WEEK



Subscribers to The Rochester Business Journal can access the digital edition archive.



SPECIAL PUBLICATIONS



Latest special: **Explore Guide 2020** or view the **special publication** archive.

Home / Today's Top Stories /

13thirty celebrates 20 years of connecting young people battling cancer

By: Velvet Spicer May 7, 2020

Melissa Sengbusch was a high school senior when she received the devastating news that she had a rare bone marrow malignancy, becoming another statistic in the fight against childhood cancer.



Melissa Sengbusch

Sengbusch refused to let her diagnosis stop her from pursuing her dreams. She didn't tell anyone about the Myelodysplasia and finished high school as planned, fully expecting to head to the University of Pennsylvania, where she had been accepted to study advanced practice nursing.

But in July 1998, three months after her initial diagnosis, Sengbusch was forced to defer her entry to UPenn while she underwent intensive chemotherapy. While undergoing chemotherapy and radiation, she enrolled in five courses at the University of Rochester, where, despite being weakened by weight loss, nausea and other side effects, she completed all of her courses with a 4.0 GPA.

In the fall of 1999, Sengbusch developed a cerebral infection that resulted in a severe seizure. She recovered and months later planned to finally head to UPenn. But in early 2000 she was dealt another blow: she had relapsed and there were no options for recovery.

She also had no real resources available to help her through her ordeal, having not yet reached adulthood, but also not fitting neatly into children's resources. Support groups for teens did not exist.

"Despite having no resources, Melissa somehow figured out how to have this really extraordinary life," said Lauren Spiker, executive director of 13thirty Cancer Connect Inc. and Sengbusch's mom.

Sengbusch died on June 22, 2000, at the age of 19 after living with cancer for two years. Before she died she learned to crochet and crocheted an afghan, she took pottery lessons and created art for her family members, she planted an herb garden and she made plans with her family about her impending death.



Lauren Spiker

"It was three nights before Melissa died and we were at home and she and I were talking and I told her how proud I was of how she lived her life. I thanked her for everything I have learned from her through this," Spiker recalled emotionally. "She said, a lot of people say those kinds of things to me, but I'm not sure that everyone will do anything differently because of it. And then she issued me a challenge, which brings us here, 20 years later: She said, 'If you've learned anything

from me through all of this, do something with it, something to make a difference, to make things better."

But what could she do, Spiker thought.

"If I could find some way to help other teenagers like her going through this terrible experience, at least have the opportunity for the life-affirming experiences that Melissa figured out how to find on her own, that maybe that would be a good way to keep my promise," Spiker explained. "I knew there was a real gap in support for our teenagers because I had watched Melissa try to straddle both of those healthcare systems (for children and for adults) with no navigation to help."

Within months, Spiker had founded Melissa's Living Legacy Teen Cancer Foundation, now known as 13thirty.

"Our mission then was the same as it is today, 20 years later," Spiker said. "Our mission was simply to help teens like Melissa live their very best lives today."

Spiker made the decision early on to spend no time, money or energy on cancer research because, as she put it, "people much smarter than I are working tirelessly at that every single day."

"What I saw with my daughter was that there was a need to figure out how to live today," she recalled. "Little by little I started pulling kids together."



13thirty Cancer Connect Inc. is celebrating 20 years of helping teens with cancer. (Provided photo)

At a time before HIPAA privacy regulations, Spiker was able to go to the hospital and ask if there were any teenagers with cancer. She would talk to them about their diagnosis and what they needed.

"We started with one project. I decided we would create a website designed just for teens with cancer, with good information written in a way they would understand and be interested in and a way to connect with others," Spiker said. "I saw from my daughter's experience, next to having a life-threatening illness

like cancer, the next most devastating thing was a sense of isolation, of being alone."

Although initially the nonprofit organization had little local support — Spiker often was told her organization would never work and to let the "big guys" do it — when the Children's Oncology Group, a clinical trials group supported by the National Cancer Institute and the world's largest organization devoted exclusively to pediatric cancer research, reached out to her, she knew her fledgling agency would, in fact, work.

"It was a stroke of luck, coupled with a characteristic of 'don't ever stop,'" Spiker said. "'No' just means 'not this way.'"

Beyond the group's website, Melissa's Living Legacy matched small groups of teens together and they met at Spiker's home. They had sleepovers and an annual picnic, all the while developing relationships with others who were experiencing the same types of things.

It was 15 years ago when John Nichols' son, Quin, was diagnosed with leukemia. Quin was 16 and the family was terrified, the elder Nichols said.

"It's hard enough being a teenager when you're healthy and all of a sudden your life is turned upside down by this diagnosis," said Nichols, who has been a board member of 13thirty for five years. "Thankfully the social worker at Strong (Memorial Hospital) advised us of this new organization."

That organization was Melissa's Living Legacy, and when Quin was well enough to travel, he and the family visited.

"Quin was able to find that support group and nobody had to dance around the issue that Quin's got cancer because everybody has cancer," Nichols said. "That was 15 years ago. Quin's about to turn 31 and he's still connected."

By 2009, the organization had grown and was making its mark both locally and nationally. Melissa's Living Legacy moved into a small space at the Al Sigl Center, where it remains today. By 2015, its programs were large enough that the nonprofit expanded to include young adults and rebranded, changing its name to 13thirty Cancer Connect to reflect the range of ages the organization served.

"One of the reasons we expanded our mission was because by this time some of the kids we met as teens were now 20-somethings and they were still hanging around," Spiker said.

"Their challenges as young adult survivors were different, but no less difficult."

In July 2019, 13thirty opened a facility in Syracuse. With four staffers in Rochester and two in Syracuse, 13thirty continues to expand its offerings and operates on a budget of \$350,000. Thousands of teens and young adults have taken advantage of the organization's programs in the last two decades, and last year more than 160 people were served by the nonprofit.

"Everything we do revolves around a peer support program," Spiker said.

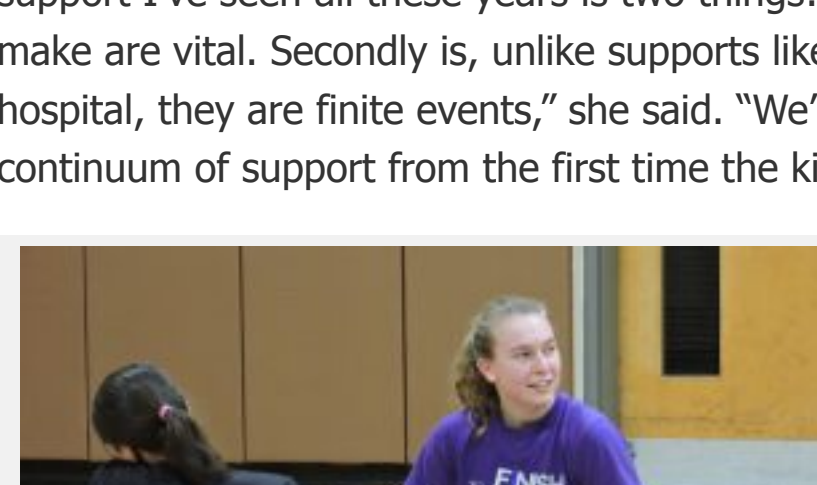
Programs fall into three categories that include wellness and fitness, expressive arts and things that are just for fun. Wellness runs the gamut from fitness programs to nutrition, the goal being to help the youngsters regain the level of activity, strength and endurance they had prior to their diagnoses.

"We've taken our kids boxing. We have climbed mountains. We have gone canoeing. We have a 5k race every year, which this year is going to be virtual," Spiker said.

Participants also can take advantage of the organization's expressive arts programs which include painting, sculpting, pottery, journaling and creative writing. Last year 13thirty started a slam poetry club with the goal of helping the teens find a way to process the experience unique to them creatively.

The "just for fun" offerings are meant to bring about meaningful social interactions through game nights and bowling outings, festivals and more. And parents are welcomed and encouraged to join in programs designed just for them, Spiker noted.

"What's unique about 13thirty, in my opinion, and what differentiates us from any other support I've seen all these years is two things: the face-to-face connections that our kids make are vital. Secondly is, unlike supports like camp or activities that happen in the hospital, they are finite events," she said. "We're able to provide a very comprehensive continuum of support from the first time the kids are diagnosed."



Michelle Hopkins takes part in a program at 13thirty Cancer Connect Inc. (Provided photo)

Michelle Hopkins was diagnosed with ovarian cancer six years ago at the age of 20. She had emergency surgery to remove a softball-sized tumor and a second surgery to determine staging of the disease. Fortunately, Hopkins never needed chemotherapy or radiation.

As a student at St. John Fisher College, Hopkins learned about 13thirty from a counselor there. She was hesitant at first, unsure of whether she would fit in given that she didn't need traditional treatments for her cancer.

"After about a year I started getting involved with programs, and it's like a second family," she said of the organization.

As an athlete, Hopkins got involved in the agency's fitness programs.

"After I had surgeries I didn't feel like myself and I didn't feel like I could do what I used to do," she said. "Your self-image is definitely very different. (13thirty Fit) is one of my favorite programs because it helps me get back into fitness and working out."

And she participates in a number of other free programs the organization offers including game nights.

"What's cool is you can be in a room with other people that have been through it and you don't have to explain yourself. You don't have to explain what happened or why you feel a certain way or what was hard for you," Hopkins said.

Despite the effect the COVID-19 pandemic has had on business, the future of 13thirty holds growth, Spiker and Nichols said.

"It's always been our vision to continue expanding our support to other communities," Spiker said. "This is going to be a difficult revenue year this year; it may be longer than we expected before we can open another new physical site. But we may use this time to create virtual programs and new service delivery channels to expand the model that has been so successful here all these years."

And she has no intention of stopping what she is doing. In fact, this week, in celebration of 13thirty's 20th anniversary, the organization began a \$20K/20 Day Challenge to raise \$20,000 in 20 days, which Spiker and her husband, Doug, plan to match.

"It all started because my daughter was always smarter than I. I know that she knew if she tasked me with something that it would help me reconcile the most tragic thing that will ever happen in my life. It put some purpose behind what I would do from that point forward," Spiker said, pausing between tears. "I often say, when I die, if even a smidgen of people who know my daughter's story remember my name that will be quite an accomplishment because literally thousands of kids in the last 20 years have benefited from the services that we've provided. And it's all because one kid was pretty cool."

vspicer@bridgetowermedia.com / 585-653-4021 / @Velvet_Spicer

Share this:



YOU MIGHT ALSO LIKE

Bausch Health stocks slide as company posts earnings decline

May 8, 2020

City will mail out 480,000 face masks

May 8, 2020

RPCN planning Zoom forum

May 8, 2020

LEAVE A REPLY

Logged in as lauren@13thirty.org. Log out?

Post Comment

☐ Notify me of follow-up comments by email.

☐ Notify me of new posts by email.

Search RBJ Archive



E-NEWSLETTER SIGNUP

Sign Up for Rochester Business Journal's e-mail alerts. Bring the day's business headlines directly to your desktop or mobile device free of charge.

